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# Telephone (Science Edition): What We Can Learn From the Vaccine Controversy About Science Communication

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# **Telephone (Science Edition):**

# What we can learn from the vaccine controversy about science communication

A thesis submitted to Regis College The Honors Program In partial fulfillment of the requirements For Graduation with Honors

Robyn Krystal de Dios

May 2018

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## Acknowledgements

I would like to thank everyone who has helped me throughout this process (with all its ups and downs). In particular I would like to thank my advisor Dr. Chamberlin for guiding my thought process and analysis as well as my reader Ms. O'Neil who read my many drafts and ensured their clarity. I would also like to thank the Regis Honors Program for giving me the opportunity to write this thesis and explore a question I've always wondered: how do we decide?

#### **Science Communication: A Complex Telephone Network**

In comparison to the communication of other types of information, science communication has a greater level of complexity due to its association with science. However, the mechanisms by which it works can still be explained through various models. One such model is the game of telephone. Science communication and the game telephone are quite similar in that telephone players play the same roles as those involved in science communication. You have the givers of information (often scientists) at one end conveying their findings or conclusions and various receivers throughout that line of communication. Furthermore, just like with any game of telephone, messages can be misinterpreted or even misheard. As a result, you may wind up with a completely different conclusion when you reach the end.

Nonetheless, as stated in the beginning, science communication still retains a degree of complexity that causes complications when it is played out in the real world. For, instead of being a part of a single telephone line, you find yourself more so associated with a telephone network. In this network, you are at the intersection of many lines of communication that arise from various sources. Consequently, you may find yourself overwhelmed by the amount of information that comes your way which makes it difficult to discern what is true and what is not. However, in the end you still manage to somehow choose to believe, select, or endorse a particular message. But why? What allows you to ultimately choose one message in the end over the many others that come in?

Furthermore, you must also ask whether the messages you choose to endorse influence your choices. After all, when faced with an important decision you tend to research all the possible outcomes to determine what the best choice is for yourself or those involved with you. This is particularly true of health decisions. In the internet age, it has become quite easy to personally educate yourself on various conditions or lifestyle choices that may benefit you—no medical degree required. With just a few key words entered into google you can find information that will allow you to create a lifestyle that is tailored specifically to your health needs. In fact, according to a report done by Pricewaterhousecoopers consumers utilize social media in particular to view many types of information posted by other patients such as health-related videos/images, their personal or familial experiences with disease, and health-related consumer reviews they've posted (PriceWaterhouseCoopers, n.d.). Now, whether this information will be helpful with regards to treatment or preventive measures remains debatable. This is because, if the information obtained from those sources contradicts the information you receive from your primary healthcare provider, conflicts and communication barriers can arise. Again, the question of how or why a particular source is chosen over another comes up. Does the content presentation matter, does your own predisposition influence what you will believe, etc.? Additionally, what will happen if the source you choose to believe in results in conflict? What will be the consequences of such conflict? In order to investigate this, this thesis will be taking a closer look at the vaccine controversy.

This controversy arose due to the disagreement between most medical experts and parents a part of the anti-vaccine movement. The disagreement concerned whether

vaccines are safe for children and whether they are even necessary with the advances medicine has made since the first required immunization in 1809 (Orenstein & Hinman, 1999). However, how did this disagreement come into being? For, if medical experts are the ones advising parents on the health of their child and most of these medical experts advocate for vaccines then where did the opposing opinions arise from? The answer lies in the fact that in addition to consulting their pediatrician for child health information many parents also consulted other sources such as the internet, the news, and television (Moseley et. al., 2011). Although, even though parents do consult these outside sources they aren't widely followed, but it was found that white parents were three times more likely than African Americans to follow advice from television and newspapers (Moseley et. al., 2011). This in turn suggests that there is some valuable insight some parents find in these outside sources, and the form that these parents most likely gained insight by is a narrative. Now, while you may initially believe narratives to solely be associated with literature or a story, according to the oxford English dictionary, the narrative is simply "An account of a series of events, facts, etc., given in order and with the establishing of connections between them" (Oxford English dictionary, n.d.); hence, a narrative can come in many forms as long as it involves the interweaving of ideas into a cohesive entity.

With regards to the narrative these parents encountered, they found a narrative of hope for their child. For, many of the parents who spear headed the anti-vaccine movement felt despair over their child's autistic condition. However, these narratives, for the most part, were presented in the form of personal accounts that described the

experience of other parents, so why were parents more inclined to believe the advice given in these narratives over that of their child's pediatrician? The answer to this question lies in how the information found in outside sources (e.g. news and social media) is presented differently than those that are found in more scientific or academic sources. Unlike science articles, the news and social media weave together some factual information with personal stories of the people involved. Such allows for the creation of an argument that appeals to you logically and even emotionally. In other words, this type of writing humanizes the facts which can potentially make them more relevant and better understood by the public. In contrast, science articles are more technical, data heavy narratives highlighting those results and data in an effort to remain impersonal and unbiased. In other words, a scientist's aim in writing a science article is to allow the results to speak for themselves without having to frame or encourage a specific interpretation of the data.

Nonetheless, this difference in communication method can lead to communication barriers between science/medical experts who convey facts one way and parents who have read those facts in a specific context. For that reason, scientists as well as the public need to understand why narratives (factual or personal) make effective and valuable communication tools. For that reason, as this thesis engages the vaccine controversy it will specifically hone in on and analyze the narratives both sides present (i.e. for or against vaccines) within the controversy. However, in order to provide context for the narratives to be analyzed, a brief history on the origin of vaccine fears and their evolution over time as well as the origins of the current controversy will be provided

before delving into any narrative analysis. Furthermore, to fully explore the question of why narratives are effective communication tools and why their inaccuracies are dangerous, the psychology of how you make decisions based on the information presented to you will be addressed. Lastly, this work will conclude with the consequences of the vaccine controversy, with a particular focus on misinformation and what can be done to combat it.

### **History of the Vaccine Controversy**

I will Revered Mather. I will administer the variolations if thou believe twill save lives.

Father... Father... Father! Twill hurt?

Pardon, I was pondering something. What was the question?

Twill hurt father?

I presume twill hurt seeing as I need to puncture the skin in order to inoculate. Other than that I cannot be certain.

I trust father. I am certain thou are skilled.

I hope thy words are true Tommy. I hope thy words are true.

Although the interaction just described is purely fictional, the individuals, the technique, and event described are real. On June 26, 1721, Zabdiel Boylson did perform variolations on his son Tommy as well as his slave Jack and Jack's son Jackie (Allen, 2007). Variolations, such as those performed by Zabdiel Boylson, had been performed for thousands of years since their development in Asia (U.S National Library of Medicine, 2002). The basic idea behind variolations was that if an individual was exposed to small pox a milder form would be induced resulting in immunity to the deadlier form. (Link, 2007, p.11). This is the same principle used for vaccines. In fact, you could say variolations were the primitive or crude versions of vaccines. Another similarity vaccines and variolations share is a history of controversy.

#### A Time Old Tale Riddled with Controversy

First and foremost, the usage of variolations by physicians was found to go against the Hippocratic Oath a physician must take. The oath states that one "will do no harm" to one's patients (U.S National Library of Medicine, 2002). This perception of harm is not unfounded, for to administer variolations a physician first had to puncture the skin. Additionally, a physician could potentially endanger his patient's life by exposing them, healthy individuals, to a life threatening disease that they could have avoided by more indirect means. When viewed in this manner, variolations appear to only cause harm which completely goes against the oath physicians swear upon.

Besides the ethical conflicts for physicians, there was also a religious conflict with the practice of variolations. You see, during the time Zabdiel Boylson administered variolations to those in his household, the main philosophy behind disease was that it was meant to be "like a spiritual journey... a passive experience" (Allen, 2007, p.28). That is to say, you were not supposed to actively prevent its occurrence. Furthermore, diseases (particularly small pox) at this point in time were heavily tied to sin. Even Cotton Mathers, Boylson's minister who convinced him to perform variolations, held that small pox was a form of divine punishment. This is evident from the language of a medical treatise he wrote which included phrases such as "'All of the watery pustules which now fill thy skin are but little emblems of the errors which thy life has been withal" (Allen, 2007, p.27). Furthermore, others at the time found that "to sicken oneself, as a way of preventing God from sickening you was a great spiritual risk" (Allen, 2007, p.27). In other words, in purposefully exposing yourself to disease to protect yourself against illness you risked endangering your soul's place in heaven. This is because disease was meant to be "like a spiritual journey" (Allen, 2007, p.28). Consequently, if you wished to improve your relationship with God you should accept the chance of sickness and not try to prevent it, for the trials that came with disease were seen to strengthen one's spirituality. Also, the act of accepting the times of sickness as well as the times of health demonstrated your trust in God and is a true testament of your faith in his deliverance. Based on this religious philosophy, variolations or any type of disease prevention would be viewed as a barrier or obstacle in your spiritual journey and growth. Consequently, you can imagine the opposition Zabdiel Boylson received for these procedures, for it was not only Cotton Mathers who felt religious conflict over variolations practices. This is illustrated by the publications written at the time about the issue.

"...making a Wound, in order to communicate Disease, which is an Abuse unto the Text, 'They that are whole need not a physician, but they that are sick,' and a horrid Violation of the Intent of our Lord" (Several arguments proving, that inoculating the small pox is not contained in the law of physick, either natural or divine, and therefore unlawful, 1721, p.9).

You can find similar sentiments towards vaccinations in the present with some religious groups arguing that vaccines go against the natural order (Grabenstein, 2013). However there are also other religious objections to vaccines that involve concerns that receiving some vaccines could violate dietary laws of practioners as well as beliefs in the ethics of vaccine production when animal derived (Grabenstein, 2013). Nonetheless, religious

opposition to vaccines isn't as extensive today as it was in the 18<sup>th</sup> century. Some religions even advise their followers to undergo immunizations. Such is the case for Judaism which has a primary value of "acting to save one's life, or another's life" (Grabenstein, 2013, p.2014). Religious leaders even emphasize the communal benefits of disease prevention (Grabenstein, 2013). Currently, many faith-based organizations even focus on providing primary prevention, such as vaccines, to those who lack access to medical facilities (DeHave, Hunter, & Berry; 2004).

#### Vaccine Mechanics 101: How do they work?

However, the modern day vaccines these organizations administer are radically different in comparison to the small pox variolations Zabdiel Boylston first administered back in 1721. On one hand, while variolations had the possibility of exposing individuals to full virulent versions of the small pox virus, modern vaccines tend to use modified versions of the virus they target. These modified viral forms are produced in laboratories and are attenuated or inactivated (Link, 2007, p.12); therefore, they tend to be safer and produce milder disease states. Other types of vaccines may not even contain the whole virus. Instead, they contain products that the virus produces or pieces of the virus such as their protein coat (U.S Department of Health and Human Services, n.d.).

Now, even though vaccines have different types, they all ultimately work by the same mechanism. This mechanism essentially involves the introduction of viral material (whole virus, virus product, protein coat, etc.) into the body. After the introduction of viral material into the body, your immune system responds to the appearance of foreign material (i.e. infection) by either having leukocytes directly destroy the viral material

introduced or stimulate B lymphocytes to produce antibodies (Klimpel, 1991). This whole process is known as the primary response; however, the activation of this response isn't what physicians are ultimately targeting through vaccines. What physicians hope to establish is the groundwork for a secondary immune response to occur.

In comparison to a primary immune response, a secondary immune response is more specialized and can specifically target a virus. This is because a "memory" of what to notice when encountering a specific virus has been cultivate through the first exposure (e.g. by directly being infected by the virus or by getting vaccinated). This memory is established through the alteration of some T lymphocytes from the primary immune response. These lymphocytes undergo changes in functional ability that allow them to essentially act as watch dogs for the specific virus that induced the primary response (Pennock et. al., 2013).

#### Vaccine Development: Trials and Tribulations

Nonetheless, like with many other medical technologies, it has taken a lot of time to understand how vaccines work and how to successfully produce them. Consequently, like with any other invention or innovative tool, there were mishaps along the way before vaccines reached the level of development and production you see today. In the early years of vaccine development, some of these mishaps had no detrimental effect, such as the case with the yellow fever vaccine. This vaccine was used in the 1930-40s (Link, 2007, p.26) on various individuals, including those who were part of the World War II armed services. However, in 1966 it was discovered that the vaccine had been contaminated by avian leukosis, a virus that was known to cause many different types of

cancers in birds (Link, 2007, p.26). Furthermore, avian leukosis was closely related to a cancer causing virus in mammals. Luckily, those who received the vaccine appeared unaffected, so it was generally assumed that avian leukosis was harmless to humans. This conclusion was further supported by a Veterans Administration study that found there to be "no increases in cancers twenty years after immunization" (Link, 2007, p.26).

Nevertheless, not all imperfections or mistakes were as forgiving. On another occasion, when a live measles vaccine was licensed in 1962, a killed virus version of the measles vaccine was also released (Link, 2007, p.32). The killed version appeared safer than the live version since it didn't pose the same risks, such as the possibility of "reverting to the wild natural invasive form" so it was widely used (Link, 2007, p.14; p.32). However, after one to two years of being vaccinated, individuals who had received the killed version of the measles vaccine came down with measles. Later, studies done on the vaccine in 1965 found that the antibodies produced from the vaccine "rapidly disappeared…even after booster doses" (Link, 2007, p.32). Additionally, a pediatrician from the University of Colorado at Denver, Vincent A. Fulginiti, observed cases of children who contracted measles five years after vaccination and experienced symptoms different than regular measles which came to be known as "atypical measles" (Link, 2007, p.32). In this case, the vaccine didn't work as intended and even lead to the development of a new form of the disease within those vaccinated.

Nonetheless, vaccines have come a long way as a result of these failures because these failures helped to refine the process to develop and implement a vaccine. In fact, vaccines nowadays are heavily regulated and undergo a lot of testing before FDA

approval (Hoyt, 2012). Additionally, the whole process from research to production involves several stages: priority setting (where they type of vaccine and the desired characteristics are defined), research (where initial development of a vaccine occurs), clinical evaluation (involves testing the vaccine for efficacy, safety, potency, and purity), licensure (company applies for product license with FDA by providing documentation of manufacturing process, quality control, and clinical study results on safety and efficacy), production (begins with pilot production of vaccine for further testing of safety and ability to initiate an immune response, afterwards the vaccine manufacturing is scaled up), recommendations for use (parameters for when a vaccine should be utilized are defined), procurement (sale of vaccine to organizations such as WHO and the US government), distribution/delivery, and surveillance of vaccine efficacy and any reported adverse effects (Sanford, 1993).

For that reason, once a vaccine completes this development and production process it's highly unlike that any adverse side effects will occur. To take a case in point, monitoring by the CDC on vaccine safety has found that only one in a million doses of the DTap vaccine will lead to a severe allergic reaction, and reports of severe brain damage or seizures are so rare that vaccines cannot be defined as the definitive cause (CDC vaccines and immunizations). However, people still continue to doubt the safety of vaccines and even insist that vaccines are obsolete since current medical technologies could easily treat an individual who has fallen fill from a vaccine preventable disease.

Nonetheless, even though current vaccine development is rigorous to ensure safety, the muddled track record of vaccines previously discussed may still bring up

safety concerns. For, it suggests there are risks involved with vaccinating, and that this risk increases with newly introduced vaccines. Additionally, some of these mishaps are relatively recent, such as the 1962 live measles virus vaccine which only occurred 60 years back. Consequently, some individuals may wonder and even doubt if all the problems with current vaccines have been resolved. As a result, some may still consider vaccines to be experimental inventions that are imperfect and require more research and development before they are absolutely trustworthy and can be considered reliable. These concerns and doubts over safety were further enhanced by the claims made by Andrew Wakefield.

#### Wakefield Adds his Name to this Controversy Ridden Tale

Initially, Wakefield's research into gastrointestinal disease development in children who had developed autism garnered little interest (Flaherty, 2011). It wasn't until a medical charity, promoting gastrointestinal research, held a televised conference that Wakefield gained support for his work. It was during this conference when Wakefield presented his concerns regarding the safety of the MMR vaccine and the risk it posed in the development of the Crohn's disease that vaccine safety in North America and England came under fire (Flaherty, 2011; Willingham and Helft, 2014). As the controversy was popularized in the media (DeStefano and Chen, 1999), Wakefield gained greater support and began to advocate for the MMR vaccine to be separated into three individual shots, for he believed that you can't assume combining three viruses into one vaccine is benign (Every Parent's Choice, 2002).

However, his research does not support the claim that there is a correlation between vaccines and autism-enterocolitis (i.e. autism induced by the gastrointestinal disease). When one actually takes a look at the articles Wakefield published, there are even doubts cast on the results of the study itself. Wakefield's first paper investigating non-specific colitis in children stated that "onset of behavioral symptoms was associated, by the parents, with measles, mumps, and rubella vaccination" (Wakefield et. al., 1998, p.637). The key phrase in this sentence is "by the parents." In other words, Wakefield found that parents made the correlation between the development of autism in their children and the measles, mumps, and rubella vaccine implying that he himself may not believe there is any correlation. Throughout the paper he continues to suggest that this correlation may not be true or accurate due to the possibility of selection bias. In other words, because the participants in the study were being referred to him, the correlation may not be applicable or significant if studied within a larger group of individuals. Furthermore, the small sample size (only twelve children) is another indicator that the observations made may not be applicable to the general populace. Interestingly enough, even with all of these holes in the correlation, Wakefield still presented the findings of his studies with great certainty. Additionally, the findings presented in this paper were enough for individuals to make a causal link between the MMR vaccine fear and a decline in MMR vaccine rates for years to come (DeStefano and Chen, 1999).

During the years after Wakefield's claims, many scientists and medical professionals conducted their own studies regarding the connection between vaccines and autism for they found the hypothesis to be lacking in support and premature (DeStefano

and Chen, 1999). Ultimately, they found no evidence that there is any correlation between vaccines and autism (Willingham and Helft, 2014). However, even with all these studies weakening Wakefield's claims, it wasn't until 2010 that Wakefield's license was stripped and his work on vaccines retracted by various reputable journals such as the *Lancet*. This work was a result of the investigation by Brian Deer, a renowned investigative journalist known for his investigations of the drug industry (Cooper, 2011)

In several reports published in the *British Medical Journal*, Brian Deer exposed the fraudulence and fabrication of Wakefield's popularized study. During his investigation he discovered that the personal history of the patients in the study were untrue. This is illustrated through an interview Deer conducted with one of the parent's whose child was a reported as the 11<sup>th</sup> child studied in Wakefield's paper.

""Wakefield told us my son was the 13<sup>th</sup> child they saw,' he said, gazing for the first time at the now infamous research paper which linked a purported new syndrome with the measles, mumps, and rubella (MMR) vaccine. 'There's only 12 in this.' Running his finger across the paper's tables, over coffee in London, Mr. 11 seemed reassured by his anonymized son's age and other details. But then he pointed at table 2—headed 'neuropsychiatric diagnosis'—and for a second time objected. 'That's not true.' (Deer, 2011).

Aside from fraudulent data and information, Deer's investigation found that Wakefield was commissioned to fabricate a study which met the following objective:

"to seek evidence which will be acceptable in a court of law of the causative connection between either the mumps, measles and rubella vaccine or the

measles/rubella vaccine and certain conditions which have been reported with considerable frequency by families of children who are seeking compensation" (Deer, 2011).

In short, Wakefield need to demonstrate a link between the MMR vaccine and another condition found in the children a part of the lawsuit (e.g. Autism and Crohn's disease) so that the information could be used for a lawsuit against vaccine manufacturers (Deer, 2011). Many of the children involved in the lawsuit were even referred to him to be a part of the study (Eggertson, 2010). Such is a major conflict of interest that could lead to skewed data interpretations, but Wakefield never disclosed this information in his paper or with the public.

However, even after this exposé regarding Wakefield's studies, there are still some individuals who support him even after he was discredited, lost his license, and had his papers researching the correlation between vaccines and autism retracted. Currently, his supporters believe him to be a victim of a slander campaign by pharmaceutical companies who manufacture the vaccines.

#### **Power of the Narrative**

After the successful creation of the polio vaccine, vaccines had been seen as a technological marvel, a sign of modernity and a symbol of innovation. This was particularly true of the polio vaccine which was met with an initial joyous and celebratory response (Jana & Osborn, 2013). The optimistic response was a result of the escalating fear for the polio virus, and it is this fear that created great demand for Salk's polio vaccine. As a result, the US government gave licenses to several companies to produce Salk's polio vaccine. Cutter laboratories was one of these licensed companies, and even though their hastily manufactured polio vaccine led to exposing thousands of children to a live polio virus (Jana & Osborn, 2013), the public didn't scrutinize the safety of the polio vaccine as they do with other vaccines later in 1970's.

During the early 1970's after the publication of a case series (i.e. medical research study that tracks individuals of known exposure) from the Hospital for Sick Children at Great Osmond Street in Great Britain claiming that 36 children suffered neurological complications after receiving the DTP vaccine, the public began to question its safety and anxieties began to arise regarding the safety of immunizations (Baker, 2003). These worries were exacerbated later in the 1990's when Andrew Wakefield claimed at a press conference that his research found a correlation between the development of Crohn's disease and autism as a result of the multi-dose MMR vaccine. These claims of neurological complications from the DTP and MMR vaccines were later discredited in

2010 after an extensive review on adverse cases was conducted by the institute of medicine. However, the evaluation of Wakefield's work in particular had come too late. His study had already become a catalyst for the anti-vaccine movement, allowing it to gain a strong hold on the public as deep fear and mistrust spread.

Interestingly, the amount of information available to individuals against the safety of vaccines isn't as easily found because not as many studies find them to be harmful to a large number of individuals. To take a case in point, monitoring by the CDC on vaccine safety has found that only one in a million doses of the DTap vaccine will lead to a severe allergic reaction, and reports of severe brain damage or seizures are so rare that vaccines cannot be defined as the definitive cause (CDC, n.d.). Consequently, there must be another resource aside from scientific research that the anti-vaccine movement utilizes to persuade others that vaccines are associated with specific dangers and risks. This highly interactive and engaging platform is the narrative, particularly of parents: parents who believe that vaccination has caused their child harm. What makes a narratives so believable to the point that even if the research presented by scientists contradicts these narratives, people are still willing to uphold them? Furthermore, what is so convincing about a story that cannot be personally verified and that only one individual has observed?

#### **Engaging Narratives**

One reason for parents being receptive to narratives is due to the same goal they all have in mind: "minimizing suffering" for their child (S. Ray, personal communication, 2017). For that reason, they will be receptive to any negative outcomes that can result

from their children receiving a vaccine; thus, they are receptive to the information they find or hear. To take a case in point, after Andrew Wakefield's claims were popularized by British media in the early 2000's measles vaccination coverage began to drop drastically in the United Kingdom from approximately 91% in 1997 to 81% by 2004 (The Organisation for Economic Co-operation and Development., n.d.). However, as demonstrated by the vaccination coverage, not every single parent automatically believed in the particular narratives the media supported or presented. Consequently, In order to better understand the narrative platform and why parents are moved to make a specific choice (i.e. for or against vaccines), you must experience and engage the stories these parents encounter. For that reason, read through the following passages and reflect on your reactions to the passages by answering the questions that follow. Also consider, before reading these narratives where do your personal beliefs lie for or against vaccines? *Narrative One* 

My son, who could count to five at thirteen months, was learning the alphabet and said, "ma, da, brover, bye" and "hi," was, in fact, a genius. The multiple stacks of books I bought him went to good use. Our days were spent looking at numbers, letters, shapes and beautiful pictures of far-away lands. At thirteen months, he received multiple vaccines at his well-child exam. Within a few days, his language, eye contact and connection to his family dissipated. He clearly had suffered an adverse reaction to his vaccines, but his pediatrician assured me that he needed to be further vaccinated to protect his health and I agreed. At his 24 month checkup, he was vaccinated again and it was the beginning of the end of

life as we knew it. Within a week or so, David became violent toward me and his dad. He, for the first time, was hitting himself in the head and banging his head on the ground. He slept very little and did not want to be bathed, have his hands washed or his clothes changed (Carrasco, 2017).

#### Narrative Two

Violent and painful convulsions course through Alijah's body as tetanus attacks his nervous system. He faces his father, back arched, blood dripping from his mouth and says 'save me daddy'. Helplessly, the father grips Alijah's hand wondering, if at any second his son's bones will break under the stress of the muscle convulsions or if his heart will stop (Hill, 2013).

#### Narrative Three

In January 2008, an intentionally unvaccinated 7-year-old boy who was unknowingly infected with measles returned to San Diego, California, from Switzerland. The resulting outbreak was the largest in San Diego County since 1991. The importation resulted in 839 exposed persons, 11 additional cases (all in unvaccinated children), and the hospitalization of an infant too young to be vaccinated. (Sugerman et. al., 2010).

#### Narrative Four

At 18 months old, Isabel Olesen of Melbourne, Australia was taken to her pediatrician's office for routine vaccinations that ended up leaving her partially blind and covered with painful blisters all over her body, just 48 hours later. "Isabel's skin was red raw, when I moved her head the skin from her eyebrows and cheek would fall into my hands. The smell of burning flesh was stuck to my hands for weeks." This whole ordeal left Isabel without the majority of her eyesight, and it was attributed to a rare disorder known as Stevens-Johnson syndrome (Elizabeth, 2017).

#### Narrative Five

On September 13, 1948, three days after her brother, Gason died from it, Martha Mason was stricken with acute bulbar poliomyelitis. A year and some odd days later, assisted by the March of Dimes Foundation, Willard and Euphra Mason brought their twelve-year-old daughter home from the hospital in an iron lung. Doctors indicated that in all likelihood she wouldn't live for more than a year (Mason, pp.xxii, 2010). However, Martha was a fighter and fought a hard battle against polio and came out victorious. But, it was at the cost of her mobility. For, the next sixty years of her life would be spent paralyzed inside an iron lung.

If the motor that powers the iron lung burns out, Armageddon moves closer. Even with a new motor on standby, I must locate someone who knows how to switch the old for the new. A small plug of mucus that a child could easily cough out will swiftly shut me down (Mason, pp.8, 2010).

Now, stop and reflect on all the narratives you've encountered thus far and then answer the questions below and take note of your answers.

1. After reading these narratives do you find some of the arguments presented convincing enough to influence where you stand on the issue?

- 2. Were there any specific descriptions that made you more sympathetic and connected to a particular narrative? If yes, what were these specific descriptions and why these specific descriptions and not others? What made them resonate with you?
- 3. Based on the possibilities presented in each narrative which worries you the most: not vaccinating leads to disease or vaccinating results in disability?

#### **Imbuing a Narrative with Power**

If you had a strong belief for or against vaccines it is quite likely that you were more receptive to specific narratives above. Although, if you were sitting on the fence regarding the vaccine controversy one particular narrative could sway you one way or the other depending on its presentation. This is demonstrated in a study where participants were asked if they would allow a hate group to stage a public rally (Nelson, Oxley, and Clawson 1997). It was found that if participants read an editorial emphasizing free speech they were more likely to support allowing the public rally in comparison to those who read an editorial about the risks it presents to public safety. With respect to vaccine support, this means that depending on what you read you may feel swayed one way or the other, and you don't have to read a lot to craft a particular opinion or way of understanding. To take a case in point, in a study where participants were exposed to a small amount of balanced information (i.e. equal amounts of information on the potential benefits and risks) concerning nanotechnology they became opinionated on the issue (Kahan, Braman, Slovic, Gastil & Cohen, 2008). In connection to people's opinions towards vaccines, this study suggests that any exposure you have on vaccines could lead you to a particular opinion. Moreover, it doesn't even matter if the source represents both sides equally, an individual can selectively support or favor parts of the source based on their own dispositions. This selectivity was also demonstrated in the Kahan study where depending on an individuals' worldview (i.e. hiearchs, egalitarians, individualists, or communitarians) they would favor the benefit or risk information provided on nanotechnology.

However, you must still ask yourself why the experiences portrayed in another's personal narrative have the influence to sway your decisions if you are selective of the information you endorse or agree with. That is to say, why would a single individual's account be more appealing and more worthy of support than statistical information in some cases? One reason is demonstrated from the snippets of narratives shared above. As you've see from just snippets of these stories, they carry powerful emotions, and it is these emotions that make you empathetic towards the narrative and the characters. Whether the narrative concerns the aftermath of an immunization or the struggles involved with disease and disability, you connect with the pain that these parents or individuals experience in their lives. Evidence-based information just can't create that empathetic link. The reason being that evidence-based information doesn't help to invoke concern for the other which some researchers find to be crucial component in building empathy (Batson et. al., 1997).

Moreover, based on the answers to the reflection questions, you may find that one narrative is more convincing than another, or perhaps you find neither to be persuasive.

But, why is that? Why do you find some stories more persuasive than others or not persuasive at all? Do some stories carry more power to influence us? According to Marshall Gregorgy, an English professor at Butler University it's not that some stories are more persuasive than others. He believes "stories can only extend invitations, not coerce effects" (Gregory, pp.3, 2009). What he means by this is that when you read a story it doesn't automatically alter your beliefs or change your perspective. Instead, it offers you insights and information that you are free to accept or reject. As a result, this means that stories only have the power to influence you if you let them. It's due to this choice of accepting or rejecting a story's invitation that allows for others to be more receptive or critical to the narratives of the anti-vaccine movement, and, again, just like with how you selectively believe information based on our current dispositions (i.e. current beliefs, values, political ideology, past experiences, etc.) you will also accept a story's invitation based on this disposition.

Furthermore, you must also ask yourself what is, or even if there is, a consequence to accepting a story's invitation? After all, changing your opinion and belief in a particular narrative can be difficult once you've accepted multiple invitations into similar narratives. For, once you've accepted the invitations to be persuaded and moved by narratives presented, you have chosen to be influenced by them. To better understand this idea, consider receiving an invitation from an acquaintance to a dinner party. Under one scenario you decide to accept the invitation and attend, but when they invite you again you decline. Now imagine a second scenario where you accept the second invitation followed by a third, a fourth, a fifth, a sixth, and a seventh. Then, when you are

invited for the eight time, but don't wish to go it becomes more difficult to say no since you've already said yes several times. The same is true regarding narratives. If you've already decided to accept a certain narrative and continue to accept the insights presented it becomes difficult to discern their truth due to their familiarity. This is due to what is known as the truth effect in which people rate statements as more true after encountering it earlier (Henkel & Mattson, 2011). Additionally, this effect is enhanced with greater repetition and has even been found to not be influenced by the reliability of the source indicating that familiarity with a particular conclusion or insight creates the illusion of truth (Henkel & Mattson, 2011).

This connection of familiarity validity can be dangerous because some of the insights or conclusions a narrative presents may be untrue, inaccurate, or even taken out of context. Take for example Isabel's narrative presented earlier. The author incorporates a quote from Isabel's mother into her article in order to establish a particular conclusion "vaccines are more dangerous than you think". However, we have no means of verifying that this is what actually happened to Isabel. The author claims that 48 hours after being vaccinated, Isabel was covered in "painful blisters" and was left partially blind (Elizabeth, 2017), but what if this correlation between vaccinations and Stevens-Johnson syndrome was incorrect. If it was incorrect and you already invested your time into reading similar stories, it would become difficult for you to not feel that vaccines lead to Stevens-Johnson syndrome and accept the unfamiliar conclusion: perhaps the Stevens-Johnson syndrome was caused by something else and was just a coincidence.

Unfortunately, you will never know what conclusion is "correct" since you aren't presented with enough information to make such a conclusion. Instead you are to believe (or not believe) the conclusion given: vaccines led to Isabel acquiring the disease. As a consequence, the insight gained from the narrative presented could be skewed and be an inaccurate representation of what actually occurred. The same may be true of Alijah's narrative, the mother's account, or any other narrative for that matter. It's for that reason that you may need to withhold from fully accepting invitations from narratives you encounter. In fact, it may be more conducive to your understanding to carry some skepticism and doubt while simultaneously being open to a perspective that may challenge what you believe to be true.

The reason for this is that even though the conclusions a narrative presents aren't necessarily all true, it does not mean, as Gregory puts it, "that they don't comprise important stuff..." (Gregory, pp.14, 2009). In other words, these narratives can still offer insights particularly in the form of a contrasting opinion. For, in having a certain idea or concept challenged you can better "negotiate our way toward the truth" (Gregory, pp.14, 2009). This is because in challenging the ideas you currently hold with new or different perspectives, you can allow them to evolve. To take a case in point, initially it was believed in ancient times that the earth was flat. Then, in the 6<sup>th</sup> century B.C Pythagoras challenges this idea, suggesting that the earth is spherical not flat (Dreyer, 1906). His hypothesis is later supported through the work done by ancient astronomers on various celestial bodies and even present day astronomers as who photograph earth from space.

consensus challenged by the public has led to a realization that their authority in medicine (even if considered experts) can be challenged and questioned. Ultimately, from this challenge, scientists and healthcare professionals have learned what needs to be prioritized when communicating the benefits of vaccines. This is best observed in the evolution of the HPV vaccine campaign.

#### A Change in Focus: The HPV Vaccine Campaign

HPV is one of the most common sexually transmitted infections (Human papillomavirus, n.d.) that selectively infects humans (Roden & Wu, 2006). It is caused by the Human papillomavirus and is spread through skin-to-skin contact (HPV infection, n.d.) entering through areas of the skin that have been damaged (Schiller, Day, & Kines, 2010). The warts caused by some strains of HPV result from the virus infecting the actively dividing layer of the skin leading to rapid growth in the infected region (Warts and Plantar Warts - Topic Overview, n.d.). Nonetheless, these warts can also appear on the hands and feet, but these particular strains aren't usually spread during sexual activity (Safe Sex and HIV Protection, n.d.). Instead, they can be spread through prolonged instances of skin-skin contact. Additionally, mothers infected with HPV can unintentionally infect their child while giving birth (Sowadsky, n.d.).

Nevertheless, not all strains result in genital warts. Instead, they can lead to cancer. In fact, out of the 100 strains of HPV known, 20 can cause cancers (Dominiak-Felden, Gobbo, & Simondon, 2015) such as cervical cancer which currently has a 50% fatality rate (Dominiak-Felden, Gobbo, & Simondon, 2015). For that reason, the FDA approved the first HPV (i.e. human papilloma virus) vaccine, Gardasil, on June 2006

(Daley et. al, 2010) which protect against some of the most common cancerous and genital wart causing strains such as HPV 16 and 18 which cause 70% of cervical cancer cases and HPV 6 and 11 which are responsible for approximately 90% of genital warts (HPV/Genital Warts Health Guide, n.d.).

Despite the clear risk associated with HPV infection, as of 2015, only 42% of adolescent girls and 28% of adolescent boys ages 13-17 have been fully vaccinated (CDC, 2013). This is quite low in comparison to vaccine coverage for other diseases such as measles with a coverage of approximately 92% as of 2015 (The Organisation for Economic Co-operation and Development, n.d.). Although, even though 42% and 28% don't cover most of the population it is a significant improvement from 15% of adolescent girls and 0% of adolescent boys in 2007 when the vaccine was initially introduced only for girls (Markowitz et. al., 2012). However, what encouraged the increase? The answer lies in the establishment of public health campaigns for HPV which focuses on two goals: one, to better educate the public on HPV and two, emphasize the connection between the contraction of HPV and cervical cancer in women.

With regards to the first goal, before the vaccine first came out, there existed no national public health campaigns that informed the public on HPV and the health risks involved when acquiring the disease (Friedman & Shepeard, 2007). As a result, much of the public remained unaware of the disease. What information they could get from the internet, health agencies, and pharmaceutical companies was inaccurate, contradicting, or confusing (Friedman & Shepeard, 2007). Furthermore, HPV vaccine was marketed as

preventing a sexually transmitted disease. For that reason, individuals or parents of children who weren't sexually active believed they didn't need to be vaccinated.

Additionally, healthcare providers didn't know how to best advocate for the vaccine. This is because it's difficult to convince a parent that their child needs to be vaccinated against a sexually transmitted disease if the child is still young and not sexually active (Hopfer & Cippard, 2011). As a result, the lack of education in patients and absence of urgency in getting vaccinated led to the perception that the HPV vaccine was unnecessary. Many young women, in particular, have experienced this with their healthcare providers who do not raise the issue of HPV vaccination or find it unnecessary for them (Hopfer & Cippard, 2011). Such leads to lowered vaccination rates which is concerning considering colleges students are disproportionately affected by HPV (Yang & Pittman, 2017).

Consequently, of these young women who are diagnosed with cervical cancer they'll have a 67% chance of surviving for 5 years (National Cancer Institute, 2012). Back in 2010, this meant 12,200 women in the United States would be diagnosed with cervical cancer, and an estimated 4,210 will die of the disease within a 5 year diagnosis (U.S. Department of Health and Human Services. n.d.). Furthermore, if these women do survive, it may be at a great cost.

At the age of 26 a Danish woman named Louise was diagnosed with cervical cancer after she had just gotten her first job as a nurse. She battled with cancer for three years undergoing various treatments including radiotherapy, chemotherapy, and surgery that led to the removal of her cervix, fallopian tubes, and 29 lymph

nodes. With the loss of her fallopian tubes she could no longer have any more children (Vaccines Today Editorial Team, 2018).

Another barrier, besides lack of education and communication by healthcare providers, to increasing the HPV vaccine rates is the existing stigma behind sexually transmitted diseases. When individuals were asked in a HPV education study done by Friedman & Shepeard (2007), terms that commonly came to mind for participants when they heard the term sexually transmitted disease or STD included: promiscuity, infidelity, shame, embarrassment, guilt, and divorce. These feelings of embarrassment and shame are even common amongst HPV positive women (Daley et. al, 2010) and adolescents getting vaccinated for HPV (Yang & Pittman, 2017) leading these individuals to not get vaccinated and not disclose that they have HPV when tested. In a study by Yang & Pittman (2017), this shame was found to be particularly burdensome to female participants motivating them to hide HPV diagnosis from those close to them or risk cutting off relationships.

Due to the shame and stigma of sexually transmitted diseases, the HPV vaccine campaign has rebranded itself with cancer doctors spear heading the movement (McGinley, 2016). For that reason, the campaign for the HPV vaccine now focuses on the fact that HPV causes cancer and barely mentions that it is sexually transmitted. With this main idea at the fore front of the campaign we've seen a large increase in vaccination rates from 25% to 60%. Why has this rebranding worked? According to Friedman & Shepeard (2007), this is because the message of cancer makes the issue of getting vaccinated more relevant to a greater portion of the public. It is for that reason, any public

health campaign must be, from their perspective, carefully designed and tested with audiences to find what content and framing is the most effective (e.g. factual information and personal stories of individuals suffering from HPV). Based on what has been discussed thus far, one of the most effective forms of content comes in the form of the personal narrative. The power of the personal narrative is even evident in Friedman & Shepeard's study where participants wanted real-life examples of individuals they could relate to in addition to factual information. Such implies that providing personal narratives in addition to factual information will allow individuals to be better informed on the choices they can make regarding their health.

# Fear and Mistrust: The Two Pillars of the Anti-Vaccine Movement

As previously mentioned, truly concerned parents want what is best for their child. As a result, these stories, in addition to medical advice, will establish their choice, for no parent, if desiring to make an informed choice will focus on one source. Instead, they will dig around and research their questions until they believe they have sufficiently researched the topic. However, can an informed choice be made when an individual is exposed to both sides of the story? The answer to this questions is sometimes. The reason for this is due to personal biases. Biases are not only your beliefs or opinions, they go much deeper than that. They are linked to the human psyche, for how the brains process information and how it allows individuals to make decisions is not 100% impartial. Especially when a polarizing issue is involved.

According to Lee & Male (2011) the fact that there exists two sides to the vaccine issue with each having their own conflicting ideologies and arguments is problematic. It results in uncertainty on which side to choose. This is evident from a study by Poland and Jacobson (Poland, Jacobson, and Ovsyannikova, 2009). In this study, they interviewed various mothers who had decided not to vaccinate their children. These women were from the same social class, age, and highly educated. From these interviews they found that these individuals felt that they had made an informed, active choice that was based on information and critical reflection. However, everyone receives or has received the same information as these women, what's different here is how each person reflected on it. For that reason, when science presents its information with impartiality and the antivaccine movements presents its narratives there is a place for uncertainty to develop. This uncertainty then allows for, as Lee & Male (2011) characterized, a heuristic cue (i.e. snap judgement).

For that reason, if both sides present arguments an individual finds equally valid, the decision ultimately becomes what an individual perceives to be less risky or more risky when deciding to vaccinate or not. As a consequence, parents motivated to find out what is best for their child may rely on their individual perception of risk. This individual perception would most likely be different from public health officials or healthcare workers who have a specialized understanding that focuses on many children instead of a single child. To better explain this difference, an understanding of how decisions are made is required.

# How do you decide?

On the surface, making a decision may seem like a one-step process where you just make a choice, but it is actually more complicated than that. In fact, researchers have defined decision- making as a "compound process with three components: decision parameters, decision making process, and the decision implementation (Chung & McLarney, 1999). However, the focus here will be the decision making process, for this component is one that can vary from individual to individual; hence, it becomes the main component that differentiates the final decisions each person will make. The reason for this is that the decision making process "is the stage where all the alternatives are

evaluated to produce a final choice" and this evaluation can be based on reasoning or even emotional processes (Albar & Jetter, 2009, p.578).

Furthermore, the reasons or emotions that comprise decisions may rely on the cognitive maps each individual creates based on their experience (Passer & Smith, 2004). The development of these maps may also explain why humans value the personal narratives of other individuals, for their experiences can be used to inform the decisions of others. In other words, other people's stories can help you build your cognitive map for a particular decision or event. Nevertheless, each individual's experiences are not exactly the same, so they will develop their own unique cognitive style, and it is this style that comes to define how each individual processes information and makes decisions based on the information obtained (Passer & Smith, 2004).

This type of model for decision making is known as behavioral decision theory which is focused on how people process information and make judgements (Albar & Jetter, 2009). In contrast, rational decision models involve an individual making a decision by determining which decision alternatives will maximize the desired outcome (Berger, 1993). Additionally, the behavioral model of decision making differs greatly from rational decision theory and may lead to systematic errors that result in irrational decisions (March, 1994). However, humans are not completely irrational when making decisions. Instead, Prietula & Simon (1989) finds that their rationality is bounded, especially when considering complex problems (Albar & Jetter, 2009). With complex problems, an individual would not have sufficient information or the ability to consider every decision alternative to find the optimal solution. Instead, they look for the best

solution that fits their needs or satisfies their circumstances (Albar & Jetter, 2009). Such may lead individuals who are reliant on heuristics to fill in the gaps of understanding when making a decision.

Heuristics is defined as "a simple rule of thumb for problem solving that follow a logic that is quite different from consequential logic" (Albar & Jetter, 2009). Consequently, parents who are trying to decide whether to vaccinate their children or not may use these tools and arrive at a different decision than their healthcare provider due to the difference in information each party has on the outcomes of vaccinations. In the case of healthcare providers, their decision to promote vaccinations may be based on a wider breadth of scientific knowledge due to their education, ease of access to this type of information, their colleagues, and expertise. By comparison, a non-medical professional who is constrained by the time they have, the resources they have access to, and individuals they know may be more selective in researching the outcomes that they are most concerned about (e.g. negative outcomes of vaccines) However, that does not mean that all individuals that are a part of the anti-vaccine movement are self- centered. Such is shown by the argument presented by Lee and Male (2011) who state that not pressuring others to vaccinate is also being a good citizen for in pressuring individuals to vaccinate means you are legislating their body. In other words, you are dictating what they must do to their own body which imposes upon their own freedom of choice and civil liberties.

# The right to choose: To vaccinate or not to vaccinate that is the choice

The perception that one's freedoms are being encroached upon is dangerous and is one of the main motivators for why people oppose mandatory vaccinations. In fact,

according to Anna Kirkland (2016), most individuals are not opposed to the idea of vaccination. What they are opposed to is the mandate that everyone needs to be vaccinated. That is to say, they have this perception that their freedoms are being encroached upon. But, how does this perception lead to complete opposition of vaccines? The reason is that when you feel that your freedom is being treaded upon, you tend to push back against those who limit your freedom. This leads to mistrust and can result in the formation of conspiracy theories surrounding why the mandate is being given.

#### **Everyone is a conspiracy theorist at heart**

Contrary to popular belief, conspiracy theorists don't simply belong to the fringes of society. You may argue that rational and highly educated individuals would not fall prey to such conspiracy theories, however, this may be wrong, for research into conspiracy theories has found that such theories can be quite infectious and spread as individuals share ideas. According to Stuart Blume (2005), the reason for this is that doubt tends to be shared and rarely arises from personal convictions. Instead, those you encounter and hear from taint later experiences (Blume, 2005). This brings us back to the narratives previously shown. When reading these stories, they will not only move your emotions but also affect your subsequent experiences and decisions. This idea that social circles help to spread doubt and suspicion may explain why a 2014 survey found that half of Americans believe in at least one medical conspiracy (Brotherton, 2015). In other words, these individuals may distrust certain medical practices or products due to the experiences and advice they receive from those within their social circle. Furthermore, another reason individuals may believe in conspiracy theories is presented by

psychologist Rob Brotherton his book *Suspicious Minds*. In his book, Brotherton finds that everyone is susceptible to becoming a conspiracy theorist, especially when you are feeling paranoid. Parents, in particular, have a heightened degree of paranoia when it comes to their children making them more suspicious and prone to mistrust if they believe someone has harmed their child in anyway. This paranoia, in turn, can be reinforced or established through the social circles that they find themselves in. In fact, the information from their social circles may even be the cause of their paranoia.

## Loss of control = Paranoia

Additionally, as Brotherton and Ropeik explain in their books *Suspicious Minds* and *How Risky is it Really?*, paranoia can further be heightened when you don't feel you are in control of a situation. As a result, the feeling of not being in control can quickly breed fear which can ultimately led to mistrust. This is demonstrated in a study done by psychologists Jennifer Whitson and Adam Galinsky (2008). In this study, participants imagined they were top administrators for an organization and were soon up for a promotion. The day before the promotion, participants find that there's an increased volume of emails going between their boss and a co-worker who sits nearby. The following day their boss informs them that they will not be promoted. Interestingly enough, even though both groups of participants had this same scenario they had very different interpretations of it depending on whether they had first recalled an experience where they had complete control or an experience that they had no control over. The group that reflected on an experience that they had no control over were more likely to feel that there was a conspiracy which ensured that they did not receive a promotion. In

contrast, those who reflected on an experience in which they had complete control were less likely to suspect a conspiracy was afoot.

In fact, you could say, the idea of control acts as a powerful fear deterrent. A study from the Journal of Personality and Social Psychology by Neil Weinstein (1980) illustrates how the feeling of control increases your optimism regarding the outcome of an event. In his study, participants rated how optimistic they were on various positive and negative events. He found that if an individual felt more control over an event (e.g. having a heart attack), the more likely they were to be optimistic about the event (e.g. surviving or avoiding having a heart attack). With regards to the parents vaccinating their children, this means they will be more likely to assume the worst possible outcome (e.g. adverse reaction to vaccine) if their child is immunized since they traditionally lack control over immunizing their children. After all, it is the state governments that require, or more accurately mandate, that children must receive a certain set of immunizations before they are allowed to attend school. Furthermore, since doctors assist in enforcing this mandate, parents feel their freedom to choose is endangered and callously disregarded by larger entities. A parent may feel that this is a grave consequence, for if the government only treats their child as a number or herd immunity statistic, how can they ensure what is best for their child. Also, the government and health care providers don't interact intimately with their children, so what right do they have on deciding what is beneficial for their child?

# **Back in control**

These anxieties and concerns are then exacerbated when parents find their child developing abnormalities. Additionally, when doctors inform parents these abnormalities may have developed due to genetics, even random chance, or unknown causes, they feel they have lost all control over the well-being of their child leading them to despair. For this reason, parents will seek out hope for their child which is why they find themselves at rallies or on the internet. In doing so parents find answers to all of their questions, with the most important being "vaccines harmed my child." With a tangible threat identified, parents can be empowered and in control over the well-being of their child once more. Furthermore, they no longer have to be "stripped of [their] intellectual autonomy" and continue to be "forced to defer to experts" (Brotherton, 2015, p.128). This type of proactive parenting is demonstrated by the five step checklist Jenny McCarthy (a prominent figure in the vaccine-autism controversy) keeps on her refrigerator on how to best help treat her son's autism (Mnookin, 2011). This list represents her own research on what she believes is best for her son.

#### Potholes on the road of personal research

However, as learned previously biases can get in the way of how one interprets the information and makes decisions, especially if you are seeking out a particular answer. This is evident from the invisible gorilla study conducted by psychologists Chabris and Simons (2010). In this study, participants were told to count the number of times individuals wearing a white shirt pass by. However, what participants didn't realize was that as they were counting white shirts, a gorilla passed through the group of people

gathered and banged its chest. About half of the participants missed the gorilla. What does this experiment mean in terms of personal research? In the case of the anti-vaccine movement, this experiment suggests that when searching for a specific answer other details can be missed. If the details are irrelevant that may be fine, but if the details lead to a different answer then they must not be ignored. They may lead to a more informed decision.

# The threat of Big Pharma

The mistrust towards vaccines is not only due to the lack of control parents have on their usage, but also on who is creating the vaccine. As Jacob Heller (2008) notes in the *Vaccine Narrative*, the discovery of vaccines and drug design over the years has moved from being associated with a do-gooder researcher to being associated with large corporations. In fact, medicine as a whole, he finds, has become more commercialized. Due to this change, mistrust can be more easily developed, leading to conspiracies due to the complexity and motivation large organizations or governing bodies may have.

#### Order, we must have order

Humans also dislike when events are random which is why you attempts to establish a motivation or purpose behind a cause. This can lead you to succumb to an intentionality bias. This bias, as defined by Brotherton, results in the assumption that "everything that happens in the world happened because somebody intended it to" (Brotherton, 2015, p.188). Now normally, as you age this intentionality bias can be controlled due to the experiences gained. In other words, as adults, you do not immediately identify the actions of objects or individuals as intentional. Instead, you find

that they could be attributed to random chance. Nonetheless, a study done by Rosset (2008) finds that when impaired (by alcohol) or under time sensitive situations, events that you are more likely to ascribe to an intentional explanation (e.g. "the sun radiates heat because warmth nurtures life") instead of a non-intentional one (e.g. "the sun radiates heat due to occurrence of nuclear fission) (Rosset, 2008). As a result, it can be argued that parents who are placed under stressful and time sensitive situations (e.g. failing health of their child) would be quick to assume a specific entity had harmed their child. As a result, the large corporations who manufacture the vaccines or the government who did not ensure the safety of the vaccines and mandated them will be seen as the perpetrators.

# **Justified suspicions**

Nonetheless, their decision to be suspicious of large pharmaceutical corporations isn't necessarily misplaced. As Ropeik points out in his book, the Merck pharmaceutical company (a company also known to produce the MMR vaccine) had questionable motives before regarding their pain medication Vioxx. Apparently, the "company may have known about [the] dangerous side effects from" the medication "before bringing the drug to market" (Ropeik, 2010, p.76). Even if the company truly didn't know, the possibility that they might have known and did not inform the public resulted in the loss of credibility. Based on this information, the concerns regarding the safety of the vaccines Merck produces would be valid. After all, how can you be certain that a company who doesn't ensure the safety of one medication will ensure the safety of its other products?

Ultimately, the presence of these large organizations and the conspiracy theories associated with them (e.g. that they are injecting harmful substances into our kids and just refuse to tell us) makes it quite easy to build paranoia and mistrust. This then characterizes the government and medical industry (and those associated with them) as villains. In turn, since the government and medical industry are the villains, by default the individuals fighting for the safety of children are the heroes. This polarization of support and criticism and characterization of the government and medical industry as villains allows for the anti-vaccine movement to gain support and advance itself.

# The Consequences of the Vaccine Controversy

In previous chapters you've seen how the types of information you consume play important roles in your decisions subconsciously or consciously. For that reason, you must be selective of the information you believe since inaccurate information can lead to the worst possible decisions that have lasting consequences.

# Misdirection: Trick to the Autism Thimerosal Connection

To take a case in point, misinformation within the vaccine controversy have led to, as described above by Brian Deer during an interview with Anderson Cooper:

"[a] distraction away from the real needs of children with developmental disorders and the real needs of families looking after them. Because, very often the families of children, particularly the ones Wakefield preys on, are people who are just desperate for answers. Some of them are financially quite challenged as well. Many of them are terrified about what is going to happen to their children in the future" (Cooper, 2011).

The reason Deer describes this whole controversy as a huge distraction is because the money that was diverted to fund Wakefield's fabricated research (or even debunk his research) could have been used to develop programs for autistic children or even be used to do legitimate research on the causes and triggers of autism in children. As a matter of fact, in order to clear up the controversy stirred up by Wakefield regarding the autism-thimerosal link the Immunization Safety Review Committee was formed by the Institute of Medicine (Institute of medicine, 2004). This committee then proceeded to conduct an

exhaustive review for three years that included "five large epidemiological studies in the United States, the United Kingdom, Denmark, and Sweden" (National Academy of Sciences, 2004). After collecting and reviewing the research the committee ultimately found that there was overwhelming evidence that "childhood vaccines are not associated with autism" (National Academy of Sciences, 2004). Nonetheless, this was a conclusion the scientific and medical community had already established. Consequently, the question remains. If all those researchers had instead investigated autistic children with a broader lens regarding potential causes, could they have learned more about how to better help these children?

# The Herd to Follow: Herd Immunity

Another consequence that needs to be considered with regards to the popularization of Wakefield's study is the decline in the number of parents choosing to have their child receive immunizations. This was observed in England where more parents began refusing the MMR vaccine after Wakefield's study was released in 1998. In fact, vaccination rates dropped from 91% in 1998 to below 80% in 2003 (Flaherty, 2011). This dip may seem relatively small, but with regards to highly contagious diseases such as measles, this immunity level is too low. In order to acquire herd immunity with diseases such as measles total prevalence of immunity must be at least 90% or higher (Fox, 1983).

By not achieving this level of immunity, widespread outbreaks can occur. This is demonstrated by the quick diffusion of measles throughout the United States after Disneyland tourists were unknowingly exposed to the virus (Zipprich et. al., 2015). The

report published by the CDC on February 20<sup>th</sup> notes that by February 11<sup>th</sup>, 125 cases of measles had been reported after initial exposure of 39 patients on December 16<sup>th</sup> to December 20<sup>th</sup> (i.e. two months prior), but transmissions were noted to still be ongoing (Zipprich et. al., 2015). As you can see from this report, only a brief period of time was needed to acquire the measles virus. Consequently, as the number of virus carriers increased, the number of cases also increased.

It must also be noted that this wasn't an isolated event. In fact, out of the 125 patients, 15 were not California residents, meaning they lived out of state. For that reason, the possibility of more outbreaks occurring throughout the country became possible. After all, you must remember that in this day and age you live in a globalized world. Consequently, you will encounter other people from different countries that still have regular occurrences of vaccine preventable diseases. Furthermore, popular tourist destinations or attractions such as Disneyland can have 24 million people attend annually (Zipprich et. al., 2015) including international visitors. As a result, these areas act as prime transmission zones for contagious diseases such as measles. Some may argue that these areas should be closed off to foreign visitors, but such would diminish the economic gains tourism provides. Instead, it is advised that you get vaccinated.

However, it may be argued that no casualties resulted from the outbreak at Disneyland. As a result, why take the risk of any neurodevelopmental disorders or other adverse side effects if outbreaks only occur once in a while? The likelihood of contracting the diseases is low after all. Additionally, modern medicine is able to cure these types of diseases if you happen to contract it. Why is there a need to take preventive

measures then? This brings us back to the concept of herd immunity. Medical professionals and scientists constantly justify vaccines stating it will ensure herd immunity because more individuals would be immune to the diseases; thus, the number of disease incidences would remain low. Nonetheless, even though they always explain this concept, they can never quite get their point across. The reason being that the benefits of herd immunity are hard to visualize statistically. After all, when comparing large percentages such as 91% or 80%, one may assume that a majority of the population is vaccinated. But, that is not always the case.

## No man is an island: Unvaccinated pocket populations:

To take a case in point, the national average of Hib vaccination for infants 19-35 months is 82.7% (CDC). Conversely, there still remains 17.3% of infants who aren't vaccinated. Now, this may not be a problem if these unvaccinated individuals are surrounded by those who have been vaccinated against Hib (i.e. are immune to Hib so they won't be able to transmit the disease to others). However, if an unvaccinated individual, an individual who can't be vaccinated, or an individual who the vaccine is ineffective against find themselves in a pocket of other unvaccinated individuals the disease can easily be transmitted to unsuspecting targets.

January 23, 2008 15-month old Julienna Metcalf did not wake up from her daily nap on time. She had been running a temperature, but her mother, Brendalee, assumed she was suffering from typical cold symptoms, but [she] grew alarmed when Julienna could not hold her head up in the bathtub, similar to a newborn. Brendalee rushed her daughter to the hospital, where doctors suspected a

particularly severe case of influenza. After intravenous fluids did not quell Julienna's symptoms, the doctor admitted her for an overnight stay. [Further] testing revealed Julienna suffered from an immune deficiency, which prevented vaccines from working as well as they should. [As a result, after contracting Hib that January] Julienna endured several seizures, brain surgery to remove a mass of fluid, sleepless nights in intensive care and endless days attached to a ventilator, but was finally released from the hospital on February 15, 2008. Though she overcame the infection, she lost all motor skills, including the ability to swallow,

Julienna's story highlights an important principle behind vaccinations: vaccinating yourself doesn't only prevent you from getting sick, but also many others who are too old, too young, or too sick to be vaccinated. For that reason, the effects of choosing not to vaccinate aren't isolative. That is to say, they don't only affect the individual who decided not to vaccinate. Instead, they also affect those around them. With regards to Julienna, the community she lived in subscribed to the idea that vaccines are more harmful than the diseases they prevent which is why many of them chose to not vaccinate (Mnookin, 2011, p.271). However, there was a price for that choice and it was paid by Julienna and her family who never made that choice.

crawl, walk, or speak (Victims of vaccine-preventable disease, n.d.).

In fact, many of the victims of vaccine preventable diseases are those who don't get to choose if they are affected or not. Nonetheless, they tend to live in these pockets of the population that choose not to vaccinate. However, not only do these unvaccinated populations endanger those who can't be vaccinated, they also become dangerous

breeding grounds for disease outbreaks. To take case in point, in January 2008 an intentionally unvaccinated child in San Diego returned from Switzerland carrying the measles virus which ultimately led to one of the largest outbreaks in the area since 1991 (Sugerman, et. al., 2010). Again, this study illustrated how even though the nation as a whole had high rates of vaccination rates against measles because of the pockets of the populace that chose not to vaccinate the disease spread rapidly infecting students in a charter school and young children at a pediatrician's office which in turn led to the potential exposure of even more individuals.

As seen from this case, a single individual can lead to the infection of many in a short period of time. Particularly alarming is the fact that some of the children from the charter school who did fall ill went to their pediatrician. This location, unlike some others, have young infants visiting. This leads to their exposure to a deadlier form of the disease since they are either too young to be vaccinated or are just receiving the vaccination that day. Consequently, it must be reiterated that when choosing not to vaccinate you do not only endanger yourself but also those you encounter within a shared space.

### The Price is Right (Vaccine Edition)

Furthermore, choosing to vaccinate is cheaper. The reason being that getting vaccinated prevents the likelihood that you will contract the disease or a deadlier form of the disease. Such prevents families, like Julienna's, from having to pay steep hospital bills for the care of their child. This is particularly important for those who live in the margins and can't afford to have their children hospitalized. In fact, according to the

CDC the cost of hospitalizing a child for a vaccine preventable disease ranges from \$3,000-\$100,000 based on the severity of the disease contracted.

By comparison, the cost of receiving a vaccine ranges only from approximately \$8-\$22 (CDC). As you can see, the cost of hospitalizing a child after contracting a vaccine preventable disease can be quite costly. For that reason, those living in poverty would be burdened financially especially if uninsured. Furthermore, since this population may not even be able to vaccinate their child due to time constraints they become a potentially unvaccinated group that needs to be protected by herd immunity. Also, unlike those in the middle and higher classes, they may not have the luxury of personal transportation or time to care and watch over their child if they do become ill (Kirkland, 2016). Consequently, their child's fate and future remains uncertain.

#### Dangers of Misinformation: Haphazard Experimentation

Although low herd immunity and misdirection of research funding are major concerns due to the many consequences listed above, there is one overarching problem that persists. This problem is the preservation and continuing support of a divisive narrative that mistrusts medical professionals and prioritizes alternative medical practices. If this polarizing narrative continues a greater divide and communication gap will be established as frustration and mistrust continue to grow on both sides.

Also, as learned previously mistrust and paranoia can give birth to conspiracy theories, and once these theories have taken hold and mistrust has developed you become more susceptible to other conspiracy theories. In fact, Brotherton points out that once you have decided to buy into one conspiracy theory you will most likely buy into many others (Brotherton, 2015, p.89). Various studies have found that Americans who believe that the government hides aliens in Area 51 are also more likely to believe vaccines are unsafe (Brotherton, 2015, p.91). Furthermore, once you've been established as a conspiracy theorist you may also be more likely to reject mainstream science and its products (Brothrton, 2015, p.124). This is quite alarming since mainstream science offers robust evidence that can help inform your choices and ensure your safety. If you refuse the knowledge that is established you may find yourself experimenting with your own health. Now others may argue that you should experiment to find what is best for you. However, if those choices are uninformed or are influenced by those who wish to take advantage and profit from you, disastrous consequences can result.

Such is demonstrated by the parents who decided to reject mainstream science after they believed their children became autistic due to vaccines. Instead of treating or seeking help from medical professionals on how to best handle their child's autism, they turned to alternative medical practices (Tsouderos & Callahan, 2009). One such treatment being chelation therapy with the drug succimer. While seemingly able to directly target the supposed cause of autism (i.e. presence of mercury) the drugs used are experimental and can be harmful. This is illustrated by the studies performed on the drug succimer. In the past, this drug was being investigated as a treatment for children with high lead exposures to see if there was improvement in cognitive development (Rogan et. al., 2004). Nonetheless, the study found that the drug wasn't effective in improving cognitive development in children. Additionally, another study utilizing a rat model found that lack of lead exposure may lead to cognitive dysfunction when being treated with succimer

(Stangle et. al., 2007). As a result, trying experimental therapies may not only cost money, but also a child's health.

#### Come to the dark side, there's hope

Although, you must not blame these parents for their rejection of mainstream science. The reason being is that they are desperately searching for hope. Hope, that their child can be normal and live a good life. In order to have this hope, they need to have answers as to what is the best way to help their child. However, the answers and hope science provides appear to be quite small in comparison to those offered by alternative medicine. As pointed out by Dr. James Laidler, you can get "hooked on the hope" individuals at autism conferences provide. He found that at these conferences "there were more treatments for autism than I could ever hope to try on my son, and every one of them had passionate promoters claiming that it had cured at least one autistic child" (Laidler, n.d.). This promise of hope is evident from an interview featuring Jenny McCarthy, a prime figure in the autism-vaccine movement: (Mnookin, 2011, p.252). In this interview she states, "Okay let's look at your choices. You have a choice of listening to the medical community which offers no hope, or you can listen to our community which offers hope...Our side at least gives you...somewhere to go".

# Problems with a Persistent Divisive Narrative

This idea that the medical community offers no hope while those of the antivaccine movement further establishes a divide between the two groups. Consequently, with their advice falling on deaf ears, scientists and medical professionals become frustrated leading to heated debates and arguments. This is illustrated by the

condescending rhetoric each side utilized to criticize the other party. On one hand, Dr. Stephen Cochi, head of the national immunization program at the CDC has characterized those a part of the anti-vaccine movement as "junk scientists and charlatans" (Levin, 2004).

Similarly, those in support of the anti-vaccine movement have sent notes to the CDC asking "how you people sleep straight in bed at night knowing all the lies you tell & the lives you know full well you destroy with the poisons you push & protect with your lives" (Harris & O'Connor, 2005). As a result of two distinct sides being established, a barrier to communication is raised which just widens the opportunity for misconceptions to spread since individuals tend to remain in information bubbles (e.g. social media circles). Additionally, since scientists do not hear the concerns of other individuals it becomes difficult for them to pinpoint what information is needed and how to best provide it to the populace.

# The Fight against Misinformation

"Falsehood flies, and the truth comes limping after it."

- Jonathan Swift, The Examiner, November 9th, 1710

As you've seen from the anti-vaccine movement, science needed to play catch up with the many conclusions other individuals were making. However, science is a slow process. That is to say, it doesn't immediately have the answers to all the questions. For that reason, it becomes quite a challenge to prevent any misconception from spreading. Nonetheless, you shouldn't be worried. Once the evidence is released to back up or invalidate previous conclusions everything should be cleared up and the truth will be revealed.

#### A Double Edged Blade: Correcting misconceptions may strengthen them

Sadly, as you've also seen with the anti-vaccine movement, there can be push back from others in accepting the conclusions brought up by the science community. One of the reasons for this is due to the backfire effect or as Brotherton likes to call it "the ultimate demonstration of confirmation bias" (Brotherton, 2015, p.233). This effect is so powerful that it allows people to convert a contradicting fact into one that supports their beliefs. As an example, when Dr. Brendan Nyhan, an assistant professor of political science at Dartmouth, sought to correct the misconception sparked by Sarah Palin concerning death panels in the Affordable Care Act, he received some push back. While the corrective information they provided did help to clear up the misunderstanding for some people (i.e. those less knowledgeable about the issue or not supportive of Palin), they still found that those who were particularly supportive of Palin and knowledgeable still held on to the belief that death panels were a part of the Affordable Care Act (Nyhan, Reifler, & Ubel, 2013).

The reason for this effect may be attributed to the difficulty individuals have in admitting that they are wrong. As neurologist Robert Burton pointed out, you live in a society where you are penalized if you don't give the right answer. This is evident from the tests and quizzes children receive in school, the more answers they get correct the higher their score will be. These higher scores are then rewarded with academic honors. Nonetheless, Burton points out that this feeling of being correct and being rewarded for being correct can be addicting. Consequently, like many addictions the feeling that something is right can be difficult to unravel. This is shown in the Challenger space shuttle study (Neisser & Harsch, 1992), where researchers had participating students describe where they were when the Challenger exploded. Students were then asked to repeat this exercise three years later. It may be no surprise that there were inconsistencies between the past and current accounts; however, what was most striking was the denial of some students when confronted about the differences between their previous and current accounts. One participant even went so far as saying "that's my handwriting, but that's not what happened".

## When is too much information too much?

However, we must not completely dismiss the aid corrective information provides since in Nyhan's study, it did help clear up the misunderstanding for individuals who weren't in full support of Palin or were less knowledgeable. Nevertheless, the question

remains. How should you relay that information? The reason you need to ask this question is that even though corrective information can help out those who are sitting on the fence, flooding these individuals with all the evidence and data regarding vaccine safety (e.g. all its potential risks and benefits) may still not be the best way to communicate what scientists have learned about. The reason being that when you provide an individual with lots of information on how to weigh their decision, it becomes more complex. According to a study performed by Dijksterhuis et. al. (2006), conscious decisions (i.e. decisions where you weigh all the options) aren't optimal for complex deliberation. In their study, participants who made a conscious decision about which car to buy under complex circumstances (i.e. comparing twelve car attributes) often chose poorly in contrast to simpler conditions (i.e. comparing four car attributes).

Additionally, much of the public are what David Ropeik (2010) classify (including himself) as innumerate. That is to say, they are not good with numbers making it difficult to interpret all of the statistical information provided on various risks such as the risk of a child having an adverse reaction to a vaccine. This would not be much of a problem if there was another way risks were communicated; however, as Ropeik (2010) points out in his book *How Risky is it Really?*, "numbers are a large part of how we learn about risk" (Ropeik, 2010, p.53) yet a lot of the population is not as skilled at understanding what those numbers mean. Currently, the primary cause for innumeracy hasn't been addressed, but it has been found that innumeracy is independent of education level (Ropeik, 2010, p.55). In a clinical study by Forrow, Taylor, and Arnold (1992), they found that when doctors were presented the results of the same study in different ways (relative risk versus absolute risk), it led doctors to prescribe different treatments based on the way the risk was presented statistically. As a result, this suggests that information of not only risk, but also science needs to be presented in another form other than numerical.

## Tools of the trade: How to combat misinformation and misconceptions

More research still needs to be done in order to identify the form scientific information can take to best ensure the public's understanding. Nonetheless, what can be done now in order to limit the spread of misinformation with current forms of communication? According to a study done by Horne et. al. (2015) the best type of information to present people with to combat anti-vaccination attitudes is still factual information. However, you may argue that images and narratives would be more effective when combating these attitudes. After all, as you've seen from the anti-vaccine movement, many of their arguments are emotionally based, not factual, so why not use the same tactics.

Unfortunately, another study has found that dramatic narratives and imagery of children suffering from vaccine preventable diseases can actually lead to parents choosing not to vaccinate (Nyhan et. al., 2014). Hearing these narratives and seeing the images of how the disease manifests increases concerns regarding vaccine safety. Although the study doesn't explicitly state why this is the case, one possible reason is that since parents had a better understanding of what a vaccine was and the disease it prevented they may find the idea of injecting the weakened form of the disease too risky. For, how do they know that their child wouldn't suffer from the complications listed or

even contract the actual disease from the vaccine? In short, dramatic narratives and disease imagery may frame the risks of vaccination as being greater than they actually are.

But, if narratives and images are counter intuitive what else can the scientific and medical communities do in order to relay the facts they have acquired? After all, as you have seen, there still remains a communication barrier due to most vaccine information being relayed numerically. Additionally, relaying corrective information isn't enough. According to a study investigating the effects of correcting influenza vaccine myths, providing individuals with corrective information "reduced intent to vaccinate among respondents with high levels of concern about vaccine side effects" (Nyhan & Reifler, 2015, p.1). For that reason, the answer to this question lies in the communication of this information. In an article by Goldstein, MacDonald, and Guirguis (2015) (individuals involved in vaccine communication and education), they emphasize the importance in designing a communication plan for health information that is proactive, listens, and is diverse in communication methods. The last two components are particularly important with regards to anti-vaccine attitudes. The reason being that many of the narratives presented by the anti-vaccine movement have a common theme of dismissive doctors who don't truly listen to the worries and concerns of parents.

Consequently, medical professionals, when interacting with patients, must not simply tell the patient information, but also engage them in a dialogue to further understand their interpretation of that information. Such would allow for medical professionals to be able to make the information more relevant. How does this dialogue

assist in making the information provided more relevant you may ask? As explained by Ropeik, when communicating risk it's not enough to relay the facts. Instead, the facts need to be offered "in ways that are most emotionally relevant" (Ropeik, 2010, p.250). Consequently, if how you perceive risk is accounted for, a greater understanding of the risks posed are achieved. Furthermore, opening up the dialogue between doctors and patients will allows for the development of trust due to patients feeling respected as their concerns are addressed and not dismissed. Such will prevent a patient from developing complete distrust of medical practices and scientific information.

#### The Eternal Battle: Combatting Misinformation is continuous and never-ending

Nevertheless, even though some methods of combatting misinformation have been successful they still remain imperfect. Such is the case for the method of providing corrective information to parents about the MMR vaccine and autism. It was found that even though providing corrective information from the CDC website was successful in the correction of misperceptions about the MMR vaccine and autism, the information still decreased the intent to vaccinate in parents with the least favorable views of vaccines (Nyahn et. al., 2014). Nonetheless, this is to be expected. After all, humans are not rational creatures, at times the reasons for a decision is actually quite fickle due to emotions. You can't remove that part of yourself, so you just have to constantly analyze and reflect on the motivations behind those decisions. Such is why "objectivity resides in recognizing your preferences and then subjecting them to harsh scrutiny" (Gould, 2000, p. 104-105). With respect to misinformation, this means that you cannot be idle. Scrutinizing your biases and the information that motivates your decisions to ensure the

best possible choice is a never ending battle. As seen from the anti-vaccine movement, the scientific community can quickly fall behind in communicating its findings. One reason for falling behind is the assumption that science represents truth to society; however, we have seen that this is not always the case.

As a result, the scientific community needs to be vigilant and attentive, ready to inform the public and prevent misinformation from spreading by finding new ways to communicate information to the public effectively. One way this has been done is by ensuring the public can easily access the correct information through trusted websites such as the CDC. Additionally, to prevent any disconnect between scientists and the public in terms of communication, social media platforms could be utilized to create forums where people can ask experts about questions or concerns they have. To take a case in point, a company known as Hello health allows individuals to contact a patient by instant message or video chat (Hawn, 2009). This platform was especially useful to Michel Rovner when he was working in Brussels, and allowed him to receive immediate advice and the correct treatment even with a language barrier present.

His Belgian translator kindly got him an appointment at a local private clinic, but he didn't speak Flemish, and he didn't know what to ask the doctors. Fortunately, Hello Health's Dr. Khozin was "on call"—and online. With a few e-mails and text messages, Dr.Khozin told Rovner what to ask (Hawn, 2009, p.368).

Nonetheless, scientists don't have to remain passive and can play a more active role by using social media platforms to address issues they care about or even inform the public about new research in their field they find relevant or will be illuminating for the public

with regards to everyday life. Many scientists already do this through publishing of articles for popular science magazines or even writing their own blogs that can be focused or broad depending on their interests. Ultimately, by taking advantage of many forms of communication and targeting many audiences, greater diffusion of information can occur allowing for dialogue. After all, it may only take a few voices to create a movement, but it takes a conversation to break-down barriers and create change.

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