

ONLINE VACCINE OPPOSITION:
IDENTIFYING TRENDS AND CONTEXTUALIZING CRITICISM

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ABSTRACT

While there are studies that have been done to show how content attributes of vaccine-critical websites have changed over time, there is very little discussion about the social and historical context of that criticism or the theoretical framework through which that criticism can be understood. To fully understand vaccine opposition requires knowing why that criticism exists, the context through which criticism trends arises, and why this criticism is taking place specifically online. Data with context is infinitely more valuable.

The purpose of this study was to identify the current trends in vaccine opposition on the internet through an examination of the content attributes of vaccine-critical websites, to situate current criticism socially and historically, and explore the theoretical basis for criticism like this residing on the internet. In addition, it aims to broaden and deepen an earlier analysis performed by Sandra Bean in 2011. To do this, vaccine-critical websites were identified through major

search engine queries and snowball-type sampling from links to additional sites off the websites previously identified. The content attributes of each website homepage were analyzed through a content analysis that utilized both the codebook used in Bean's 2011 study as well as an expanded range of codes to better facilitate the comparison of the two.

It was discovered that three content attributes appeared on more than 50 percent of the websites analyzed. One of the three attributes ("vaccines cause idiopathic illness, damage, or death") was also found on more than 50 percent of Bean's (2011) websites, which suggests that the attribute is part of an enduring theme in criticism. The other two attributes ("violation of civil liberties" and "informed choices") did not appear as frequently in Bean's (2011) study and suggest that current themes of criticism involve issues of individual freedom and bodily autonomy.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of Arts and Sciences have examined a thesis titled “Online Vaccine Opposition: Identifying Trends and Contextualizing Criticism,” presented by Sarah Ann Czech, candidate for the Master of Arts degree, and certify that in their opinion it is worthy of acceptance.

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CONTENTS

ABSTRACT.....	iii
LIST OF TABLES	viii
LIST OF ILLUSTRATIONS	ix
Chapter	
1. INTRODUCTION.....	1
2. LITERATURE REVIEW	4
3. THEORY	9
Cultural Cognition	9
The Social Construction of Reality	11
Foucault, Power, and Knowledge	13
Gendered Nature of Vaccine Opposition	20
Shifting Information Sharing Models	23
4. METHODOLOGY	27
5. RESULTS AND CONCLUSIONS.....	33
Similarities.....	34
Differences.....	39
Limitations and Future Research.....	45
REFERENCE LIST.....	48

VITA.....	51
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TABLES

Table	Page
4.1 34 Websites Containing Vaccine-Critical Messages Examined.....	31
5.1 Content Attribute Results (34 websites examined).....	33

ILLUSTRATIONS

Figure		Page
5.1	Number of Pharmaceutical Industry Settlements in the United States, 1991- July 18, 2012.....	35

CHAPTER 1

INTRODUCTION

Kennedy et al. (2005) found through their survey that parents opposed to vaccinating their children were more likely than parents who support immunizations to agree that 1) the body can protect itself without vaccines, 2) vaccines are not or only somewhat important to a child's health, 3) vaccines are given to prevent diseases that are not serious, 4) vaccines are unsafe or only somewhat safe, 5) they are not or only somewhat confident in the safety of childhood vaccines, and 6) that children receive too many vaccines in the first two years of life (Kennedy et al. 2005). Similar results can be found in the telephone surveys that Gellin et al. administrated in their 2000 study of whether or not parents understand immunizations. While the majority of the respondents agreed with and believed in the evidence regarding vaccination safety and efficacy, nineteen percent of respondents did not (Gellin et al. 2000:1099). Their study also found that twenty-three percent of parents reported believing that children receive too many vaccinations and twenty-five percent felt that the number of vaccinations the children receive might not be good for their immune systems (Gellin et al. 2000:1099). An additional study suggests that the primary concerns of parents who decide to opt out of vaccinating their children center around civil/legal rights, the safety of vaccines, and the possible influence of pharmaceutical companies on the government and/or medical professionals (Gullion et al. 2008).

A number of factors have been identified that might influence those parental concerns regarding vaccines. Pru Hobson-West suggests that the choice to vaccinate or not is intimately tied to the individual's perception of risk and trust (Hobson-West 2007). She cites Poltorak et al (2005) when she says that "choosing to vaccinate does not necessarily imply

trust” but that it is rather “more a lack of confidence in the knowledge needed to justify non-vaccination” (Hobson-West 2007:200). Hobson-west studied organized vaccination resistance groups and found that their opposition is a challenge to the accepted notions of vaccine criticism being about rugged individualism and actually about reframing these ideas about risk and trust from the standpoint of someone who is or will be injected or one whose child will be. For these parents, “risk” is all of the unknowns and uncertainties. One of those unknowns is whether or not it is acceptable for the same people who benefit from vaccination mandates to be able to determine the threshold for what an acceptable risk is with vaccines. When the unknown is greater than the individual’s knowledge, the risk is perceived as too great and there lies the lack of trust in the medical community (Hobson-West 2007).

The source of knowledge about vaccines has been shown to have an influence on parents’ opinions on immunizations as well. Anna Kata (2009) described the abundance of misinformation that consumers have access to due to the internet as a “postmodern Pandora’s box”. She suggests that anti-vaccination information on the internet is not just misinformation, but a type of discourse that rejects scientific and medical facts in favor of alternative health methods, personal interpretations, and “distrust of expertise” (Kata 2009:1709).

Choosing whether or not to vaccinate is a very personal decision. The survey results from Kennedy et al. and Gellin et al. do a fantastic job of shedding light on the type of reasons individuals report to have for choosing whether or not to vaccinate. This research, however, aims to focus specifically on those who are critical of vaccines or the vaccination schedule. Since vaccine criticism is a fairly rare phenomenon, and finding critical individuals to interview or survey would be incredibly time and resource consuming, the

focus of this research is on collective representations of vaccine criticism. How is vaccine opposition being framed by those who are critical of vaccines? How has criticism changed over time? What are the factors that have led to the evolution of recent vaccine criticism? This research aims to answer these questions by examining vaccine-critical websites, identifying content trends and themes, and contextualizing that criticism.

This research paper will first illustrate the previous research that has been done on the topic of vaccine-critical websites by introducing the works of Sandra Bean (2011), Anna Kata (2009), Davies et al. (2002), and Wolfe et al. (2002). After establishing what gap this research aims to fill in the existing literature, classical social theories will be used to explain both vaccine criticism in general and vaccine-critical websites in particular. After presenting the methodological approaches used to gather data, the results will be examined noting the similarities and differences between the results of this study and Bean's 2011 research while also trying to contextualize major themes in both works socially and historically. Finally, the limitations of this research will be addressed as well as suggestions for future research.

CHAPTER 2

LITERATURE REVIEW

When researching the topic of online vaccine opposition, it was discovered that there is very little academic research that has been done on the subject. While criticism of the safety and efficacy of vaccines is not a new phenomenon, as was addressed in the introduction, the ability for vaccine critics to gather through online communities is fairly new. This chapter will examine the works of Bean (2011), Kata (2009), Davies et al. (2002), and Wolfe et al. (2002) and discuss their findings regarding online vaccine opposition. Then, the limitations of those works will be addressed. Finally, it will be discussed how this research will not only identify trends in vaccine opposition online, but also examine the context of the criticism against modern vaccinations to help form a theoretical framework through which this type of online activism can be understood.

Sandra Bean's 2011 study on continuing and emerging trends in vaccine opposition website content served as a blueprint of sorts for this study. Her research examined vaccine-critical websites from three previous studies (Kata 2009, Davies et al. 2002, Wolfe et al. 2002) plus a set of vaccine-critical websites that she produced through a search engine query, on the basis of sets of attributes that fell under three themes: content attributes, design attributes, and credibility attributes. Bean relied on utilizing the same methods as Kata (2009), Davies et al. (2002), and Wolfe et al. (2002) to maintain methodological continuity with previous studies on the same topic.

The purpose of her study was to analyze the attributes of the vaccine-critical websites that she had gathered and compare her findings to those of previous studies of the same

nature. After determining the similarities and differences between her study and the previous research done by Kata (2009), Davies et al. (2002), and Wolfe et al. (2002), Bean was able to determine what trends were evidenced in vaccine opposition website content. She also documented new themes that had not been present in previous studies and identified these themes as emerging trends in vaccine opposition.

The issue that Bean addresses in her work is the ever-changing nature of online vaccine criticism and the kinds of challenges that such criticism creates for healthcare professionals. Bean claims that anti-vaccination websites are not a tool for convincing pro-vaccination individuals that vaccines are less safe and less effective than the medical establishment would lead you to believe, but that they “appeal to persons searching the Internet for vaccine information that reinforces their predilection to avoid vaccination for themselves or their children” (Bean 2011:1874). She concludes that monitoring the changes in vaccine-critical rhetoric online may give healthcare workers some insight into the concerns that vaccine opponents have about traditional vaccines and schedules, but attempting to challenge the websites or their creators with scare tactics or facts and figures that support the claims of the safety and effectiveness of vaccines is a misguided effort. Those types of strategies may be effective for encouraging vaccine supporters to keep their vaccinations up to date, but it is likely to do little for the people that are steadfast in their conviction that vaccines do more harm than good, which is who vaccine-critical websites are created for.

Unlike Bean, the works of Kata (2009), Davies et al. (2002) and Wolfe et al. (2002) do not examine the nature of online vaccine criticism over time by comparing their findings with previous studies. Instead, they each offer a snapshot of what online vaccine-critical activism looked like during the time frame of their research and what interpretations they had

for their results.

Anna Kata (2009) searched for keywords “vaccine”, “vaccination”, and “immunization OR immunisation” on both the American Google search engine (google.com) and the Canadian Google search engine (google.ca). Out of the 180 results, Kata only found eight sites that she classified as anti-vaccination. While the number of websites that Davies et al. (2002), Wolfe et al.(2002), and Bean (2009) examined in each of their studies was less than one hundred, Kata’s was by far the study with the smallest number of websites being analyzed. She found that common themes included, “worries over safety, encroachments on individual rights, distrust of scientific authority, advocating ‘natural healing’, promoting sanitary reform, disbelief in theories of contagion, and alleging monetary motivations as the driving force behind immunization” (Kata 2009:1714).

Kata suggests that anti-vaccination information on the internet is not just misinformation, but a type of discourse that rejects scientific and medical facts in favor of alternative health methods, personal interpretations, and “distrust of expertise” (Kata 2009:1709). This type of information that Kata talks about contributes to what Gullion et al. call “popular epidemiology”. They say that, “rooted in the social context of the individual, lay knowledge arises from numerous sources of data, which, while [they] may be viewed as illegitimate by the expert, are nonetheless considered valid by the lay person” (Gullion et al. 2008:402-403). It is because of this that Kata claims that “combating vaccine misinformation with education is necessary, but not sufficient” (Kata 2009:1715). Medically and scientifically sound information can and should be presented as a rebuttal to misinformation, but the people who are going to believe the misinformation are not going to be swayed by the evidence that is presented to them by experts that they do not trust.

Davies et al. (2002) were able to identify forty-four websites as vaccine-critical through their web search of keywords, and then “further sites linked to this original cohort of 44 were methodically identified in order of discover until 100 sites had been located” (Davies et al. 2002:22). They found that more than fifty percent of the websites analyzed in their study included explicit claims that vaccines are harmful, ineffective, erode immunity, and are alleged to cause cancer, brain damage, sudden infant death syndrome, and autism. They conclude that there is an abundance of misinformation on the internet regarding vaccines, but that facts are secondary to the emotional appeal of the vaccine-critical arguments for parents of children for whom their illness or death could not be prevented by vaccination:

Much of the appeal of the antivaccination argument lies in the genuine pain of those touched by the tragedy of childhood death or illness. Where medicine is impotent to provide a culprit for many idiopathic disorders, antivaccinationists can fill that void, providing answers and solidarity for parents who feel abandoned by medical authorities. (Davies et al. 2002:24)

Wolfe et al. (2002) also had difficulty producing an adequate number of websites to analyze from their search engine query of ten keywords. Their search yielded twelve vaccine-critical websites, and ten more were discovered through links on the original twelve websites bringing the total number of sites analyzed to twenty-two. They found that the most common claims made by vaccine-critical websites included that vaccines cause idiopathic illness, vaccines erode immunity, adverse vaccine reactions are underreported, and that vaccination policy is motivated by profit (Wolfe et al. 2002:3246). Wolfe et al. conclude that vaccine-critical websites rely on

emotional appeal to get their message across and are concerned primarily with issues of vaccine safety and the perceived lack of trustworthiness of the medical community.

While the aforementioned studies all add valuable insight into the emerging and continuing trends in vaccine criticism online, they all failed to contextualize the criticism that they found socially or historically. For example, the complete retraction of the well-known Wakefield et al. article in the *Lancet* (an incredibly flawed study that suggested a link between a protein found in the intestines of autistic children and the mumps/measles/rubella vaccination they had received) happened in 2010, but there is no mention of what kind of effect this might have had on the types of criticisms that were found by Bean. Nor is it addressed how the Wakefield et al. paper, before retraction, might have had an effect on the work that came before Bean's.

There is also very little mention of possible theoretical bases for vaccine criticism in general or online vaccine criticism in particular. Bean's work touches on Kahan and Braman's 2005 work on cultural cognition, which helps to explain why this type of criticism is found online specifically, but she doesn't make this connection in her paper.

In an effort to fill some of those gaps, the goal of this paper is to not only identify themes and trends in vaccine criticism over time, but also point to the social and historical context from whence such criticism comes from and develop a theoretical basis for vaccine criticism as a whole as well as specific online activism. By addressing the contextual aspect of online vaccine criticism, this research aims to create a deeper and wider understanding of this socially driven phenomenon.

CHAPTER 3 THEORY

The existing literature on the theoretical basis of vaccine opposition is fairly narrow. We can broaden the theoretical foundations laid by previous studies of the same topic by incorporating wider aspects of various social theories into an interpretive lens through which the data gathered in this study can be contextualized and comparatively analyzed. This section will first examine the role that the theory of cultural cognition plays in understanding why vaccine criticism is taking place online. While cultural cognition does a good job of explaining why vaccine critics would connect online, it does not give a way to understand why the criticism of vaccines exists in the first place. For that, this study relies heavily on the work of Peter Berger and Thomas Luckmann, Michel Foucault, and Siva Vaidhyanathan among others. Through an exploration of the social construction of reality, power and authority, the gendered nature of health care, and information sharing models, this research will be able to shed light on the social factors that help expound vaccine criticism in general.

Cultural Cognition

Bean cites Kahan and Braman's 2005 paper regarding public policy and cultural cognition to illustrate how the theory of cultural cognition could explain why, in spite of a large body of scientific evidence that supports the safety and efficacy of vaccines, there are still people who seek out like-minded people via the internet to confirm or support their belief that vaccines are dangerous. Kahan and Braman (2005) state that cultural cognition is a set of processes that place cultural commitments (such as strongly held beliefs on gun regulation, the environment, and vaccines) "prior to factual beliefs on highly charged political issues" (Kahan and Braman 2005:145). Cultural commitments shape the processing

of information about politicized issues, and because of this citizens “take the word of those whom they trust on issues of what sorts of empirical claims, and what sorts of data supporting such claims, are credible” (Kahan and Braman 2005:149). Furthermore, the people “that they trust, naturally, are the ones who share their values--and who as a result of this same dynamic and others are predisposed to a particular view” (Kahan and Braman 2005:149). Kahan and Braman (2005) draw on the work of Douglas and Wildavsky (1982) regarding risk and culture to support their assertions on the subject. They claim that Douglas and Wildavsky’s work indicates that people have the tendency to focus on some risks and disregard others in a way that supports or reinforces the worldview they hold (Kahan and Braman 2005:152).

Vaccine critics, like vaccine advocates and any other group with cultural commitments, are more likely to trust the information coming from those who share a similar worldview. To find others that share a similar worldview, though, vaccine critics are relegated to seeking out such a community on the internet due to the relatively small number of people who oppose vaccines. To put into perspective just how few people visit vaccine critical websites, consider this: Facebook averages about 160 million unique visitors a month, the Center for Disease Control website averages about 4 million unique visitors a month, but nvic.org (a vaccine-critical website that was analyzed in this study and one of the top ten Google search results for the word “vaccine”) averages 100,000.¹ Using the framework for the theory of cultural cognition and applying it to vaccine criticism, it becomes clear how well it does at explaining why vaccine critics congregate on the internet.

1. SimilarWeb website search, “facebook.com,” “cdc.gov,” and “nvic.org”, <http://www.similarweb.com/website/> (accessed 19 Nov. 2014).

The Social Construction of Reality

In *The Social Construction of Reality* (1966), Berger and Luckmann illustrate how institutions are constructed and maintained through social interactions. Through this construction and maintenance, institutions become an objective social reality through which groups of people are able to share specialized knowledge. Berger and Luckmann describe an example whereby an institution is created by a generation, then the knowledge from that institution is passed down to the next generation, and that this process confirms the objective reality of the institution. For the parent generation that created or is maintaining the institution, transferring knowledge about the institution to the younger generation solidifies its social reality; it becomes “real in an ever more massive way and it can no longer be changed so readily” (Berger & Luckmann 1966:59). However, the younger generation views the institution as the only reality early in their socialization, but over time begin to realize that the world that has been passed down to them is not entirely transparent. “Since they had no part in shaping it, it confronts them as a given reality that, like nature, is opaque in places at least.” (Berger & Luckmann 1966:59).

In the example used above, the institution (like any) would need legitimation to explain and justify its existence to the next generation. As Berger and Luckmann state “...it is more likely that one will deviate from programs set up for one by others than from programs that one has helped establish oneself” (Berger & Luckmann 1966:62). A number of social factors may depend on the next generation adhering to the program that institutions present, but in order to fulfill those social factors, the institutions and society would need to provide some form of legitimation to be able to convince those skeptical of the authority and knowledge that the institution possesses. The legitimacy of medicine and health care as an institution, for example, is illustrated by the strict rules regarding who gets to produce knowledge for the institution and how. The medical field is legitimate because doctors have to attend certain schools, study certain subjects, and attain certain degrees of knowledge in order to be ordained experts in the field of medicine. They have to do research and let the vigor of that research be reviewed by their peers before they can become producers of knowledge for the

institution.

The example illustrated by Berger and Luckmann applies very well to the institution of health care and especially those critical of the obligatory nature of vaccines. The majority of health care providers have long since reached the consensus that the benefit of receiving vaccinations far outweighs the possible risks that one assumes when getting vaccinated. For this reason, it is fair to assume that the majority of vaccine critics are not health care providers, so they likely “had no part in shaping” the institution of health care as it stands today. Because of this, they may be more likely to “deviate from programs set up for one by others” and need legitimation to explain and justify the existence of the external force of the institution they did not set up. Questioning the safety and efficacy of vaccines when the majority of the medical community agrees that they are safe and effective is a prime example of this. The fact that the health care industry explains and justifies its claims of legitimacy regarding vaccination is evidence that vaccine-critical websites are viewed with concern by much of the American medical community.

Berger and Luckmann also assert that our experiences shape our perspective, which in turn shapes our subjective realities. Through the dialectical process of externalization, objectivation, and internalization, the individual constructs their subjective reality. By this, Berger and Luckmann mean that the individual member of society “simultaneously externalizes his own being into the social world and internalizes it as an objective reality” (Berger & Luckmann 1966:129). Individuals are able to interpret and assign meaning to objective events, thus creating subjective realities.

A great example of this in the debate between vaccine critics and health care professionals centers on the issue of serious adverse reactions to vaccines. It is an objective reality for both vaccine critics and health care professionals that there are people who, for one reason or another, suffer serious adverse reactions and are either injured or die as a result of receiving a vaccine. The difference in the perspectives of the two groups (guided by experiences and knowledge) creates two subjective realities out of one objective reality. Vaccine critics interpret the objective reality that some people are seriously injured by their body’s reaction to a vaccine as proof that vaccines are not

safe. This interpretation by vaccine critics is often fueled by their own personal experiences with a loved one suffering from an adverse reaction or the belief that a loved one suffered an adverse reaction. The websites analyzed in this study are littered with testimonials from people who claim that their child was developing normally and reaching all milestones until they went in for a round of vaccinations, and then their child's development suffered during a period following the vaccination. Experiences like those conveyed in the testimonials from parents who believe their child's development was hindered by an adverse reaction to a vaccine have consequences for the way that the objective reality that "some people have serious reactions to vaccines" is interpreted and given meaning.

Similarly, the medical community's experience and knowledge shapes their collective interpretation of the same objective reality. The scientific community's perception of the safety and efficacy of vaccines comes from the interpretation of the statistics gathered over the past fifty plus years on the topic. The statistics have shown time and again that the risk of a serious adverse reaction following vaccination is relatively small. The medical community interprets this fact as part of a statistically small risk that is inherent to any medicine or medical intervention. Likewise, a physician or pediatrician might use his or her experience with administering vaccines regularly throughout his or her career in interpreting the objective event by recalling the number of times a patient has suffered a bad reaction to a vaccine.

The objective event described here is shared by both vaccine critics and vaccine advocates: some people have damaging reactions to vaccines. However, how that objective event is interpreted (as proof that vaccines are not safe contra carrying a small, inherent risk) creates the subjective reality that separates the perspectives on vaccine safety between vaccine critics and vaccine advocates. So, while vaccine advocates have statistics to support their claims that vaccines are largely safe and effective, it does not change the subjective reality of vaccine injury to vaccine critics.

Foucault, Power, and Knowledge

For Berger and Luckmann, knowledge is intimately tied to the social construction of reality, and they touch on how power influences knowledge when they discuss the need for institutions to justify their place in society through legitimation. Michel Foucault's work on language and power and how the ability to control the way a subject is discussed, and by whom such a subject is discussed, is essential for understanding the dynamics of power and knowledge in the criticism of vaccines and why it is occurring primarily online.

Foucault wrote extensively on the subject of power. His perception of power was different than the authoritarian, oppressive, or dominating idea that comes to mind when one generally thinks about power being exerted, and especially when that power is being exerted on other human beings. In the past, power has been wielded in such a fashion; in some instances and places, it is still. However, in works like *Discipline and Punish* (1995) and interviews like *Power/Knowledge: Selected Interviews and Other Writings 1972-1977* (1980), Foucault argues both that power does not necessarily have to be the means to a negative end, and that those in power do not exert force from the top down. He says in an interview in *Power/Knowledge* (1980) that "power would be a fragile thing if its only function were to repress, if it worked only through the mode of censorship, exclusion, blockage, and repression," and later, "That is why the notion of repression which mechanisms of power are generally reduced to strikes me as very inadequate and possibly dangerous" (Power/Knowledge 1980:59). Real power and influence, he argues, is institutionalized. Those in power do not need to "police" the masses directly because individuals will be compelled to conform on their own or by peers.

For Foucault, knowledge is the basis for power. It is through knowledge about diseases, drugs, and the body that doctors, scientists, and chemists earn the certification by

the state that labels them as experts in their fields. Their power is legitimized through the bureaucratic label that they earn. As experts, medical professionals are given the honor of defining and describing diseases, disorders, illnesses, and treatments. Through the ability to shape vaccine discourse, they are also in a position to influence policy and ultimately law. All of this power that begets more power for medical professionals is based on the knowledge they acquired through their formal training in universities.

A useful tool for understanding vaccine discourse on the internet is Foucauldian discourse analysis. This type of analysis focuses on Foucauldian theories about language and power, specifically how controlling how a subject is discussed realizes power relations and creates more power relations. Kendall and Wickham (1999) outlined five steps for using the Foucaultian notion of discourse that they gleaned from an excerpt from Henriquez et al. (1984) where the authors carefully defined discourse.

The steps are as follows:

1. The recognition of a discourse as a corpus of ‘statements’ whose organisation is regular and systematic
2. The identification of rules of the production of statements
3. The identification of rules that delimit the sayable (which of course are never rules of closure);
4. The identification of rules that create the spaces in which new statements can be made;
5. The identification of rules that ensure that a practice is material and discursive at the same time. (Kendall and Wickham 1999:42)

Step one

When it comes to childhood vaccinations, there are already in place a set of statements that are organized in a regular and systematic way. One needs only to look at the informational pages on websites for major health organizations such as the CDC, FDA, and the American Academy of Pediatrics (AAP) to see that there is a method in place to talk

about childhood vaccines. When vaccines are discussed on any of these websites, such discussions often include 1. how vaccines are one of the greatest public health achievements in the 20th century; 2. how important high vaccination rates are to herd immunity and keeping those who cannot vaccinate safe; 3. that while vaccination may come with a small amount of risk of an adverse reaction it is far out-weighed by the benefit of guarding against vaccine preventable diseases; and 4. that vaccination is what is in the best interest of the health of our children and our communities. The experts in the medical community have created this dialogue, and organized it in a regular and systematic way.

However, vaccine critics do not seem satisfied by the discourse being dictated solely by the medical community. Online activism appears to be a way for vaccine critics to challenge the accepted role of the medical community and resist the mainstream discourse by creating their own counter-discourse. By examining the most frequently occurring content attributes on vaccine critical websites, we can conclude that the discourse about vaccines from vaccine critics emphasizes the importance of being informed about all aspects of vaccines before choosing whether or not to vaccinate, as well as the right to bodily autonomy.

Step 2

Step two for utilizing the Foucauldian notion of discourse analysis builds off step one. Once a set of statements on a topic has been found to be organized in a regular and systematic way, the next step is determining how those statements are made.

In much of the western world, it is generally accepted that the people who have the privilege of determining discourse are the acknowledged experts in their field. Max Weber wrote about the creation of the expert through bureaucracy saying that, “the more

complicated and specialized modern culture becomes, the more its external supporting apparatus demands the personally detached and strictly ‘objective’ expert” (Weber, Gerth and Mills 1946:216). It was established through modern bureaucracy that the way to prove legitimate expertise was to gain certification through a system of “rational, specialized, and expert examinations” that modern bureaucracy was prepared to oversee through educational institutions (Weber, Gerth and Mills 1946:240-241).

By going through the socially appropriate channels to obtain a diploma from an accredited university, those in the medical community are bestowed the opportunity of being deemed experts in their field. They have studied the biology and chemistry of the human body, the disease, and the medical interventions to prevent such diseases, and their degree confirms this to the world. They have the right credentials to have the power to influence the set of statements that make up the discourse surrounding vaccines and their safety and efficacy.

For vaccine critics and their counter-discourse, statements do not need to be made by anyone with specific credentials. Jenny McCarthy, a model, actress and outspoken vaccine critic, spoke passionately on an episode of Oprah Winfrey’s talk show in September of 2008 about her belief that a one-size-fits-all vaccination schedule for children is what led to her son, Evan, becoming autistic. When Oprah, the host, read a statement from the CDC stating that there is no science that supports the autism-vaccine claims, McCarthy replied, “At home, Evan is my science” (McCarthy 2008:6). For vaccine critics, expertise defined by a diploma or certification does not hold more value than a parent whose expertise is defined by their experiences with their child. This is emphasized by the incidence of areas on the vaccine critical websites dedicated to personal testimonials.

Step 3

After establishing how the statements that make up vaccination discourse can be made, the next step in the Foucauldian discourse analysis is to determine what can and cannot be said. In the context of vaccination and this research, the content attribute that appeared on over 50 percent of the websites analyzed in both Bean's (2011) study and this one was the claim that vaccines cause idiopathic illness, damage or death. This might be due to one of the things that cannot be said by the medical community in vaccine discourse: vaccines are 100 percent safe all of the time.

In fact, it is a statement that the medical community cannot ethically or legally claim about any drug or treatment, and one would be hard pressed to find someone in the medical community that would venture to do so. The fact of the matter is that with any medical intervention, there is a certain amount of risk involved. This is not to say then that all drugs are bad and that the medical community does not care about the safety of the drugs that they use, it is simply that diseases, drugs, and the human body are all more complicated than that. Can vaccines cause idiopathic illness, damage or death? Absolutely, but so can a daily multi-vitamin supplement if the person taking it is unaware that their body reacts negatively to one of the compounds used in the vitamin.

What cannot be said in the statements that make up the vaccine-critical version of vaccine discourse is that vaccines hold no societal benefit. In the same way that mainstream vaccine discourse cannot claim that vaccines are 100 percent safe for everybody under all circumstances, the majority of vaccine-critical discourse concede that vaccines are not entirely bad either. They acknowledge that there are societal benefits to vaccines, but only if they are made safe and effective.

Step 4

The fourth step is concerned with establishing where discursive statements can be made and how those spaces are created. For mainstream vaccine discourse, there are established locations for the creation of statements in the spaces that bureaucracy has deemed legitimate for the task. These settings are in places like the clinic, the laboratory, or in peer-reviewed journals where only appointed experts are allowed. The use of the idea of a “legitimate space” is due to the fact that the spaces are created in the same way that the experts are: they are made legitimate through bureaucratic certification.

For the counter-discourse produced by vaccine critics, the location of where statements can be made is more lax than mainstream discourse. Counter-discursive statements are largely made online, in and among communities of like-minded individuals. Statements are unlikely to be made in the legitimate spaces such as clinics or the peer-reviewed journals because those spaces have set rules about the statements made there and who is able to make them. Counter-discourse does not seem to have any such rules in place. The spaces where statements can be made are created out of the necessity of wanting to contribute to the discourse. The impression that is made by the bulk of the vaccine-critical websites analyzed in this study is that there is a desire to be active in vaccine discourse, but the inability to do so without an official status or without bureaucratically approved data.

Step 5

Finally, the fifth step in Foucauldian discourse analysis is ensuring that a practice is material as well as discursive. When Kendall and Wickham describe this in their explanation of each of the steps, they state how the rules ensure that “prison practices are always about discourses such as penology . . . *and* the materiality of prison structures and prison life”

(Kendall and Wickham 1999:45). Given this definition, mainstream ideas about vaccines are about discourses such as biology, chemistry, epidemiology, and statistics. It is through these sciences that mainstream vaccine discourse is both produced and framed. The materiality of vaccines can be found in the clinic where it is displayed through the improved health outcomes of children in the developing world when they have been introduced to vaccination.

While the mainstream discourse is produced and framed by the sciences, discourse is about anecdotal proof and the unknowns in the popularly accepted discourse for vaccine critics. It counters the assured statements from statistics and epidemiology that there is a one in one hundred thousand chance of experiencing an adverse reaction from a vaccine severe enough to disable or kill with the question about how a parent should be comfortable with those statistics when that “one” could be their child . . . or was their child. The materiality of their discourse can be found in the children who suddenly stopped developing normally or suddenly started developing health conditions that the medical world cannot explain, as well as the desperation of their parents for answers.

Gendered Nature of Vaccine Opposition

Surprisingly absent from previous analyses of online vaccine criticism has been the acknowledgment that since women, as a whole, are the majority of healthcare decision-makers in the United States, there is a gendered nature to vaccine opposition. According to the U.S. Department of Labor statistics, women make approximately eighty percent of family healthcare decisions and are most likely to care for a family member when one falls ill².

2. United States Department of Labor, “General Facts on Women and Job Based Health,” <http://www.dol.gov/ebsa/newsroom/fshlth5.html> (accessed 10 Jan. 2014).

Additionally, a 1996 study found that men were almost three-times more likely than women to have their health-seeking behavior influenced by the opposite sex (Norcross et al. 1996). It is clear, given these statistics, that women have enormous power over healthcare consumption and are highly influential in health-seeking behaviors.

The fact that women are the primary healthcare decision makers in families in the U.S. suggests that there might be a gendered nature to the most recent criticisms of vaccinations and vaccination schedules. Female-spearheaded criticism to healthcare, like vaccine criticism, is not a novel phenomenon and has its roots in a subsection of Second Wave feminism. Second Wave feminism, as described by the Encyclopedia Britannica, was the women's movement of the 1960s and 1970s where feminists were inspired by the Civil Rights movement and focused on issues of gender equality and justice.³ The Women's Health Movement (WHM) of the 1960s, and the feminist theories that came out of it, specifically focused on gender equality and bodily autonomy in women's health and provides a way of understanding where the recent healthcare related criticism is coming from and why the concept of "choice" figures so prominently on many vaccine-critical websites.

Some argue that the Women's Health Movement began in the early 20th Century with Margaret Sanger and the fight for women's reproductive rights through the use of birth control measures. However, the WHM as it is known today gained the traction necessary to qualify as a true social movement in the 1960s and 1970s. The broad goal of the movement was to fight for women's reproductive rights. The fight for reproductive rights culminated in the passage of *Roe v. Wade* in 1973 which struck down state laws that considered abortion

3. Encyclopedia Britannica online, "Feminism," <http://www.britannica.com/EBchecked/topic/724633/feminism/216009/The-postsuffrage-era#toc216008> (accessed 12 Jan. 2014).

illegal in any case other than in an effort to save the mother's life.⁴ The ruling found that state laws prohibiting abortion were broad and infringed on women's Ninth and Fourteenth Amendment rights.

After the victory of *Roe v. Wade*, the movement's focus shifted toward broader issues of women's health and women's role in health care decision making. It was during the 1970s that there was a rise in women's self-help groups that emerged out of women's dissatisfaction with health care (Nichols 2000:56). The problem that the movement found in the established health care system was that it was largely paternalistic and often coercive. The common goals of the women's self-help groups were "reclaiming power from the paternalistic and condescending medical community and assuming control of their own health" (Nichols 2000 on Greary 1995).

The core concept that ties together the WHM and the rise of vaccine-critical sentiment is the idea of paternalism. Paternalism, as described by Gerald Dworkin (1972), is the "interference with a person's liberty of action justified by reasons referring exclusively to the welfare . . . of the person being coerced." While the concept of paternalism does not appear as a content attribute in the analysis overtly, it will be argued that content attributes such as "government secrecy or cover-up", "profit/conflict of interest", and "vaccines are ineffective/temporary" serve as proxies for covert themes of paternalistic control.

Paternalism is framed as an attack on bodily autonomy in both the WHM and vaccine criticism. For the WHM, paternalistic control came in the form of barriers to reproductive freedom such as anti-choice politics and an increase in the number of emergency cesarean

4. Cornell University Law School, Legal Information Institute, "Roe V. Wade," http://www.law.cornell.edu/supct/html/historics/USSC_CR_0410_0113_ZS.html (accessed 12 Jan. 2014).

section deliveries (an increase large enough to make the necessity of such procedures questionable). For vaccine critics, it comes in the form of vaccination mandates for schools and some jobs. In both situations, bodily autonomy is viewed as under attack because they are required (sometimes by law) to have something done to their bodies that they do not agree with. It is not surprising, then, to see the theme of needing to be given the “choice” make the best health care decisions for one’s self and family from the WHM being echoed in modern vaccine criticism.

Shifting Information Sharing Models

The final key to understanding why vaccine criticism is found primarily on the internet lies in information sharing models. The information sharing model world-wide for most of the second half of the 20th Century was the broadcast model. In this model, information is broadcasted from a central information hub (like a television or radio station) out to an audience. This model works in only one direction, from broadcaster to audience, and is a passive method of information consumption. The audience cannot speak back to the broadcast, nor can they control the type of information that being presented for consumption from a broadcast unless they change to a different broadcast.

However, with the advent of the internet, information has become increasingly digitized. This, combined with the widespread use of the internet in recent decades, created a new option for information sharing: the peer-to-peer model. Peer-to-peer (p2p) information sharing is exactly what it seems in that it allows individuals to share information with other individuals and consume information from other individuals mutually and actively. Manuel Castells calls this type of p2p model one of “horizontal networks” and says that “horizontal networks of communication built around peoples’ initiatives, interests, and desires are

multimodal and incorporate many kinds of documents” (Castells 2010: xxviii). He says that these horizontal networks constitute a new form of communication that he calls “mass self-communication”:

It...is self-generated in content, self-directed in emission, and self-selected in reception by many who communicate with many. This is a new communication realm, and ultimately a new medium, whose backbone is made of computer networks, whose language is digital, and whose senders are globally distributed and globally interactive.

(Castells 2010: xxx-xxxii)

If a broadcast model is one person speaking and ninety-nine people listening, the p2p model is all one hundred people being able to speak and/or listen as they please.

Naturally, there are arguments for and against peer-to-peer information networks. While they allow almost anyone to be a producer of information, they also do not have any kind of gatekeeper to verify that the information being produced is true. They constantly create more information, but individual ideas get lost when millions of people are producing at the same time. All information is special and is given a space to be communicated, but when everything is special, nothing is.

Siva Vaidhyanathan described p2p communication networks in the intro to his book *The Anarchist in the Library* as a way to, “browse, use, reuse, alter, play with, distribute, share, and discuss information” and that “these are valuable behaviors that help creators and citizens shape their worlds. The strange interactions among technologies, ideologies, and desires that have emerged in the past decade have opened up new ways to be creators, consumers, and citizens” (Vaidhyanathan 2004: xii). However, with the rise of the freedom

in the ways that we exchange information (anarchy) through peer-to-peer information sharing, there became a rise in the perceived need to control it (oligarchy). Vaidhyanathan calls this an “information arms race” (Vaidhyanathan 2004:xii).

Both types of ideologies are dangerous on their own. Vaidhyanathan describes how with an information oligarchy basic freedoms of speech and expression are in danger of being denied, but an information anarchy allows “potentially dangerous and alarming expressions” to be easily found, distributed, or deployed (Vaidhyanathan 2004:xiii).

As distributed information systems gain prominence and importance, the reaction to them grows fierce. Distributed systems tend toward anarchy. Centralized systems tend toward oligarchy. The space between these models is shrinking, offering no middle ground, no third way.

Efforts to minimize the effects of too much freedom or too much information-based contraband tend to quash legitimate uses, as well as the flow of beneficial content. (Vaidhyanathan 2004: xiv)

Vaccine-critical sentiments online are often viewed by the medical community as potentially dangerous, while the monopolization of legitimized knowledge by the medical community is perceived as the ability to infringe on the personal freedoms of vaccine critics. While it is true that because of the unregulated nature of p2p networks there is misinformation about vaccine safety and efficacy on vaccine-critical websites that are potentially dangerous, it is important to recognize that the broadcast model comes with its own potential dangers. In 1983, the vast majority (ninety percent) of the American media was

controlled by fifty corporations, and now it is controlled by just six.⁵ It is not unreasonable to be suspicious about the enormous amount of power each of those six corporations wield in framing the public discussion about the safety and efficacy of vaccines. Just as the medical community is concerned that vaccine-critical rhetoric contains misinformation, vaccine-critical websites are concerned that the consolidation of power over the media has created misinformation as well. This type of online activism through a new form of information sharing is a method of civil resistance and utilizing the internet as a way to challenge accepted knowledge is a deliberate push back against the broadcast information sharing model.

5. Ashley Lutz, “These 6 Corporations Control 90% Of The Media In America,” <http://www.businessinsider.com/these-6-corporations-control-90-of-the-media-in-america-2012-6> (accessed 18 Oct. 2014).

CHAPTER 4 METHODOLOGY

The decision to use a content analysis approach to vaccine-critical literature was inspired by a website content analysis that was done by Sandra Bean in 2010 (published 2011). Bean used a popular search engine to identify the most common websites that appeared when searching for vaccine critical information and analyzed the websites' anti-vaccination rhetoric. She later followed up on the websites that had been cited in previous content analyses on the same topic and found that many had changed or even disappeared over time. This, she argues, points to the dynamic nature of the internet and the changing nature of the anti-vaccination arguments.

If the websites that Bean (2011) located through her literature review changed between the times those articles were examined and when Bean published, there is a possibility that there has been more change to the original websites and those located through Bean's search. In addition, aspects of anti-vaccination activists' focus could have changed or were being challenged between 2010 and 2013. For this research topic, a cross-sectional content analysis of vaccine-critical websites was deemed the most appropriate way to approach the data and to add to the body of knowledge about the rhetoric being employed by vaccine-critical websites.

In addition to keeping methodological continuity with Bean's (2011) research, content analysis offers a number of advantages when examining vaccine-critical sentiment on the internet. Being that content analysis studies documented texts and artifacts, it is a research method that is unobtrusive that can allow a researcher access to groups with very specific views and opinions without the group knowing that it is being observed. This is

important when observing vaccine criticism because the topic is sensitive in nature to begin with, and vaccine criticism is fairly uncommon. If one tried to employ another method of data collection, like interviewing individuals who make it known publicly that they are against vaccination, a researcher might run into issues of not being able to locate enough individuals to interview, having their data skewed due to the interviewee not being open and truthful during an interview on a sensitive topic like the medical decisions being made for his/her family, or the subject being more outspoken and radical than typical vaccine critics as shown by wanting to be interviewed about their criticism. With content analysis, researchers are not limited by the resources nearest to them and they can gather data without disturbing the group that they are studying. These two aspects create more data to be analyzed that is not altered or tainted by a researcher's presence, and make content analysis ideal for studying vaccine criticism on the internet.

To obtain the data for this study, the list of websites containing vaccine critical messages that were identified in online searches were performed between August and September of 2013 using the same ten keywords that were employed by Wolfe et al. (2002): *vaccine, vaccinate, vaccination, immunize, immunization, immunise, immunisation, anti-vaccination, anti-immunization, and anti-immunisation*. Each keyword was searched for on Google.com, Yahoo.com, and Bing.com (the three most commonly utilized search engines as determined by 2010 Nielsen ratings at the time that the data was gathered). In a study done by Eysenbach (2002), it was found that when internet users search for a certain term or keyword, ninety-seven percent of the time the users only view the first ten results.

Due to these findings, when each of the ten keywords were entered into each of the three major search engines, only sites in the first ten search results were viewed. When

viewing each website, only the homepage, or first page, was examined for vaccine-critical content. For the purpose of this research, a “homepage” is, “the page typically encountered first on a Web site that usually contains links to the other pages of the site” as defined by Merriam-Webster. If vaccine-critical content was found on the homepage, the website’s address was added to an Excel file under the keyword and search engine that produced it.

Determining whether or not vaccine-critical content was present on each website was somewhat subjective in that there were not key words, phrases, or images that were singled out as symbolizing vaccine criticism. On the whole, website content was determined to be vaccine critical if it declared the dangers posed by vaccines but none of the benefits; gave instructions on how to opt-out of vaccines through exemption laws; suggested connections between vaccinations and various diseases, ailments, and disorders such as autism, allergies, SIDS, and diabetes; suggested that there is a conflict of interest between the medical community/ “Big Pharma” and vaccination mandates; supported “natural”, “holistic”, or homeopathic medicine over traditional methods; or any combination of the above. The objective of the data collection was not to find anti-vaccination websites per se, but sites with the common theme of being critical or skeptical of vaccines and vaccination schedules.

By limiting the search to the ten most popular sites produced by each keyword in each search engine, only eleven websites emerged. Of those eleven sites, seven of them appeared on the list of websites that Bean (2011) analyzed and four did not. The limitation of utilizing only the ten most popular sites for each keyword searched is that vaccine-critical sentiment is fairly uncommon. By the very nature of the subject matter, there are not many websites that exist. The goal in limiting the search to the ten most popular sites was to

represent the vaccine critical websites that were most likely to show up when individuals search for the keywords provided.

Since very few websites were produced through the search engine results, the data gathering method needed to be redirected in order to gather more vaccine-critical websites. The focus shifted to a form of snowball sampling whereby the researcher followed links from vaccine-critical websites that had already been gathered to websites that did not emerge during the search engine query. This method produced five additional websites from www.avn.org.au, six additional websites from www.thinktwice.org, one additional website from www.nvic.org, two additional sites from [educateyourself.org](http://www.educateyourself.org), two additional sites from <http://www.nccn.net/~wwithin/vaccine>, three additional sites from vaccinations.inoz.com/links, and 4 additional websites from www.vaclib.org. In all, twenty-three new websites were added to the list. Adding in the eleven websites that were gathered from the search engine method, the total number of websites analyzed for this research was thirty-four. The names of the thirty-four websites utilized for this study as well as their location on the world wide web are located in Table 3.1

After data in the form of websites were established, screen shots were taken of the homepage of each site and coded using the same codebook that Bean (2011) established and used. These codes identified various vaccine-critical themes and characteristics and allowed for those features to be quantified. When new codes were discovered, they were added to the existing codebook. In total, ten new codes were added to the codebook that Bean established. Once all codes were recorded, row and column totals were figured to determine the number of codes that appeared on each site and the number of times during the coding of the 34 websites that each code appeared. The data from this research allowed for quantitative

analysis of the manifest content of vaccine-critical websites. Doing this gave the researcher the ability to determine what content attributes were most and least commonly being employed by vaccine-critical websites. By determining the most common content attributes, a picture can begin to develop regarding the fears and concerns of the vaccine-critical activists. Also, by determining the most and least common attributes, a spectrum can emerge between the concerns of the more mainstream activists and the websites that appeal to a school of thought that is more on the fringe.

Table 4.1: 34 Websites Containing Vaccine-Critical Messages Examined

Website Name	Web Address
National Vaccine Information Center	nvic.org
Natural News	naturalnews.com
Warnings About Vaccine Expectations (WAVE) NZ	ias.org.nz
Vaccination Liberation	vaclib.org
Think Twice	thinktwice.com
Australian Vaccination Network, Inc.	avn.org.au
Vaccine Dangers	vaccinedangers.com.au/anti-vaccine-networking-flyers/
Vaccination News	vaccinationnews.com
Vaccination Information & Choice Network	nccn.net/~wwwithin/vaccine.htm
The Truth About Gardasil	truthaboutgardasil.com
ChildhoodShots	childhoodshots.com
Vaccination Information Service	vaccine.inoz.com
Global Vaccine Awareness League	gval.com
Parents Requesting Open Vaccine Education (PROVE)	vaccineinfo.net
Kids Need Options With Vaccines (KNOW Vaccines)	know-vaccines.org
Maryland Coalition for Vaccine Choice	mdvaccinechoice.wordpress.com/

Table 4.1: 34 Websites Containing Vaccine-Critical Messages Examined
Continued

Website Name	Web Address
Michigan Opposing Mandatory Vaccines (M.O.M.)	momvaccines.org
NJ Alliance for Informed Choice in Vaccination	njaicv.org/
People Advocating Vaccine Education (PAVE)	vaccineducation.com
World Association For Vaccine Education (WAVE)	novaccine.com/vaccine-risks/
International Medical Council on Vaccination	vaccinationcouncil.org/start-here-2/
Vaccine Information Coalition (VIC)	vacinfo.org
Vaccine Free	vaccinefree.org/index.php
Educate Yourself	educate-yourself.org/vcd/
Vaccine Awakening - Barabara Loe Fisher Blog	vaccineawakening.blogspot.com/
Generation Rescue	generationrescue.org/resources/vaccination/
SmartVax	smartvax.com
Inside Vaccines	insidevaccines.com/wordpress/
Intuitive Parenting	intuitiveparenting.org/immunization/
Health Sentinel	healthsentinel.com
Immunization News - ReliableAnswers.com	reliableanswers.com/med/immunization. asp
Children of God for Life	cogforlife.org/category/vaccines/
International Medical Council on Vaccination	imcv.info/
Vaccines: Are They Really Safe and Effective?	vacbook.com/vac.htm

CHAPTER 5
RESULTS AND CONCLUSIONS

Table 5.1: Content Attribute Results (34 websites examined)

	N	%	% Bean
			(n=25)
Safety and Effectiveness			
Poisons, additives, or ingredients	15	44	80
Vaccines cause idiopathic illness, damage, or death	26	76	76
Vaccines erode immunity	2	6	32
Multiple simultaneous vaccines increase risk	3	9	12
Under-reporting of reactions	3	9	36
Vaccines are ineffective/temporary	12	35	32
Use of aborted fetal tissue	3	9	8
Diseases have declined	2	6	32
We don't know enough about vaccines to deem them safe	2	6	*
Vaccines are/have been contaminated	2	6	*
Naturally acquired immunity is better	4	12	*
Vaccines are not necessary	2	6	*
Civil Liberties			
Violation of civil liberties	18	53	44
Parental rights	10	29	16
Religious objections	2	6	*
Totalitarianism	4	12	20
Alternative treatments			
Alternative treatments	14	41	20
Critiquing biomedicine	1	3	4
Implied debate	2	6	16
“Back to nature”	3	9	24
Conspiracy theories/search for truth			
Profit/conflict of interest	6	18	52
Collusion	9	26	20
Government secrecy or cover-up	12	35	20
Manufactured threat	5	15	4

Rebel doctors	1	3	4
Fear-mongering	3	9	8
Unusual theories, if unique theories about the purposes of vaccination were presented	3	9	16
Privileged information	6	18	8
Informed choices	17	50	24
Herd immunity is a myth	1	3	*
Diseases were on the decline before the vaccine was created	1	3	*
Manipulation/coercion into vaccination	6	18	*
Surveillance	1	3	*
Paternalism	2	6	*

* Denotes a new code that was not a part of Bean's 2011 codebook

As expected, there were some thematic similarities in content attributes between the results of this study and Bean's 2011 research, and there were some differences. This chapter will examine those similarities and differences while also discussing the possible contextual influences for the major themes observed in both studies. Finally, the methodological limitations to this research will be addressed as well as suggestions for future research.

Similarities

Both studies found that a common concern among vaccine criticism was the claim that vaccines cause idiopathic illness, damage, or death. In Bean's (2011) study, the content attribute concerning vaccines causing bodily harm appeared on nineteen of the twenty five websites analyzed. In this research, it appeared on twenty six of the thirty four websites analyzed. In both studies, the content attribute claiming that vaccines cause idiopathic illness, damage, or death appeared on seventy six percent of the websites examined. As such, it was the most commonly occurring content attribute in this study and the attribute appeared in twenty three percent more websites than the next most common attribute

(violation of civil liberties, fifty three percent of websites analyzed). In Bean’s (2011) study, it was the second most common attribute behind the concern of poisons, additives, and ingredients in vaccines, and appeared on four percent less websites than the most common attribute.

This is not surprising when one considers the number of legal settlements the pharmaceutical industry has had to make in the past ten years. Doctors Sammy Almashat and Sidney Wolfe compiled a report on pharmaceutical industry criminal and civil penalties for the non-profit organization Public Citizen (Almashat and Wolfe 2010, 2012). For their report, Almashat and Wolfe wanted to determine the number of civil or criminal settlements made between state or federal governments and pharmaceutical manufacturers. They examined public reports found on the Department of Justice website and the websites for individual state Attorney Generals and recorded when each settlement press release was published and the amount of each settlement.

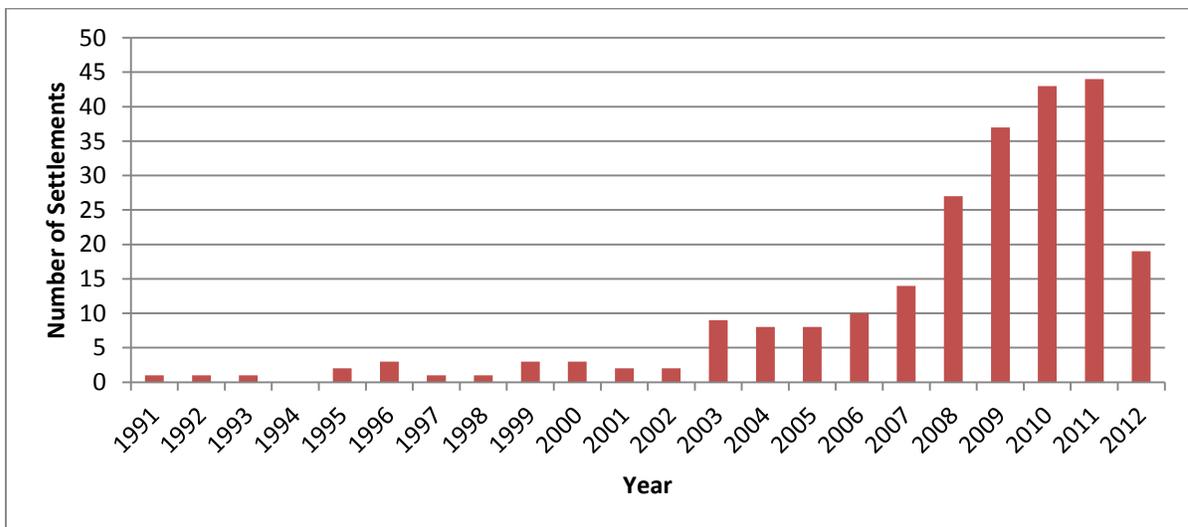


Figure 5.1: Number of Pharmaceutical Industry Settlements in the United States, 1991- July 18, 2012 (Almashat and Wolfe 2012:34)

Their data show that in the ten years before 2003, the number of settlements made per year was three or less. Then, there was a jump to nine cases in 2003 (almost as many as the previous four years combined), and a sharp incline from 2007 through 2009 where the years saw fourteen and thirty-seven settlement cases respectively. The number of settlement cases reached its peak of number of settlement cases in 2011 with forty-four, but that could likely be due to the fact that it was the last time they had data from the entire year (Figure 1). What their data seems to point to is a marked and sharp increase in litigation against large pharmaceutical manufacturers in the past ten years that is unlike anything that had ever been seen before. They state that the cause of the increase is uncertain, but reason that it could be due to increased violations by pharmaceutical companies and an increase in enforcement from state and federal governments (Almashat and Wolfe 2010:22).

However, it is important to note that in their September 2012 update to their original study, the two admit that one of the limitations to their study is that (to their knowledge and mine) there exists no official, comprehensive record of actions taken against the pharmaceutical industry, and some settlements are not publicized online at all (Almashat and Wolfe 2012:21). They also point out that the alleged violations that the companies are being penalized for are likely to have occurred several years before the settlement, so the data that they recovered is a poor representation of real-time trends (Almashat and Wolfe 2012:21). The two concede that their data is, in all likelihood, incomplete because of these facts.

While the data from Almashat and Wolfe's 2010 and 2012 studies hold little value for describing the trend of litigation against pharmaceutical companies statistically, they do highlight a growing trend that has been gaining momentum over the past ten-fifteen years: drug manufacturers are messing up legally and are being held accountable for their wrong-

doings in public. It is possible that the ever-increasing number of settlements in the past decade or two might help explain why concerns about vaccines causing bodily harm have been very prevalent on vaccine-critical websites in the recent past.

It could be argued that if people are aware that pharmaceutical manufacturers are facing criminal and civil penalties for wrong-doing, they are likely to trust that industry less. Combine that with the frequency at which the settlements were occurring between 2007 and 2011 (when data for Bean's 2011 study was gathered), and that apprehension can seem wholly justified. This particular argument can be explained and supported by Pru Hobson-West's findings from her 2007 article in *Sociology of Health and Illness*. Hobson-West's article was an examination of vaccine decision-making by organized vaccine resistance groups. She found that, contrary to the idea of radical individualism, resistance groups' "critique is articulated through stressing the complex, multifaceted nature of both risk and health" (Hobson-West 2007:207). What does this have to do with concerns of vaccines causing idiopathic illness, damage, or death and drug manufacturers' settlements?

The main focus in Hobson-West's (2007) article was the importance of the ideas of risk and trust and what they mean to individuals critical of vaccines. She found that the resistance groups she was studying were reframing what "risk" meant in the context of vaccines and other pharmaceuticals. For these groups, risk information (for drugs, in this case) is constructed as a strategy and that through this, the dominant narrative about the success of vaccines is called into question (Hobson-West 2007:2004). Risk is then reframed as all of the unknowns and uncertainties, in turn questioning the methods for testing the safety of vaccines (Hobson-West 2007:205). By focusing on the uncertainties, Hobson-West

claims that the groups she studied were undermining “the value and relevance of official risk discourses” (Hobson-West 2007:205).

By questioning the methods for testing the safety of vaccines (and thus, questioning their safety altogether), the issue from the vaccine-critical standpoint becomes: how can individuals trust that vaccines are safe when the same companies that produce them are facing lawsuits for drug manufacturing violations? From this perspective, drug manufacturers are the group that stands to gain from vaccines being deemed safe and effective, so their value as the determinants of the risk associated with vaccines is questionable at best.

There is importance in having control of the discourse on a topic, and Foucault wrote extensively on the power that can be gleaned by having control over how conversations are framed (Foucault 1980, Foucault 1995). In this case of the safety of vaccines, the health industry controls the discourse and is allowed that control by the public due to the industry’s medical expertise. Their knowledge in medicine is legitimized by their education and certification as experts. What the vaccine critics in Hobson-West’s study argue, though, is that this dominant narrative comes from the healthcare industry that, although given the status as “experts” by the public, also stand to gain financially if their drugs are found safe. This is where trust comes in. It is difficult for the people in Hobson-West’s study to trust the medical community about the acceptability of risks associated with vaccination. Vaccine critical groups frame risk as all of the unknowns, and for them, one of the unknowns is whether or not vaccines are deemed safe by drug manufacturers because doing otherwise would harm their business.

Considering the fact that Hobson-West studied this topic in 2007 and it appeared prominently in the data for both this study and Bean's 2011 research, it can be assumed that concerns about vaccines causing idiopathic illness, damage, or death have been a common theme throughout this particular phase of waning support of vaccinations. It should also be considered that a reason why this particular matter seems to endure in vaccine criticism is that the idea of the safety of a drug or medication is subjective. What the medical community deems as an acceptable risk is framed by the statistics on the likelihood of a serious adverse reaction. For vaccine critics, acceptable risk is likely framed by personal and emotional ties to a child assuming that risk. The interpretation of what "safe" and "acceptable risk" each mean to the medical community and vaccine critics is not likely to ever be the same, which is why this study expects concerns about vaccines causing idiopathic illness, damage, or death to continue to be a frequently observed attribute on vaccine critical websites.

Differences

Both this research and Bean's 2011 study found three content attributes that appeared in 50 percent or more of the websites analyzed. The two studies had one attribute in common that appeared frequently, just discussed in the "similarities" section of this paper. The other two frequently occurring attributes were different in each of the studies. Where the attributes have not changed can suggest the enduring themes of vaccine criticism, the differences in commonly found content attributes between the two studies may point to the social, political, and cultural differences between 2010 and 2013.

In eighty percent of the websites that Bean (2011) analyzed, the concern about poisons, additives, or questionably safe ingredients being in vaccines appeared. This content

attribute appeared more than any other in Bean's study, the prevalence of which strongly suggests that it might have been a main component of vaccine criticism at the time of her research. Concerns about vaccination efforts being fueled by profit or drug manufacturers with a conflict of interest in the matter appeared on thirteen (fifty-two percent) of websites analyzed.

This research found that eighteen sites of the thirty-four analyzed (fifty-three percent), contained claims that mandatory vaccines required for some schools and places of employment are infringing on one's civil liberties and violating bodily autonomy. The other attribute that was most frequently observed was the expression of the need for individuals to make informed choices about vaccination, and it was found on fifty percent of the websites analyzed.

To fully understand the changes that have occurred in vaccine criticism, it is important to recognize the context from which the differing criticism arose. During the time surrounding and preceding Bean's 2011 study (with data gathered during 2010), there were events that had either taken place or were taking place that could have had an influence on the type of dialogue found on vaccine critical websites. Most notable were the height of the thimerosal safety debate and the Andrew Wakefield paper that suggested a link between autism rates and the measles, mumps, and rubella (MMR) vaccine. While there are, no doubt, countless factors that influenced the vaccine-critical dialogue in 2010-2011, the elements discussed here represent a couple aspects that could have played a noteworthy role in how vaccines were being discussed.

The concern of poisons, additives, or the ingredients in vaccines during the time of Bean's research is likely due to the attention that the pharmaceutical preservative thimerosal

was encountering during the beginning of the 21st century. In 1999, there was increasing concern from the United States Public Health Services (USPHS) about thimerosal, a mercury-based preservative used in many childhood vaccines. The concern came from the realization that because thimerosal is mercury-based, is used in childhood vaccines, and infants receive many vaccines in their first six months of life, that vaccines might be inadvertently exceeding the FDA's recommended maximum for exposure to methyl mercury.

The risk needed to be investigated (per the FDA Modernization Act of 1997), and in September of 1999 the USPHS and the American Academy of Pediatrics (AAP) released a joint statement declaring their agreement to remove thimerosal from childhood vaccinations due to the "unknown and probably much smaller" risk posed by aggregate levels of methyl mercury in infants after vaccination (Pediatrics 1999:568). The consensus was that it was better safe than sorry to remove the thimerosal preservative in case the research found that it was posing an unintended risk to infants. The Global Advisory Committee on Vaccine Safety (GACVS), an advisory board created by the World Health Organization (WHO) to provide a "reliable and independent scientific assessment of vaccine safety issues" ("Patient safety" 2014), held a special meeting in 2000 to evaluate the data regarding the safety of vaccines and also found that there is "no evidence of toxicity in infants, children, or adults exposed to thiomersal in vaccines" (Global Advisory Committee on Vaccine Safety 2002). Since 2001, no childhood vaccines in the United States have been manufactured with thimerosal as a preservative except for multi-dose vials of influenza vaccines ("Timeline: Thimerosal in Vaccines (1999-2010)." 2010)

Despite these findings and the removal of thimerosal from vaccines starting in 1999, the thimerosal controversy endured. In 2001, an article titled "Autism: a novel form of

mercury poisoning” was published in the journal *Medical Hypotheses* that claimed that government data suggests that autism is induced by the mercury poisoning that children are exposed to through the thimerosal used in childhood vaccinations (Bernard et al. 2001:462). (It is important to note that *Medical Hypotheses* is not a peer-reviewed journal and that the authors of the piece are parents who launched the parental advocacy group Safeminds.) In 2005, Robert F. Kennedy published an essay on Salon magazine’s website titled “Deadly Immunity” reporting that he was present when scientists and doctors got together for a secret meeting in 2000 where they discussed the safety concerns about vaccines, how to spin the negative data, and what should be done to keep the American people in the dark about how dangerous vaccines are.⁶ Finally, in 2006, David Kirby published his book *Evidence of Harm: Mercury in Vaccines and the Autism Epidemic: A Medical Controversy* which played on the concerns of parents not only about thimerosal in vaccines, but also the idea that autism spectrum disorders are caused by vaccines.

Even though years had passed since thimerosal had last been used in routine childhood vaccinations and several studies had concluded that the negative effect of thimerosal from vaccines on children was minimal (if any), the debate seemed to continue among vaccine critics. Due to the highly publicized nature of this particular debate and the fact that criticism of thimerosal endured long after studies found that it was not as hazardous as it was once feared to be, it is possible that the thimerosal debate had an influence on the content of the vaccine critical websites that Bean (2011) analyzed in her study.

6. Robert F. Kennedy, Jr., “Deadly Immunity,” http://www.robertfkennedyjr.com/articles/2005_june_16.html (accessed 23 Feb. 2014).

The second element that could have had an important influence on the conversation taking place online about the safety and efficacy of childhood vaccines on the internet was the paper published in the *Lancet* by Dr. Andrew Wakefield in 1998. The paper became the banner under which vaccine critics could gather. The Wakefield et al paper provided empirical, scientific research published in a peer-reviewed journal that drew a correlation between vaccines and developmental delays like the ones commonly observed in autism spectrum disorders. It gave weight and legitimacy to vaccine critics' claims that vaccines cause or aid idiopathic illnesses. The notoriety of the paper, plus the widely and instantly available nature of academic papers via the internet in the 21st century, might have helped to usher in a trend of parents accessing, studying, and interpreting academic papers in their own homes.

Wakefield's paper is a very well-known publication, so it is possible that it had an effect on the vaccine-critical discourse taking place on the internet during the time before the paper was formally retracted. Bean's study was published in 2011, but she gathered her data during February and March of 2010 (Bean 2011: 1875). Wakefield's paper was partially retracted in 2004, but formally retracted in February of 2010 after the General Medical Council's Fitness to Practise Panel found that elements of Wakefield's paper were incorrect or unethical (General Medical Council 2010).

Given the focus on mistrust of the medical community that was frequently found on vaccine-critical websites in Bean's 2011 study and the relevancy of the events when Bean was gathering her data, it is possible that the enduring debate about the use of thimerosal in vaccines and the Wakefield et al. (1998) paper had an influence on the content attributes that Bean found during her research.

The data for this research was gathered roughly three and a half years after Bean (2011) gathered her data, but the contextual events that might have influenced the type of content found on vaccine critical websites differed considerably. When data was gathered for this research in September/October of 2013, content relating to the Wakefield et al. (1998) paper or the debate about thimerosal were largely unobserved on vaccine critical websites. This might be due the growing body of science against the claims that the MMR vaccine causes autism and that thimerosal in childhood vaccinations resulted in mercury poisoning. Instead, the events that occurred preceding the data being gathered for this study were largely of a political nature, and focused on individual liberties.

In the year prior to the date when data was gathered for this study, the media was teeming with major stories that involved civil liberties and personal freedoms. Both progressive and conservative issues were represented, and highlighted the highly politicized time with focus on the rights of individuals. To begin with, 2013 was an important year for marriage equality milestones with the Defense of Marriage Act (DOMA) being struck down and six states legalizing same-sex marriages. Gun rights were also a highly contested issue during that time. In the wake of the December 2012 shooting at Sandy Hook Elementary school in Newtown, Connecticut, legislation was proposed to ban assault rifles, limit magazine capacity, and support universal background checks for purchasing a firearm. Activists saw an expansion of gun control laws as an infringement on their Second Amendment right to bear arms. With the roll-out of the Affordable Care Act, there were outcries that being obligated to purchase insurance infringed on civil liberties. Finally, when Edward Snowden leaked details of the National Security Administration's (NSA) extensive

surveillance programs in June of 2013, there were concerns that Americans' right to privacy had been violated.

All of these prominent news stories suggest that the personal rights and freedoms of American citizens was a major topic of discussion in 2013. From the right to marry to the right to bear arms, the United States seemed to be very concerned with individual freedoms. This appears to have even influenced the content attributes of vaccine critical websites on the internet. Whereas the focus of vaccine criticism in 2010 was one of distrust and suspicion, the focus of vaccine criticism in 2013 seemed to be on civil liberties and individual rights (per the most frequently appearing content attributes in each study).

In short, it seems that the social, cultural, and political context of a temporal space have an influence on vaccine criticism and the content attributes found on vaccine critical websites.

Limitations and Future Research

While this research provides a snapshot of the vaccine-critical discourse that existed on the internet in late 2013 and the ways that online vaccine-critical discourse has evolved since Sandra Bean's 2011 study of the same nature, it does have a few limitations.

This research did not compare content attributes to any previous research other than Bean's 2011 study. Due to time and scope limitations, this study was only able to show the changes in vaccine-criticism on the internet between 2010 (the year that Bean gathered her data) and 2013 (when the data for this study were gathered).

Another limitation to this research was the sample size of vaccine-critical websites that were analyzed. Thirty-four websites is by no means a comprehensive list of all vaccine-critical websites, but given the marginal (if vociferous) nature of vaccine criticism, vaccine-

critical websites are infrequent. However, when compared to the sample sizes from the works of Bean (2011), Kata (2009), Davies et al. (2002), and Wolfe et al. (2002), a sample size of thirty-four falls into the middle of the range. It was important to represent websites that had enough of a web presence that it could be assumed they characterized the type of sentiments proposed by vaccine critics. If a website could only be found from a link on a webpage that is several links away from a more prominent site, it was assumed that the conversations taking place there do not represent the majority of vaccine-criticism, but a far fringe like the website itself.

Additionally, with some of the websites it was unclear how to distinguish when they were last updated. Some of the more professional looking websites featured blog posts, Tweets, or links to news articles; all of which signify that the group or organization was/is still active with their site content. Other sites were labeled at the bottom of the page as being last updated or reviewed on a certain date. For others still, there were no immediate ways to tell if the content presented on the site was added two days ago or two years ago. This is important to note because if the purpose of this study was to examine how vaccine-critical content on websites has evolved since 2010, but the data for this study includes websites that have not been updated since 2010 or 2011, then the data has the possibility of being flawed and not properly representing vaccine-critical website content of 2013.

Despite these limitations, the heart of this research and its aim still remains. It may not be able to say anything about the dialogue of vaccine-critical websites for any time frame other than from 2010-2013, but it can be used in conjunction with work that has already been done on the topic to create a more complete picture of how that dialogue has evolved over the past decade or two. This research might have a small sample size, but sample size cannot

be expected to be large when investigating a marginal group. It might have been unclear when the content on some of the websites was published, but the same problem could have affected the results of researchers in previous years examining the “current” vaccine critical discourse online. Part of the purpose of this research was to add to the body of knowledge of the evolution of vaccine-criticism on the internet, and it did so.

To be able to see clearly the ways that vaccine-critical discourse evolves over time, it is important for researchers to continue to do cross-sectional studies like this one periodically to add to the body of knowledge that previous research has established on the topic. To say this work is analogous to putting together a puzzle may be trite, but it is suitable; with each new piece, with each new study, the picture becomes clearer. Comparing the results of this study to those of Bean (2011) may only be joining two pieces together, but when added to the analyses performed by Kata (2009), Davies et al. (2002), and Wolfe et al. (2002), larger themes and patterns begin to become more visible. In addition to identifying trends or new themes in vaccine opposition over time, it is equally important to contextualize those observations socially, historically, and theoretically. What is being said by vaccine critics is just as important as who is saying it and why.

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