Characterization of the Relationship Between Media Technology and Development of the Anti-Vaccination Movement

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Introduction

Vaccination is one of the most cost-effective methods for prevention of the spread of infectious diseases. In many cases, vaccine introduction to the general public nearly eliminated contraction of the target disease, such as the 96% decrease in polio incidence in the first 7 years after the Salk and Saban polio vaccines were introduced (Nature, 2010). While fringe groups have expressed vaccine opposition as long as the vaccines themselves have existed (Rao, 2011) publication of a paper by Andrew Wakefield falsely linking the Measles, Mumps, and Rubella (MMR) vaccine to autism onset in children catalyzed an unprecedented wave of vaccine antagonism in America. This exponential rise in vaccine opposition has become known as the 'anti-vaccination movement.' Though the movement lacks a centralized administrative body, it has propagated the spread of false scientific information about vaccine safety and efficacy and contributed to the resurgence of preventable diseases that were previously eliminated in the United States, such as measles (CDC, 2019). In the past 21 years, advancements in media technology such as the Internet and social media that have radically changed how people disseminate and receive information from one another have coincided with the exponential spread of the anti-vaccination movement. This STS Thesis investigates how the development of media and communications technology affected the growth of the anti-vaccination movement after publication of the Wakefield paper through the lens of Actor-Network Theory (ANT). Its research methods include documentary research, historical case studies, policy analysis, discourse analysis, network analysis, and wicked problem framing. This research aims to answer the following questions: How did anti-vaccine rhetoric suddenly become so prevalent in

America? What is the degree of responsibility held by media organizations in verifying the accuracy of the information they disseminate? Are people entitled to make health decisions that may jeopardize the health of others? How have American policymakers navigated the boundary between protecting public health and overstepping individual freedoms?

Precursors of the Anti-Vaccine Movement

The first opposition to vaccination occurred in Britain following the spread of the smallpox vaccine. Vaccination became widespread throughout Europe after Edward Jenner presented research on smallpox inoculation to the Royal Society of London in 1796, which demonstrated efficacy of inoculation from cowpox-infected donors at preventing contraction of smallpox in humans (Wolfe & Sharp, 2002). Laws passed between 1840 and 1853 made vaccination compulsory in Britain, sparking violent riots and protests from the newly formed Anti-Vaccination League in London that led to the inception of the "conscientious objector" clause. The concept of conscientious objection allowed parents to obtain exemption from vaccinating their children due to personal beliefs, and its implementation in British law established a precedent that later spread to the United States (Wolfe, 2002). 'Religious exemption' clauses still exist in the United States today, though laws vary between states. In the past decade, skyrocketing quantities of unvaccinated children in schools have opened the doors to outbreaks of preventable diseases such as pertussis, measles, and mumps, prompting lawmakers to reconsider vaccine exemption clauses and sparking protests from so-called "anti-vaxxers" (CDC, 2019).

Many of the falsehoods claimed by the movement are derived from true events. The Cutter Incident of 1955, in which 120,000 doses of polio vaccine containing live virus were

mistakenly administered despite passing safety tests during production, resulted in over 40,000 cases of polio in children who received the vaccine. While almost none of the cases affected the central nervous system, 56 children did contract paralytic polio and 5 of them died. The infected children then spread polio among their families and communities, inducing multiple epidemics that paralyzed another 113 people and killed 5 (Offit, 2005). Today, anti-vaxxers use the Cutter Incident and other cases of children suffering adverse reactions to vaccines as proof that all vaccines cause illness. Although events such as the Cutter Incident sparked outrage when they occurred, the spread of anti-vaccine sentiment in the 1900s was miniscule compared to the modern movement because the methods by which information is disseminated are now so drastically different (Hussain, 2018). With the proliferation of user-generated content on the internet and the spread of social media across geographical and generational boundaries, anti-vaccination rhetoric has received unprecedented media coverage and converts (Rao, 2011).

Use of Actor-Network Theory to Analyze Ideological Spread

Actor-Network Theory, the primary STS framework chosen to analyze the research question, asserts that scientific and technological advancements are driven by shifting relationships between human and non-human entities and nothing exists outside those relationships. Initially developed by French STS scholars Bruno Latour and Michel Callon in 1991, the ANT approach involves identifying 'actors' involved in the development of some innovation and studying their interactions at the micro level (Cressman, 2009). An actor may be a human, animal, object, or process- all are treated as having equal capacity to influence their network. Applying the same level of agency to humans and nonhumans remains a controversial tenet of the theory that scholars criticize for ignoring pre-existing structures such as institutional

power (Cresswell, 2010). Research conducted using ANT is also commonly criticized as "entirely descriptive" and "failing to provide explanations for social processes" (Sheldon, 2010). While these criticisms are often accurate, the onus is on the user to apply ANT in a manner that avoids such pitfalls. Since a network's interactions may branch exponentially throughout the entire known universe and its history, the researcher must decide which actors are relevant and which interactions are meaningful to the questions being asked.

In the context of this research, ANT is applied to the growth of the anti-vaccination movement. The developing scientific theory at the center of the network is the concept that vaccines cause harm, while the infrastructure of the network consists of interactions between doctors, patients, pharmaceutical manufacturers, lawmakers, and the anti-vaxxers themselves. These interactions largely consist of online content such as posts in anti-vaccination forums, conversations in Facebook groups, and arguments in Twitter retweets. Interactions between vaccine-hesitant parents and doctors, as well as anti-vaxxers and lawmakers, are also important components of the movement's infrastructure.

Research Question & Methods

The research investigates the following question: How have developments in media and communications technology since 1998 influenced the growth of the anti-vaccination movement?

The research question is investigated through a combination of discourse analysis, historical case studies, policy analysis, and wicked problem framing. Discourse analysis of scientific literature is a necessary component for both the medical and statistical aspects of the research, as a wealth of scientific publications have analyzed both the medical science of

vaccines and the dynamics of public sentiment towards vaccination. The data was collected by searching the internet with keywords such as 'anti-vaccination movement,' 'vaccine sentiment,' and 'preventable disease outbreak.' Online search databases were used to isolate journal articles published after 1999, while specific data for incidence of diseases such as polio and measles over time were obtained from the Center for Disease Control and World Health Organization websites. Publication of the Wakefield paper in 1998 is explored as a historical case study using primary documents such as the retracted paper itself and secondary documents such as rebuttal papers published between 1998 and 2004. Policy analysis is applied to vaccination exemption laws in various states, especially the 2019 ideological exemption policy reversal New York and its resulting protests. Wicked problem framing is appropriate since there is no perfect solution to a conflict of ideology and values between groups of people.

Results and Discussion

Sociotechnical Climate Preceding Revitalization of the Anti-Vaccine Movement

As technological advancements increased access to the Internet through the 1980s and early 1990s, its content shifted from provider-controlled (coined "Web 1.0" by researchers) to user-generated ("Web 2.0") (Kata, 2012). This "second generation" of the Internet is characterized by the ability of users to not only create information, but also interact with one another through applications known as social media. Popularization of the Internet during the "dot com boom" of the 1990s allowed a rapidly increasing quantity of users to create and consume largely unregulated content, especially in relation to health and medical science (Kline 2003 and Wolfe 2002). The Wakefield paper was published at the height of this technological boom, during a period of extensive discourse around the possibility of environmental factors

causing autism in children and when parents of children under three years old were generally too young themselves to remember the devastating effects of polio and its eradication by the Salk vaccine during the 1960s (Nevison, 2014 and Rossignol & Frye, 2012). While Wakefield and his supporters laid the foundation of fear and misinformation, the introduction of personalized content curation and group chatting by social media platforms such as Facebook rapidly intensified the echo chamber effect on content consumers (Kata, 2012).

Initial Responses to the Wakefield Paper

Though Wakefield had acquired a veil of legitimacy by managing to land Britain's most respected medical journal, *The Lancet*, rebuttals came from the scientific community almost immediately. As anti-vaccine sentiment became publicized through news organizations, websites, and even pro-vaccine rebuttals to the Wakefield paper, connotations with vaccines slowly changed in the mind of the American public. The transmogrification of this network relationship was partly due to the age of its actants. Throughout the first half of the twentieth century, frequency and severity of polio outbreaks increased in the United States, crippling over 35,000 people each year at the height of the epidemic during the late 1940s (CDC). Terror gripped the country each summer when outbreaks peaked, as panicking parents kept their children indoors and public health officials imposed travel bans and quarantines on affected towns. The introduction of the Salk polio vaccine in 1955 allowed people to witness the near-complete elimination of the disease in less than a decade- polio incidence was reduced from 57,879 cases (21,000 paralytic and 3,145 deaths) in 1952 to 72 total cases in 1965 (Ochmann, 2017). The last case of polio that originated in the United States was in 1979 (CDC). Because mass vaccination had so drastically reduced the number of people paralyzed in wheelchairs and

iron lungs, most young American adults in 1998 had not personally witnessed the impacts of these conditions on people they know. Additionally, cases of measles, mumps, rubella, and pertussis had reached historic lows that weakened the relationship between parents and the morbidity of preventable diseases. Reduced disease incidence weakened the association between vaccination and preventing death in the collective American mind, replaced by the association between vaccination and rare cases of allergic reactions or complications in children sensationalized by media. A common anti-vaccine assertion is that vaccines are unnecessary *because* these diseases have become less common (Kata, 2012). Years after *The Lancet* retracted the Wakefield paper, fears of autism remain a frequent justification for vaccine avoidance. A 2019 study of MMR vaccination in kindergartens identified lower MMR vaccine coverage in the 17 states that allowed nonmedical exemptions (Benecke, 2019), illustrating the tenacity of the association between vaccination and autism Wakefield created in the American public.

Pharmaceutical Companies as Actants of Vaccine Hesitancy

During the second half of the twentieth century, medical science and technology advanced in leaps and bounds previously unheard of in America. Salk was considered a national hero for his work on the polio vaccine during the 1950s, especially praised for refusing to patent the vaccine (CDC, 2019). Throughout the 1980s, pharmaceutical companies were lauded for creating a slew of drugs targeting previously untreatable conditions such as cancer, rheumatoid arthritis, depression and anxiety, chronic pain, cancer, bacterial infection, and heart disease (Lyman, 2019). The industry then destroyed its positive association with the public in an ongoing series of scandals. A common generator of outrage is price hiking, the practice of acquiring older generic drugs and drastically raising product cost under a different brand name. In 2015, chief

executive of Turing Pharmaceuticals Martin Shkreli was dubbed "the most hated man on the internet" after acquiring daraprim, a 62-year-old drug used to treat rare bacterial infections in HIV/AIDS patients, and raising its price by 5,000% overnight (Pollack, 2015). Marathon Pharmaceuticals was similarly criticized two years later for implementing a 6,000% price increase on deflazacort, a drug for children with Duchenne muscular dystrophy that had previously been available as a generic in Europe and Canada (Herper, 2017). Other highly criticized behaviors that strengthened the association between pharmaceutical companies and greed include contributing to and profiteering the opioid crisis in America (Purdue Pharma, 1996-current), bribing doctors to overprescribe fentanyl-based opioids that killed over 8,100 people (Insys Therapeutics, 2012-20), committing Medicare fraud (Natural Molecular, 2012-15), and hiring then-president Donald Trump's personal attorney to lobby the federal government (Novartis, 2018) (Lyman, 2019). The deaths, criminal charges, civil penalties, and negative publicity generated by these practices have eroded the trust the American public once had in the pharmaceutical industry and poisoned the associations between vaccine manufacturers and parents deciding whether to vaccinate their young children. As the manufacturers and 'salesmen' of vaccines, pharmaceutical companies are actants in the anti-vaccination movement network whose actions have lent the appearance of legitimacy to some anti-vaxxers' claims.

Early Network Building Through the Internet

Increased access to health-related information online dramatically changed the landscape of the patient-doctor relationship and the healthcare industry, including attitudes towards vaccination (Forkner-Dunn, 2003). As medical knowledge previously restricted by textbooks and journals became freely accessible to laymen through the Internet, the balance of power in the

management of patient's healthcare shifted from being held exclusively by physicians to patients. A 2002 study of 22 anti-vaccination websites' content and design found that the websites espoused highly similar claims and cited each other as references for false assertions (Wolfe, 2002). Wolfe et al. used a metasearch program incorporating 10 other search engines to review 772 links that ultimately connected 12 web sites promoting anti-vaccine information. Analyzing links from the 12 original sites revealed 10 more anti-vaccine web sites, yielding a population of 22 web sites for study. The most common content claims among the sites were that vaccines cause "idiopathic illness (100% of sites)," vaccination degrades a person's immunity (95%), adverse reactions to vaccines are underreported (95%), and vaccination policy is profit-motivated (91%). The most widespread design attributes of the sites were the "presence of links to other anti-vaccination sites (100% of sites), information for legally avoiding immunizations (64%), and the use of emotionally charged stories of children who had allegedly been killed or harmed by vaccines (55%)." While the degree of distrust in medicine and types of conspiracy theories varied among the sites, they all relied heavily on emotional appeal to attract readers. Therefore, as the authors of anti-vaccine sites established relationships between one another through direct links and references, they engaged with readers personally through creating associations between vaccination and child endangerment.

Normalization of Anti-Vaccine Viewpoints through Celebrity Endorsement

Emphatic endorsement from celebrities in the 2000s made anti-vaccine rhetoric plausible to a wide audience of young mothers (Vasconcellos-Silva, 2015). Jenny McCarthy was key in the transfer of vaccine mistrust to popular media following the 2007 release of her book, *Louder than Words: A Mother's Journey in Healing Autism* (Kata, 2012). In appearances on the Oprah

Show, Larry King Live, and Good Morning America, McCarthy expressed certainty that the MMR vaccine had caused her son to develop autism. When questioned on her claims, McCarthy touted her "mommy instinct" and the "University of Google." An integral aspect of her narrative was use of the Internet to obtain medical knowledge, bypassing traditional providers of healthcare-related information. Watching a celebrity espouse personal views on television, especially relating to a topic as emotionally charged as child welfare, affects the associations people build upon when they develop their opinion of vaccines. Legitimization of vaccine opposition by celebrities fostered vaccine hesitancy in a larger audience of content consumers, causing a surge of concerns about vaccine safety (Vasconcellos-Silva, 2015).

Community Spread of Anti-Vaccine Rhetoric Through Facebook

A 2018 study of interactions between 2.6 million Facebook users over the span of seven year and five months found that highly polarized communities emerge from users' consumption habits (Schmidt, 2018). The cohesiveness of several large anti- and pro-vaccine communities were quantified by tracking the amount of likes and comments made on each page, as well as which pages each user liked. One notable trend observed on both sides was more active users tended to consume material from a smaller variety of sources than less active users. However, the anti-vaccine users were more 'active' in their community, which led to the conclusion that anti-vaccine attitudes are rooted more deeply in the "social and psychological background" of an individual than pro-vaccine attitudes. This suggests that anti-vaccine communities are more "personal" and that adoption of anti-vaccine beliefs is catalyzed by an individual's emotional connection with others, an attribute that has been observed in previous studies of conspiracy-theory-oriented groups. In a 2019 study of parental attitudes towards vaccination, surveys

distributed to over 1,000 parents in elementary schools, an "unfavorable parent's opinion" toward vaccination was found to be "conditioned by a direct or indirect knowledge of people harmed by vaccines" (Facciola, 2019). These results suggest the importance of interpersonal emotional connections in the spread of vaccine hesitancy and opposition among social groups.

Impact of Varying Vaccination Policies Between States

Laws regulating criteria for vaccine exemption vary between states, with the critical difference being whether "ideological and/or religious exemptions," commonly referred to as non-medical exceptions, are valid criteria for parents to avoid vaccination (Seither, 2019). Even among states with identical exemption criteria, differences in policy language and implementation methods lead to vastly different statewide immunization outcomes (Bradford, 2013). Requirements parents must meet to obtain a non-medical exemption range in strictness from individual approval by the state department of health to checking a box on a form. In a longitudinal study on the effects of state policy on vaccine coverage between 2002 and 2012, Bradford et al. developed a model for evaluating effectiveness of exemption policies while counting for state-level socioeconomic characteristics such as poverty rate and adult education level. They found higher vaccine-preventable disease incidence in states with lax requirements for obtaining non-medical vaccine exemption, while states with more stringent policies generally exhibited lower rates of both vaccine exemptions and vaccine-preventable diseases.

Though average statewide percentages of vaccinated individuals suggest sufficient coverage for herd immunity, these values are skewed by significant heterogeneity in nonmedical vaccine exemption rates within each state (Omer, 2009). Individuals refusing vaccination tend to exhibit geographic clustering, creating communities with high concentrations of unvaccinated

people and elevated local risk of preventable disease incidence. Though not all causes of geographic clustering are known, the CDC states that many preventable disease outbreaks occur in "tightly-knit communities" united by factors such as religious identity and education level (CDC, 2019). In 2019, New York State experienced severe measles outbreaks concentrated in unvaccinated Orthodox Jewish communities stemming from individuals contracting the disease while abroad in Israel (CDC, 2019). New York repealed its nonmedical vaccine exemption policy several months later, which sparked outrage and protests from anti-vaxxers ("Parents of Unvaccinated Kids in NY Decry Religious Exemption's End," 2019). This change in legislation disrupted the anti-vaccine movement's network by providing anti-vaxxers with foes to rally against, both through protests against the New York State Senate and responding to a nationwide barrage of derision on social media. Negative emotional responses to harsh criticism from "outsiders" may strengthen relationships between individuals within the anti-vaccine movement and cement their convictions.

Limitations & Potential for Future Work

Interstate variations exist not only in policies determining vaccine exemption, but also in methods of data collection and classification by schools(Bradford, 2012). The depth and breadth of the research is limited by the time constraints of the spring semester and graduation. Rather than developing original code and algorithms to datamine and track social media pages, quantitative data was obtained from previous research that employed similar methods in analysis of online content. Future work on anti-vaccine sentiment could be greatly enhanced by accumulating more data on the activity of these communities at more recent dates. Additionally, the availability of quantitative data on social media communities and engagement is limited.

Most studies have been limited to Facebook, Twitter, or other anti-vaccine website traffic. There is great potential for datamining communities on Instagram, which boasts numerous easily found conspiracy-theory based user pages, as well as Pinterest and Tumblr. Another factor future studies could investigate is COVID-19 and the extensive discourse surrounding it on social media, which may have profound effects on how the general public views vaccines and healthcare workers.

Conclusion

Anti-vaccine sentiment has existed since the creation of vaccines themselves, but has never possessed such a large following before now. The spread of false ideas about vaccine effectiveness and safety was initially sparked by Wakefield in 1998, and effectively incited fear in parents motivated to protect the health of their young children. Widespread use of unregulated Internet content nurtured the formation of anti-vaccine echo chambers through the 2000s, but the migration of parents onto social media, especially Facebook, exacerbated the anti-vaccine echo chamber effect more rapidly than any previous media. Content-curating algorithms that personalize users' suggested interactions with posts and each other quickly form and polarize cohesive communities, entrenching anti-vaxxers in their views and facilitating recruitment of vaccine-hesitant individuals. Study of the movement's growth must be further conducted by examining interactions of parents within online communities and how emotional connections are made between individuals through outrage and fear of vaccine mortality and side effects.

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