How Divergent Risk-Characters Rewrite the Anti-Vaccination Narrative

A Thesis Presented for the

Master of Science

Degree

The University of Tennessee, Knoxville

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May 2021

DEDICATION

This thesis is dedicated to my mom Alice for always showing up. Her strength and compassion work cohesively to make the world a better place.

ACKNOWLEDGEMENTS

The completion of this thesis would not have been possible without the help of my amazing committee, including Dr. Michael Palenchar, Dr. Derrick Holland, and Dr. Laura Miller. The support of the College of Communication and Information has been astounding since the beginning of my recruitment with Dr. Sifan Xu. I truly appreciate the kindness of everyone in the School of Advertising and Public Relations. I would also like to thank my cohort, as they have created lifelong friendships that made Knoxville a home.

ABSTRACT

The modern narrative originates in 1998, when a paper by a British medical journal *The Lancet* alleged that the measles-mumps-rubella vaccine may cause autism and bowel disease (Wakefield, Murch, Linnell, & Casson, 1998). The funding of the publication was deemed erroneous, yet the research sparked a connection between vaccines and disorders that would soon undermine public confidence in vaccines. Still today, the debate on vaccines poses a threat to public health in the United States of America as "opt-out" rates, particularly in states with recent outbreaks are increasing (Ratzan, 2011).

This study sought to examine what factors contribute to divergent behavior in previously unvaccinated children from the lens of narrative theory and the framework of communication accommodation theory. The narrative analysis draws into question the role of Fisher's (1984) contribution to narrative theory alongside Palmlund's (2009) typology of risk characters. The proposed methodology utilizes six qualitative interviews in order to identify the various stimuli that contributed to divergent or convergent behavior within previously unvaccinated individuals. This strategy provides an environment of open-ended discussion and findings that would organically result from the interview process to the point of redundancy. Three main questions along with multiple prompt questions (see figure 1) were formulated in order to accurately and efficiently carry out the interview process, which catered to the participants extrapolation of their narrative. Data from the participant's answers was analyzed through the use of thematic analysis (Braun & Clarke, 2006) in order to identify patterns in the resulting stimuli affecting behavior. Furthermore, the study sought to provide insight and implications to researchers, students, and practitioners that traditional theories such as narrative and communication accommodation theory stand applicable in the plight to grasp the idiosyncrasies contributing to the

latent effects of the vaccination crisis. The results of this study suggested that future health strategies should aim to: (1) establish trust of medical institutions, (2) validate parental decisions, rather than judge them, and (3) encourage independent research (especially outside of social media). The theoretical implications advise that that perceived risk be more closely associated with the creation of narrative in future studies. The practical and societal implications involve the de-stigmatization of the COVID-19 vaccine and other vaccines for the purpose of developing herd immunity against harmful diseases.

Key words: Anti-vaccination, communication accommodation, divergence, narrative, risk

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CHAPTER 1 INTRODUCTION

How Divergent Risk-Characters Rewrite the Anti-Vaccination Narrative

The progression of the anti-vaccine movement has been ranked in the top ten threats to global health according to the 2019 CDC report. Instances of vaccine hesitancy have gained momentum, creating conflict between protestors and medical authorities. This study sought to examine the subsequent behavior of previously unvaccinated children by studying their perception of risk into adulthood. This research project did this through analyzing Fisher's (1984) narrative theory along with Palmlund's (2009) typology of risk bearers and risk informers in order to intertwine the contributions of communication accommodation theory's variables (Soliz & Giles, 2014).

Additionally, risk literature lends a framework propelling the constructivist lens while interpreting a narrative perspective. Palenchar and Wright (2007) draw upon this understanding in their proposal stating, "For risk communication and other public relations professionals, one of the pitfalls to understanding how stakeholders develop their sense of self through narrative based on public information that should empower them in risk and crisis situations is to rely primarily on their own view of themselves, utilizing organization narratives to describe and influence other enacted narratives" (p. 4). The key component in this argument is realizing how one's narrative is predominantly formed before an observable behavior occurs. Studying previously unvaccinated children begins by first recognizing their own characters and plot lines intertwined in expectation and perceived risk. Paired with the lens of narrative theory, the beliefs of the target individuals were studied through communication accommodation theory's framework against one's family of origin. Divergent and convergent behavior in contrast with

one’s family of origin has the potential to reveal key variables at play in the longevity of the vaccine hesitancy narrative.

CHAPTER 2 LITERATURE REVIEW

Anti-Vaccination Movement

The World Health Organization (WHO, 2019) has identified vaccine hesitancy as one of the top ten threats to global health. Vaccine hesitancy is defined as the resistance or refusal to get vaccines even though they are available. The WHO also identified multiple reasons people are reluctant to get vaccines, such as "complacency, inconvenience in accessing vaccines, and lack of confidence" (p. 1-2). The researcher aims to understand the story of the anti-vaccination movement by unraveling the variables that drive divergent behavior of adults who were not vaccinated as children. To properly do this, this paper must first review the history of the anti-vaccination movement to see how it has developed overtime.

History. Though the anti-vaccination movement has become exceedingly popular within the last two decades, it is not a new concept. The first documented immunization was in ancient China during the Song Dynasty in 10th Century B.C. Vaccinations in their early days were referred to as *inoculations* and were first introduced in Paris in 1763. Although they were banned later that year due to the French Parliament fearing improperly quarantined patients spreading their illnesses to other Parisians, that year marked the rise in outbreaks of smallpox across Europe and therefore the rise in popularity of the inoculation of children.

Historically, the Catholic church also contributed to vaccine hesitancy, which was apparent in Rev. Edmund Massey's sermon in 1772 called "The Dangerous and Sinful Practice of Inoculation" (Hussain, Ali, Ahmed, & Hussain, 2018). In this sermon Massey claims that to get a vaccine is to escape punishment from God. In 1796, the smallpox vaccine was invented, but was met with distrust in the medical institution. The Vaccination Act of 1853 required vaccinations for infants and immediately there was a built resistance around the legislation

(Measles & Rubella Initiative, n.d.). This anti-vaccination movement eventually made it to America in the 1860s (Blume, 2006). The Secretary to the National Anti-Compulsory Vaccination League Mary Hume-Rothery claimed that enforcing penalties for not getting vaccinated was like "legalising bodily assault" (Durbach, 2002, p. 64).

The Anti-Vaccination Society of America was active in the late 1800s and early 1900s (Youngdahl, 2012). The development of the movement led to further protests such as The Leicester Demonstration March of 1885, which consequently led to a new act in 1898 that removed penalties for not getting children vaccinated (Measles & Rubella Initiative, n.d.). The smallpox outbreak ultimately led to the legal case of Jacobson vs. Massachusetts in 1902 (Dubé, Vivian, & MacDonald, 2015). In this case, Jacobson questioned the government's authority to require smallpox vaccinations as Jacobson believed it was his right to make these health decisions (Mariner, Annas, & Glanz, 2005). Massachusetts won in this case stating herd immunity was more important at this point in time to properly address the smallpox outbreak (Mariner et al., 2005).

By the 1940s, it was recommended for individuals in America to get the DTP (Diphtheria, Tetanus, Pertussis) vaccine as well as the smallpox vaccine (Offit, 2019), but this recommendation was still met with great protest. Dubé, Vivian and MacDonald (2015) identified the 1950s and 1960s as the golden age of vaccination acceptance, in which parents widely accepted the use of vaccinations to prevent diseases, but vaccination resistance still occurred on a smaller scale. A documentary aired in 1982 entitled "DTP: Vaccination Roulette," that contributed to the movement as it claimed vaccines could cause mental damage, and in some cases, even seizures (Brenneman, 2015). Brenneman argued this documentary launched much of the modern anti-vaccination movement.

While there are a few reasons the anti-vaccination movement has gained traction in recent years, the largest and perhaps most effective controversy that backs it is the vaccination-autism controversy, which was initiated with the published study by discredited British ex-physician Andrew Wakefield. Wakefield's scientific study and paper claimed a link between the measles, mumps, and rubella vaccine (MMR) and autism. After allegations of misconduct against Wakefield surfaced, the British General Medical Council took on an investigation in 2010 and found Wakefield had not only been dishonest in his research but had also mistreated developmentally disabled children and had acted against the best interests of his patients. Wakefield's 1998 publication was retracted, and he was barred from practicing medicine in the United Kingdom. Although his entire study has been discredited and referred to as a great medical hoax (CDC, 2019), Wakefield has continued to defend all of his research, founded the non-profit "Strategic Autism Initiative," and is the director of two companies: Medical Interventions for Autism and the Autism Media Channel.

Current Situation. To determine whether the movement is led by traditional Catholic beliefs (Hussain, Ali, Ahmed, & Hussain, 2018), distrust in medicine (Measles & Rubella Initiative, n.d.), or belief of harm to the body (Durbach, 2002) is pertinent in understanding the current state of the vaccination movement. New factors are introduced in the controversy such as social media and celebrity endorsements. Smith (2019) discusses how the anti-vaccination movement has significantly changed through the use of Facebook and online networks. Networked publics have become a place where ordinary people can become a media outlet (Boyd, 2010). Even celebrities are involved and support the movement reaching millions of followers who often idolize them. In 2007, celebrities and influencers like Jenny McCarthy started taking the stage and speaking out about their beliefs on vaccines. McCarthy announced

her son was diagnosed with autism, but blamed it entirely on the MMR vaccine, even though the study in which her beliefs were based had already been retracted and marked as falsified information by the British General Medical Council (CDC, 2019). Actress Jessica Biel spoke out against California State Bill 276 which limits exemptions for vaccines but denied her involvement in the "anti-vaxx" campaign (Antrim, 2019).

In 2000, there were no cases of measles transmitted by citizens of the United States of America within its borders. Thirteen years later there were three large outbreaks of measles in communities where children were not vaccinated due to philosophical or religious beliefs. According to the CDC (2019), in 2013 there were 159 cases of measles in 16 states, 668 cases in 27 states in 2014, and 188 cases in 24 states in 2015. According to Bloom, Marcuse and Mnookin (2014), the main reason why this health concern is returning is our inability to relate to skeptical parents that vaccinations are actually saving lives. Researchers looked at how effective narrative theory can be when used correctly, but the key part of using it is being able to relate to the audience. Not being able to relate to the skeptical anti-vaxx parents is the main downfall in trying to reverse this upcoming health scare (CDC, 2019).

These parents are relying on the information they are receiving from scare tactics of anti-vaccine groups, Wakefield's retracted study, and ill-informed celebrity advocates (Bloom et al., 2014), to which to base their beliefs. Our main tactic going forward has to be to identify a narrative, or in other words, find a way to relate. Without a personal connection to the opposite side, these parents will rely on their own maternal and paternal instincts to protect their children in the only way they are seeing fit, by rejecting vaccinations and the science behind them. Even Dubé's (2015) research pointed out that these anti-vaxxers tend to cluster together, which leads to an increasingly high rate of transmission of diseases that could be prevented by vaccines. This

fact is a perfect example of how we can make this situation more relevant and personal to the anti-vaxxers because there is a high risk that their own children could be at risk and next in line to contract one of these illnesses.

By somehow finding a way to relate to those maternal and paternal instincts and making the situation more personal, we can find a solution. These parents are searching for their own narrative; they want and need an explanation of why their children are the way they are (Covello, 2009). Their children being born with autism does not resonate with them and they are searching for every explanation and story that helps them cope and puts the blame elsewhere.

Previous research found that the major issues the anti-vaxxers had with vaccinations were a fear of possible side effects for their children, distrust in vaccinations and what they claim to help prevent, and a general lack of information and comprehension of immunizations or even immunization services (Marti, De Cola, MacDonald, Dumolard, & Duclos, 2017). The authors' study and analysis revealed that 29% of all countries have completed an evaluation on the level of vaccine hesitancy, therefore suggesting that vaccine hesitancy is now of major importance in more than just a few countries globally (Marti et al., 2017). The researcher would like to identify what narratives are most prominent in maintaining consistent and strong support in the anti-vaccination movement. Most likely the movement is successful because of a collection of reasons listed above. Still, before assumptions are made about the anti-vaccine community, it is important to understand its current state as well as its foundational beliefs.

COVID-19 Vaccination

Now, it's important to consider how this vaccine hesitancy in a modern-day pandemic affects the overall anti-vaccination movement. Of course, vaccinations cannot be discussed outside chaos surrounding the COVID-19 vaccine, which was distributed for the first time in

December 2020. As the Pfizer or Moderna vaccination was distributed to the medical front line healthcare workers, there was some apprehension as to the long-term effects. Pfizer's vaccine is a series meant to be given twice, three weeks apart (FDA, 2021). This vaccine is approved for those 16 years and older (FDA, 2021). Moderna is another company working to distribute a COVID-19 vaccination that is approved for those 18 years and older (FDA, 2020). Moderna is also a series meant to be given twice, a month apart (FDA, 2020). Both of these vaccinations may prevent COVID-19, but are not FDA approved vaccine to prevent the disease (FDA, 2020; FDA, 2021). In March 2021, Johnson and Johnson (J&J) also developed a single shot vaccination that was 66.3% effective in clinical trials, but these trials tested on variants (CDC, 2021). Another trial indicated the placebo group faced multiple ill effects (16 hospitalizations and 7 deaths), but the J&J vaccine group had none, making it 100% effective in preventing hospitalizations and deaths (Bai, 2021). This vaccine is notably based in DNA versus mRNA genetic material (Bai, 2021). The J&J vaccine was approved for emergency use by the FDA in Feb. 2021 (Lovelace, 2021).

According to the LA Times (Dec. 18, 2020), California small-business owners and far-right groups teamed up with anti-vaxxers to protest the COVID-19 vaccine. The movement is being led by a group known as Freedom Angels 2.0 (LA Times, Dec. 18, 2020). This is just one small example of the distrust of the COVID-19 vaccine. As COVID-19 has become a polarized political issue, especially within the heat of the 2020 presidential election, some support for the vaccine had decreased. According to a Gallup survey, on Oct. 12, 2020, only a couple months before beginning wide distribution, only 50% of Americans said they would agree to get the vaccination (Saad, 2020). The Guardian (Hanmer-Lloyd, 2020) recognized the delicate way in which COVID-19 anti-vaxxers must be communicated with, recommending a more empathetic

approach to those who are unsure of the vaccine. If anti-vaxxers are immediately dismissed as crazy, they will defend their opinions more fiercely, a phenomenon known as the backfire effect (Hanmer-Lloyd, 2020). This approach will be explored more thoroughly in the discussion of the results, once the researcher understands more about what has created divergent behavior for those who previously were not vaccinated. Perhaps this will provide insight to the overall anti-vaccination movement and how we may better approach vaccine hesitancy.

Communication Accommodation Theory

During the 1970's, Howard Giles theorized an interpretive perspective on the extent to which people converge and diverge communication and behavior styles to fit a desired role (Soliz & Giles, 2014). His research led to the formation of communication accommodation theory, a concise framework towards a further understanding of how people attribute a specific communication practice in reference to their perceived message sender. The theory takes special notice into the motivation individuals possess to either maintain, decrease or create a social distance in their context of interpersonal or macro-group spheres (Soliz & Giles, 2014). "Over the course of its lifespan and through various developmental trajectories, communication accommodation theory has proved to be a broad-reaching theory offering a comprehensive explanation of the cognitive antecedents and communicative variation in our interpersonal and intergroup interactions" (p.124). The divergent and convergent behavior outlined by Soliz and Giles (2014) refers to the direction in which communication and behavior interacts with a particular stimulus emitting a verbal or nonverbal language that either mirrors or defects from the pattern of the perceived.

The theory poses dynamic implications towards the following variables of one's family of origin, and the character roles at play in narrative theory within the anti-vaccination

movement. One's family of origin is simply understood as the family in which one is raised. A tangible model in which to watch the implications of the theory manifest and potentially evolve over time is one's family structure. For the sake of this study, it was crucial to recognize the influence the family of origin (FOO) has in creating dynanism across the human race. "Although it is inappropriate to provide people with the impression that the FOO creates patterns that cannot be overcome and addressed, it is also inappropriate to dismiss the influence of the family of origin as irrelevant," (Busby, Gardner, & Taniguchi, 2011, p. 260). The family unit serves as the primary socializer for children; therefore, communication is evidently intergenerationally transmitted.

Benson, Larson, Wilson, and Demo (1993) collectively noted that intergenerational communication is a process. This process entails several years of varying degrees of the increasing amount of subjection to peers, coaches and the community altogether. In order for communication in the family of origin to be an integral part of a person, it must be observed, repeated, and regurgitate a reaction by the individual. One of the assumptions of Soliz and Gile's (2014) theory is that people make changes on the communication they learn, which leads to differences in how they themselves communicate. There has been significant research on communication accommodation theory regarding intergenerational aspects (Coupland, Coupland, Giles, & Henwood, 1988; Fox & Giles, 1993) which was prominent in this research study. Despite this multitude of research, Gallois, Ogay and Giles (2005) called for further research on social norms and intergroup relations. While this may be most commonly related to intercultural communication, it works as well in the ideal of intergenerational expectations, specifically health expectations. They call for an increased understanding of social norms which can be developed from any number of influential characters in individuals' lives. This study sought to contribute to

this understanding of social norms through divergent characters narratives and risk assessments in the anti-vaccination movement.

Ultimately, converging or diverging behavior is due to what is perceived as acceptable in their situation or more so the motivating factors that one perceives will impact self-continuity. Convergent and divergent behavior produces stark contrasts to one's family of origin initially when the child emerges into a season of independence - eliciting behavior that allows a distinction between parental influence and individual decision making. With this theoretical lens, studying the evolution of communication and behavior in children whose family were anti-vaxxers is worthy of research. Whether adults choose to diverge or converge with the controversial health choices of their family of origin deserves investigative inquiry to advance the field.

RQ1: For adults who were not vaccinated as children, what contributes to divergent behavior regarding their choices to vaccinate themselves and/or their own children?

Narrative Theory

According to communication accommodation theory, we then must understand the narratives of those involved in vaccination decision making. Fisher's (1984) study introduced the narrative paradigm in five elements, but this study aims to focus on one in particular: influence of the environment. The influence of the environment is particularly important during crucial years of growth in childhood and adulthood. We process the events of our lives by putting them into a sequence and ultimately creating a story (Holquist, 2011). Landa (1990) defines narratives as a "semiotic representation" of people creating causation between events. Stories therefore can create connections and increase learning (Alterio, n.d.). Because of the vast uses of narrative

theory, it has been adopted in a wide variety of disciplines, such as psychology, religion, philosophy, law and performance studies (Richardson, 2000).

Narrative theory allows practitioners to analyze various phenomena through the concept of time, creation of plot, development of voice and the idea of a "reader" (Richardson, 2000). Some scholars even argue that to successfully recover from a crisis, practitioners must create a narrative to sensically lay out what happened and what will happen in response (Boudes & Laroche, 2009). No matter how narrative theory is put to practice, the pertinence regarding the ways in which individuals view their relationships to people and places in undenying. Hinyard and Kreuter (2016) recognizes narrative approaches as a "promising set of tools for motivating and supporting health-behavior change" (p. 789). Though it is seen as a promising tool, there are still major gaps related to how to use these narratives most effectively (Hinyard & Kreuter, 2016). For the purpose of this research, narrative theory is used to analyze the lagging effects of the anti-vaccination movement. Identifying these narratives in conjunction with perceived risks (discussed in the next section) aimed to give insight on how to use these narratives in the most effective manner.

For the narrative of the growing anti-vaccination campaign, persuasion is a crucial factor in the debate. The divisive narrative at play is the rhetoric that suggests vaccinations lead to autism - a bubbling discrepancy reaching the judicial boundaries of the United States Congress. "The narrative paradigm can be applied to competing narratives about an autism-vaccine link to enhance understanding of why different audiences appear to be persuaded by different narratives" (Hoppin, 2016, p. 46). This study dissected the evident differentiating narratives at hand - two different rhetorics contrasting in the same scene. This dichotomy of narratives not only manifests at a macro-level, but also within the microspheres of a family unit wherein

different individuals within the same family unit take on differentiating opinions and communication regarding a specific behavior or belief. This divergence due to varying narratives introduces the second research question.

RQ2: For adults who were not vaccinated as children, what elements of their narrative contribute to divergent behavior regarding choices to vaccinate themselves and/or their own children?

Risk Theory

Risk communication is fundamentally focused on understanding the idiosyncrasies of risk bearers in relationship to the objective risk and perceived risk of the phenome. While risk management if focused on the actual manipulation and control of risk, risk communication is based on focusing on how risk bearers, risk arbiters and other involved with informing the public about risk is executed (Heath & Palenchar, 2016). Risk communication researchers define risks as the "possibility that human actions or events lead to consequences that harm aspects of things that human beings value" (Kates & Kasperson, 1983. p.1). According to the researchers, this definition implies that the severity of experienced harm depends on the causal relationship between a stimulus (human activity or event) and the consequences.

The goal in this research is to understand the compounding effect of the risk bearer's narrative in the wake of the anti-vaccination movement to reconcile the implications of how an individual may divert from risk. In order to better understand the narrative paradigm, Palmlund (1992) created the risk narrative analysis that identifies six risk character features related to risk discourse: risk bearers, risk advocates, risk generators, risk researchers, risk arbiters, and risk informers. Palmlund defined risk bearers as those who perceive themselves as or are actual victims of the negative consequences of the risk. In the anti-vaccine movement, the anti-vaxx

parents identify themselves as the risk bearers because of their perceived risk that is forced upon their families by mandatory vaccines. She defined risk arbiters as characters in the risk narratives who take actions to save risk bearers from present or future risks. For the purpose of this study, the focus will be set on risk bearers (the children of anti-vaxxers) and their new role as risk arbiter parents, and how their roles in the risk narrative display longevity within the anti-vaccine movement.

RQ3: For adults who were not vaccinated as children, what elements contribute to their perception of risk regarding their choices to vaccinate themselves and/or their own children?

CHAPTER 3 METHODS

Phenomenology

For examining perceptions and descriptions of previously unvaccinated children begins by first recognizing their own characters and plot line intertwined in expectation and perceived risk, a phenomenological approach is an appropriate overarching methodology. Phenomenology is one of the accepted methods to develop knowledge and understanding from everyday life experiences (Berger & Luckmann, 1966). Phenomenology recognizes the narrative from a first-person point of view, necessary to understanding intentionality behind divergent and convergent behaviors from their family of origin (Smith, 2013). It also allows researchers to investigate meaning apart from respondents' accepted understanding that is entangled in repetition (Daymon & Holloway, 2011). Asking participants to share the elements of their childhood and early adulthood that promoted divergence is key. It is worth noting that participants already attempted to create meaning of vaccinations apart from their family of origin, but a phenomenological approach also allows them to speak unentangled from their current viewpoint of vaccinations. Long-form interviews enable the participants to expand on this increased awareness outside of the stipulations of their everyday life (Smith, 2013). Long-form interviews based on semi-structured interview guides are a foundational instrument of research of the phenomenological tradition. Long interviews are essential to conduct explorative, qualitative research. Interviews will give us access to pertinent cultural information that helps individuals and communities understand the world (McCracken, 1988). These reasons qualified long-form interviews as the most appropriate approach for this study.

Procedure

Data Collection. Recruitment began via Facebook with a post on a group named "Vaccines Save Lives." This public Facebook group has about 8,000 members and remains active with several posts each day. The post for recruitment will read as follows:

> Hi there, I am a graduate student at the University of Tennessee, Knoxville asking individuals over the age of 18 who were not vaccinated as children but decided to vaccinate as adults to take part in a research study through interviews. The interviews would take place via Zoom, estimated to take no more than an hour. The questions ask you to tell your story. The results would be used in my thesis which will hopefully then be published. Any information that would expose your identity will NOT be used to ensure anonymity.
>
> You would be asked to complete a consent form prior to the interview. Please contact me via Facebook messenger or email at shelby.luttman@utk.edu if you have any questions or know someone who might be interested. You can also contact my thesis chair for verification at mpalench@utk.edu. This research study has been approved by University of Tennessee, Knoxville's Institutional Review Board which monitors ethical research practices. Thank you!

Recruitment from this page was slow, and the researcher expanded to several other public Facebook pages that discuss vaccinations (whether pro-vaxx or anti-vaxx). There was significant pushback, or more accurately hesitation, from the moderators of several groups as they doubted the authenticity of the project or cited the core values of the group as a place where participants do not wish to be questioned. This is an important element that will be discussed in the results. These difficulties and the suggestions of a few participants encouraged the PI to branch out to

another form of social media, Reddit. Though not long lasting, the PI's experience on Reddit was overrun with internet trolls who claimed she was simply aiming to produce results in favor of vaccinations to receive a paycheck from Pzifer. It was also on this platform that individuals reached out claiming they would only take part in the study if their identity would remain completely anonymous, even to the PI. This was not feasible for the current study as it required a consent form to be completed before interviews could occur. This consent form is provided in the appendices.

During the process of each interview, the researcher first asked if she could record the session to later create a transcript. Post each interview, the researcher will transcribe the interview. Interviewer's notes and transcriptions were saved in a secure drive on a computer in which only the researcher has the password, and that computer was stored behind a locked door for the protection of interviewees' identities. Each interviewee at this point was assigned a letter and was henceforth identified as such. Between her own notes and the direct transcription of the interviews, the researcher began analyzing data. Interviews were conducted to the point of saturation.

Sampling. The researcher used purposeful snowball sampling, as this population is niche and not easily accessed, especially as the issue has become increasingly polarized. To qualify for this study, research participants had to be previously unvaccinated children who are now adults over the age of 18. The participants had to portray divergent behavior regarding their vaccination behavior as children. Virtual, long-form interviews via Zoom sought to identify the various stimuli that contribute to divergent behavior. The sample of the study included two young mothers and four young adults. The differences between these groups are discussed in further detail in the results section.

Modified sampling. As the researcher began her collection of data, it was found that qualifications for the study needed to be adjusted to properly represent a conclusive sample. Many individuals responded to the recruitment post asking if they could still participate if they were only partially vaccinated as children, meaning their guardians demonstrated some sort of vaccine hesitancy, if only to some vaccinations. The qualifications and recruitment statement were then reworded to say, "not *fully* vaccinated as children." This led to more responses from the community.

Misinformation on social media and amongst community groups is the most common factor of uncertainty. It is worth noting that a significant number of people who reached out to the PI were not raised anti-vaxx, but found the movement in early parenthood on social media. Since then, many of these individuals have diverged and become pro-vaxx. These individuals are not included in this sample as the PI is studying divergence from the family of origin, and how this can be used to create effective, health messaging.

Measures. This study frames three research questions, the first of which informs the others. Research question one asks, "For adults who were not vaccinated as children, what contributes to divergent behavior regarding their choices to vaccinate themselves and/or their own children?" This takes the general feedback of participants into consideration regarding their divergence from their family of origin. Research question two asks, "For adults who were not vaccinated as children, what elements of their narrative contribute to divergent behavior regarding choices to vaccinate themselves and/or their own children?" This question is highly interconnected with the first research question but asks about it through the frame of their own narrative experiences. It is important that the interviewees were able to share their experiences as it opens conversation up to topics the researcher may not have considered. The third research

question asks, “For adults who were not vaccinated as children, what elements contribute to their perception of risk regarding their choices to vaccinate themselves and/or their own children?” This question indicated how perceived risk informed the participants divergence from their anti-vaxx parents. It could be particularly helpful in how to outline future health messages regarding vaccines.

The interview was divided into three main sections asking about: (1) general health and community experiences in childhood, (2) positive or negative experiences regarding their family’s choice to not vaccinate, and (3) how they came to their decision to diverge from their family of origin. These questions aimed to encourage the sharing of personal experiences in their family of origin as well as the indirectly extract their perception of health risk. The full interview guide is presented in the appendices (Appendix I).

CHAPTER 4 FINDINGS AND DISCUSSION

Data Analysis

Data was collected to the point of redundancy. Responses from the participant's answers were manually coded using Braun and Clarke's (2006) thematic analysis, which includes six phases: familiarization with data; generation of initial codes; searching for themes; reviewing themes; defining and naming themes; and production of the report. Familiarization with data began during data collection. It requires repeated reading of responses and note-taking for coding ideas. The generation of initial codes stems from what researchers find interesting in the data. During this phase, the researcher manually and systematically worked through the data set. As this phase is less formal, the researcher preliminarily coded by highlighting and writing notes on the transcripts of the interviews. This helped in the process of identifying themes, which is phase three. This involves "sorting different codes into potential themes" (Braun & Clarke, 2006). This data will then be visually represented to help researchers organize the themes accordingly. This helps identify which themes are most significant and allowed the researcher to separate candidate themes and sub themes. In phase four, the PI will refine these themes. This occurs on the coding level as you verify the codes categorized into the theme form coherent patterns. It also occurs on a macro level as the researcher ensured individual themes accurately reflect the data set. In phase five, the themes were defined and named based on their narrative. It is pertinent to identify what is most interesting about the content, and to not just paraphrase it. Lastly, the researcher produced a report that tells the story of their data through the thematic analysis.

Thematic Analysis

The PI navigated through the six phases of Braun and Clarke's thematic analysis (2006). Once the final phases of analysis were completed, the researcher then discussed further implications of the results, especially in relation to the COVID-19 vaccination.

Once the interviews were transcribed and pseudo named, initial codes were collated. The researcher proceeded to familiarize herself with the interviews, especially during the transcription process. This was more a process of retaining information; therefore, there is not much literal, written analysis included in step one. One expected, general finding though was the aggressiveness in which people commented on recruitment posts. Pro-vaxxers most commonly commented on recruitment posts claiming their parents were not idiots (or any other synonymous adjective). Anti-vaxxers were more likely to accuse the study of being swayed by capitalist motives or funded by major pharmaceutical companies. These combative responses further polarize the topic in ways that ostracize or invalidate other individuals' parenting decisions. This polarization has only become more detached and static through the development of the COVID-19 vaccinations. These implications are discussed in further detail later in the paper.

After reviewing the general themes, the PI narrowed the themes of divergence into three categories: (1) establishing trust, (2) receiving validation, and (3) performing independent research. These themes are summarized visually in the following chart (Figure 1) that addresses hinderances and recommended actions. It is worth noting the hinderances are much more ingrained and will not be influenced by health messaging or personal communication alone.

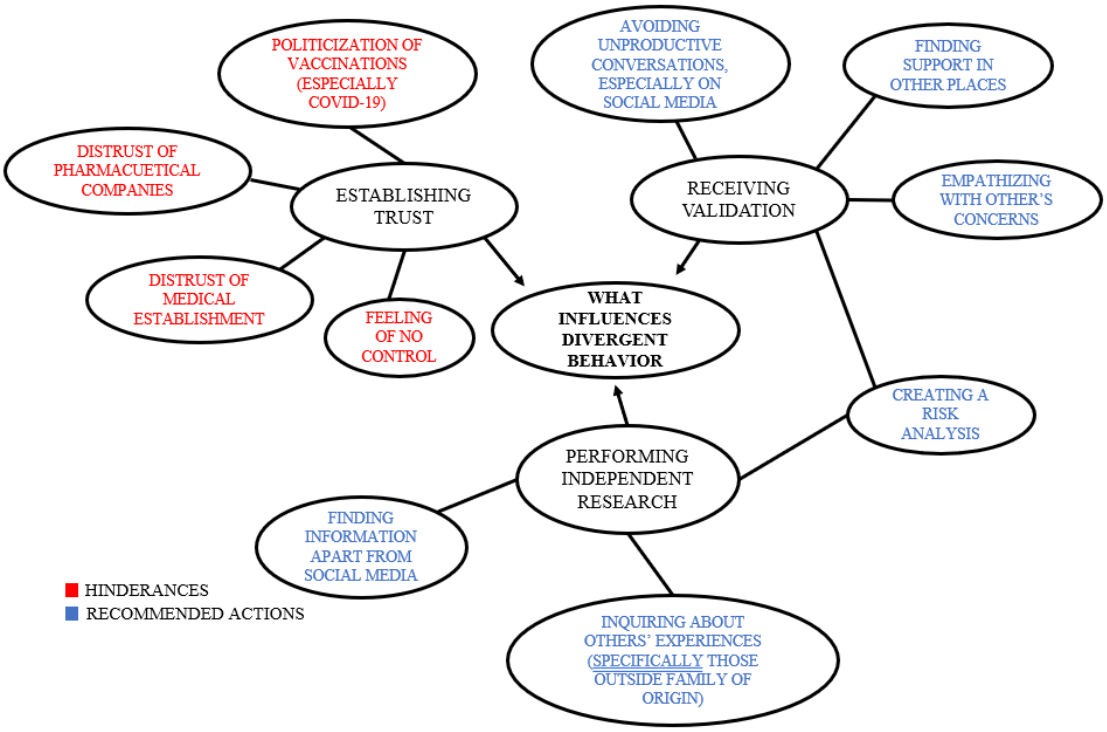

Figure 1 Visual summary of findings.

Establishing Trust

One identified code during this phase of analysis was naturopathic tendencies that either purposefully exposed children to a disease, such as chickenpox (Participant B), or saw catching the illness as the best way to build immunity to it (Participant C). Religious concerns and naturopathic tendencies were not necessarily mutually exclusive though, as some participants (for example, Participant B) claimed their parents' naturopathic ideals stemmed from distrust in medical establishments and their questionable ethics that challenged some Catholic values. Even as there is some overlap, naturopathic tendencies are still coded as their own sector since multiple participants (Participant A and C) outwardly expressed their parents' tendency to look for natural solutions for reasons unrelated to religion. Participant C commented,

> "I think I was talking to a friend and she said our parents were crunchy before crunchy was a term. (laughing) That's what she said, so they, you know, ate organic food did all… you know, I don't think elderberry syrup became a thing [until] recent years, but they used echinacea tea and homeopathic remedies and um did their best to be healthy, organic and all of that and it all was almost part of the lifestyle. Like uh um it was not religious for any of the people that I knew. Although they may have used religious exemptions to get away with it (laughing)."

This was supported by Participant A's claim who expanded on the experience of partially vaccinated children in a naturopathic home:

> "Ah, generally, I think that my parents just liked to do things at home as much as they could. And they were also- they're- my parents are nervous people. And so like, a good example of this is they wanted to do like a home birth for me. But then labor started, and then they went to the hospital. And so like, similarly, my mom was like, really trying to

handle things with herbs and stuff. But as soon as like anything serious happened, like, we would just go to the doctor. And so I would say that my mom and especially, but also, to an extent, my dad, they were trying to- like, they totally felt like systemic medicine, and like hospitals and stuff, were like, for profit situations, which did well, when they kept people dependent on them. And that corporate medicine and stuff like that is like, you know, maybe got some problems to it. And so to the best of their ability, they tried to keep us like drug independent and stuff and, you know, do preventative stuff. But as soon as it fell apart, or as soon as like I broken arm or something like that, it wasn't like they were just like tying me up to a stick, like they immediately took me to the hospital. And so like, I don't know, I would say my relationship was one of like, a healthy distrust of hospitals, maybe and like medicine. But at the same time understanding that I we too, are ignorant folk. And, you know, at times, you know, maybe just give up your opinions to the experts" (Participant A).

Participant D also explained her mother's distrust of medicine as a key factor that kept her from getting vaccinated and the medical community served as someone to blame.

"But she has like severe distrust of healthcare providers in general. So she, we didn't take our dogs to the vet, we didn't… like I rarely went to the doctor. But I got meningitis as an infant. And so I'm partially deaf in this ear. And uh my mom just like, didn't really like the way that the doctors were, I guess she just didn't trust the health care provider to do what they needed to do. And so my hearing problems caused like more um… what's the word I'm looking for? It caused her to be more upset, I guess, if you will, like she needed someone to like blame and push that on. So she's very distrustful of doctors ever since" (Participant D).

Through phase two, there were several initial codes established. One of these was the role of religion in vaccination decisions. Participant F expanded that much of the distrust of medical systems in Catholic communities comes from the rampant discouragement when they express concern about the use of aborted fetus cells in the production of vaccines. Another Catholic participant (Participant B) indicated that not all vaccines were denied to them, but the most common of these would be the HPV vaccine as it was not decent to speak of sex in their religious communities. In other interviews, it seemed Massey's 1772 sermon called "The Dangerous and Sinful Practice of Inoculation" (Hussain, Ali, Ahmed, & Hussain, 2018) still had traction in Catholic communities. Participant E explained this vilification of vaccines,

> "My mom was very religious. And because of that, there was a lot of conversations around vaccines that like if it did come up, she would say like, 'I'm not putting that in my body. Like that's not healthy. It's not like- God gave me an immune system.' It wasn't like a conversation I- that's not the correct word. I guess like more when the topic came up, those are some things that she said" (Participant E).

Another participant openly spoke of the backlash to expressing Christian ideals in relation to vaccines:

> "There's this kind of disregard for the morality or the ethics of like Catholics and Christians in general. And I noticed- because I- after my story online went viral, I was added to a bunch of pro-vaxx groups, and I actually left them because there was a certain- a certain- what's the word, disdain for Christianity that kind of reinforces this distrust? I would think- of medical of the, you know, of the intentions of medical professionals, you know, that I, I, you know, you can't- I don't separate science and religion. You know, I think you can have both. I think one informs the other and to have a sort of disdain or on-

> what is it just not taking seriously, the ethical concerns of a large denomination, like the Catholic Church is pretty huge." (Participant F).

More than one participant shared their experiences in how parents attempted to create natural immunity. Participant B shared their personal narrative of purposefully being taken on a playdate with another child that had the chickenpox and being made to rub the soothing cream on her so they would contract chickenpox. These were referred to as "Pox parties" (Participant F). In Participant B's familial circumstance, it was not even mentioned during childhood that contracting chickenpox made you more susceptible to shingles later in life.

> "Oh, so the chicken pox is a funny story. I don't know if you're going to get into this more. But um, my mom actually, my mom actually had me like, go on a playdate with a friend who had the chickenpox and made me like rub the cream on her so I would get it. And I did get the chickenpox. But I felt like that's the thing that a lot of moms did was they like, they had these playdates where they like, made their kids get the chicken pox, because they didn't want their kid to get the vaccine. So that's something I feel like I thought was normal when I was a kid when it was happening, but now I'm like, I think I'd much rather would have preferred to have vaccine than to have chickenpox" (Participant B).

Lastly, as many vaccinations are required for school, it was more likely that individuals were homeschooled if they were not fully vaccinated (Participant C). Participant D commented that in their experience, many parents who were anti-vaxxers homeschooled their children in search of some level of control they did not feel in their own childhood. Although this is purely suggestive, it could demonstrate a difference between nonvaccinated children in a public school and homeschool setting. Those that were partially vaccinated in this study, did so primarily for

the need of going to school. Though of course there is always the topic of religious exemptions in an educational setting.

Establishing trust can be recognized as an essential element to creating divergent behavior in favor of vaccinations. Trust in the medical establishment has drastically decreased as pharmaceutical companies have profited so immensely from the mass production of several responsive and preventative medications. Many are also hesitant to trust the CDC and the FDA as governmental organization are also challenged by the politicization of healthcare, especially within the 2020 presidential election. Establishing strong relationships of trust between these organizations and their contenders will not be a quick transition, especially as the U.S. serves as an individualistic society. Medical organizations can continue to work on building this trust through providing financial transparency and working to meet hesitancy with grace as well as understandable breakdowns of the medical advice. As the politicization of vaccines has made it a hot topic, organizations might also want to consider the use of local activists and increased health education in schools, starting in elementary school.

Receiving Validation

Participants fell into two main categories: young adults and young mothers. There is some overlap of opinion within these two categories. Of the interviews conducted, two participants were parents of young children. Their concern most rested on the decision to minimize any suffering to which their children may be exposed. Interestingly, Participant C shared with the researcher that now they thought “the best immunity is- is the one where you don't have to suffer to get it.” This illustrates that divergent characteristics involving vaccination behaviors could be directly related with understanding the level of suffering for children. Despite the perceived level of suffering, many participants (Participants A, B, C, D, E) were careful to

make the distinction that though they were not fully vaccinated as a kid, their parents still loved them and took care of them. This suggests an expected negative judgement of their parents when sharing their vaccine experiences, though not many participants admitted to having negative interactions with others regarding their vaccination history. Relatedly, the initial code of validation was particularly present in the young mother category.

The code of religion was an existing argument of historical vaccine hesitancy (Hussain, Ali, Ahmed, & Hussain, 2018). This hesitancy has been built into the structure of several Catholic communities for centuries. At this is the most longstanding persuasive element in the anti-vaccination movement, it is important to address it as such. Any narrative theme addressing the divergence of those from Catholic communities expressing vaccine hesitancy should be careful not to dismiss the concerns just on the basis of religion. This religious concern has been integrated into their belief systems so long, that it will not be dismantled in a matter of decades. Many parents have taken the approach Participant E referenced when they referenced what their parents said, “I'm not putting that in my body. Like that's not healthy. It's not like- God gave me an immune system.” This indicates that religion and naturopathy are sometimes correlated in their understanding that God would want them to use natural remedies.

As Participant E emphasized, it is not necessarily about the facts, though those are important. Every parent wants to feel as though their parenting decisions are validated, no matter the reason the belief is held. This validation can be sought from a variety of sources, be it Facebook or local communities. Participant F indicated that she performed a kind of “risk assessment” to determine whether vaccinations were a healthy risk to her children. When deciding whether to vaccinate her own children, she calculated the risks associated with

vaccinations, primarily potential symptoms, and compared these to the risks associated with everyday life, including just buckling up her kid and driving to the grocery store.

> "I can't remember the numbers, exactly. I crunched the numbers. It was like one and 100,000 chance that you'll get one of [the vaccines] bad symptoms, and it was based on- man, I can't remember the name of it now. But you know, the reporting system, if everything that was reported as a Vaccine Injury were actually true, then well, 'How bad is it? Like, what's the risk?' And I knew that the risk of just buckling my kid into the car and driving them to the grocery store was like one in 5,000, or something like that, of getting in an accident. So, I was like, well, I take that risk every day. And I consider that to be a healthy risk. So, one in 100,000, that seems like that should be a healthy risk too if I'm being consistent with my own self" (Participant F).

The risk assessment conducted by Participant F relates to this need for validation through logic. Participant E called out the need for this validation we he said, "One of the biggest hurdles isn't information. It's not research. It's not confidence, but it's encouragement, and it's validation in what they're doing is right." For many young people, this validation has been found when asking questions on social media, such as Reddit and Facebook. Unfortunately, sometimes these networks serve to create more confusion than clarity. Validation in general is threatened with the use of accusatory language that claims anti-vaxxers do not love their children. This validation is also threatened when children diverge from their family of origin. It can harm familial relationships in irreparable ways. Participant E shared a story of his stepbrother refusing to let him hold his Easter basket because he was vaccinated and "might get him sick." So, not only does the divergence cause separation between parents, but also potentially between siblings of variant ages.

Feeling validated in decision making is an important element that cannot be overlooked, especially with young parents. The number of channels providing parental advice seems to continuously grow, and no matter which facts those parents hear, the thing they most strive for is to know they are doing the best thing for their children. Especially as the young people in this study diverged from their family's vaccination customs, they were clear to validate their parents' decisions with reassurances of their love. Too often, anti-vaxxer parents are attacked on the basis of not caring about their children's health. The goal is not to validate every behavior, but to validate the *intentions behind* the behavior.

Performing Independent Research

Lastly, performing independent research was a clear theme of divergence for participants. Repeatedly, participants indicated they did not even discuss vaccines with their families as children. This lack of exposure creates an echo chamber of ideas that do not allow for conflicting viewpoints to emerge. For example, Participant C said,

> "I still see people making the same arguments that were made 30 years ago, that didn't go well for us. Or even like the whole vaccines causing autism thing, which has been disproven again and again and again. That people still believe um- it just, it just drives me- now it just drives me nuts because I understand how to read a paper and look at data and it seems clear. But um, but I still know people that I grew up with that are adamantly anti-vaccine. And it is almost like their cause that they've decided, they're- that they see danger in vaccines. It's almost like a cause to them to convince other people not to vaccinate."

If health communication experts wish to be effective in combatting misinformation, they must find ways to penetrate the communities spreading false information and approach them in a

way that respects their intentions but opens the discussion to proven scientific evidence. Most of the participants explained they diverged from their family of origin as they proceeded through college or did personal research that provided significant, logical information. There is always the creation of new narratives as individuals marry into new families and take their influence into account. Participant F decided to do the previously referenced risk assessment due to her mother-in-law's influence. She said,

> "And when I mentioned to my mother-in-law that I was not going to vaccinate, she was just shocked because she had actually contracted rubella as a child and almost died. And all of her brother- brothers contracted a bad case of measles. And so- at the same time- so she told me her story about almost dying from rubella. And it got me rethinking like, I guess it just never occurred to me because I had chickenpox [and it] was no big deal as a kid, so I thought it was just an inconvenience. But to think that as a child, you and your siblings could have just died kind of made it seem like maybe the diseases might be a bigger risk than the vaccine" (Participant F).

The codes of religion and homeopathic tendencies were so prominent that they can be identified as their own potential themes that guide individuals to convergent or divergent behavior. The primary findings of this study indicate that individuals who were not vaccinated as children most commonly emerged from either Catholic or naturopathic communities, with some overlap. This was to be expected according to the history of vaccine hesitancy, but this research delved into the personal narratives of individuals from these communities and elaborated more on the growing naturopathic movement in the "mommy sphere" (Participant F). An overlapping definitive element of both religious and naturopathic communities was the concept of control, particularly educational control.

Another code worthy of mentioning relates to the timeframes in which participants were made aware of their parents' vaccination hesitancy. When Participant B was denied her HPV shot, this was when she first realized their parents displayed vaccine hesitancy. As the HPV vaccine is first recommended for children 11 or 12 years of age (CDC, 2020), this means this participant did not become aware of their parents' vaccine hesitancy until around this age. Other participants did not really indicate much exposure to this issue until they reached adulthood. Participant C commented that more than not, vaccinations just did not come up in conversation. Even interparental conversations did not seem to be a huge factor, as vaccinations decisions were mostly left up to the mother. At least one participant (Participant A) did indicate that extended family did question their parents' vaccination decisions. More times than not though, vaccinations were not openly discussed in any extended family setting.

Production of report

These findings in many ways confirmed the historical causes of vaccine hesitancy in modern times, whether that be on the grounds of religion (Hussain, Ali, Ahmed, & Hussain, 2018), distrust, lack of information or protective instincts (Marti, De Cola, MacDonald, Dumolard, & Duclos, 2017). The research itself does not provide generalizable results, but instead deeper insight into the experiences of a select group of individuals during the creation and incubation of their vaccine narrative. The first research question asked about this divergence in a general sense: For adults who were not vaccinated as children, what contributes to divergent behavior regarding their choices to vaccinate themselves and/or their own children?

The answer to this main question is provided through the named themes in phase five of the thematic analysis: establishing trust, receiving validation, and performing independent research. The second question asks the same thing, but through the lens of their personal narrative: For

adults who were not vaccinated as children, what elements of their narrative contribute to divergent behavior regarding choices to vaccinate themselves and/or their own children? It is this narrative element that develops a voice and creates a plot (Richardson, 2020) in the participants' history. The plot of childhood to adulthood, and then again transitioning into parenthood, has provided a unique understanding of the perception of risk at different points in participants' lives. This relates to the third research question: For adults who were not vaccinated as children, what elements contribute to their perception of risk regarding their choices to vaccinate themselves and/or their own children? The turning point for most of the individuals who participated in this study was their creation of some kind of risk assessment or search for information outside of their family of origin's values. Notably, Participant B found that though she had received required vaccines, she was still faced with the decision about the HPV vaccine at the age of 25. Now she wondered whether it was worth it to get this vaccine, and perhaps there needs to be more messaging for those interested in vaccinations later in life that answers these kinds of questions. Participant F called for opportunities to increase vaccination education in school systems, as well. These resources could allow for children to understand the purpose of vaccinations and answer questions before they become doubts. Of course, these risk assessments cannot be completely informed from the public school system. The reframing of medical institutions will be a multi-level approach that will not happen overnight. It will take the education of several generations, the penetration of online echo chambers spreading false information, and the sense of control for those who just want the best for themselves or their children.

CHAPTER 5 IMPLICATIONS

Practical Implications

This research emphasizes the need for validation alongside factual information in health communication, especially pertaining to vaccinations. Perhaps this takes form through sharing narratives like those that participated in this study. The unknown is daunting, but what if health messages about vaccines sought to make stories *more* known. Share the story of the unvaccinated woman who caught mononucleosis as an infant and lost partial hearing in one ear. Share the story of the children who went on chickenpox playdates and are now more susceptible to develop shingles. Share the story of the kid that respectfully disagreed with his mother on vaccinations and is working to put their relationship back together. It is the real stories about what people fear most that will sway them. For health messages to be effective, they must combat the fear inside individuals that say something else. For divergent characters to become a more optimal part of the narrative, their actions must feel justified- validated. The harsh reactions to recruitment exemplify the extent to which the backfire effect (Hanmer-Lloyd, Nov. 26, 2020) has served its polarizing purpose. As distrust in government and medical organizations is at an all time high, the researcher suggests health messaging starts from a more local level, maybe even local forums. This would provide a place for individuals to ask questions to health professionals in their area who most identify with their fears and concerns. Local professionals are also more likely to have higher credibility in rural communities where distrust has peaked, especially during the 2020 presidential election.

Theoretical Implications

This research contributes to the understanding of narrative theory because it illustrates the importance of the perception of risk involved in the creation of narrative. It also illustrates direct

implications of the perception of risk through various points of life. As children, the participants trusted their parents to do these risk assessments themselves, as they should. As they came into adulthood, their understanding of the risk changed for a variety of reasons including (but not limited to) the creation of new familial narratives and exposure to new information. This research also answered Gallois, Ogay, and Giles' (2005) call to contribute to understanding how social norms influence convergent or divergent behavior. Social norms in this case shifted as the participants came into adulthood. The social norm of vaccine hesitancy was accepted blindly as young children, but the introduction of new points of view introduced new social norms from peers and some communities online.

Societal and COVID-19 Implications

This study analyzes the perceptions of vaccinations during a major international health crisis. The societal implications of this amplify the WHO's claim that vaccine hesitancy is a significant threat to global health. The results of this paper indicate a greater need for trust, validation, and independent research. If these needs are met, it is hopeful that the discussion of vaccinations will become less polarized. Also, as the mass distribution of the COVID-19 vaccine continues, this research can yield significant impact in its acceptance. The intricate way in which interviewees from this study approached how they spoke about their anti-vaxx parents is indicative of how other pro-vaccination individuals might delicately approach those who are hesitant of the COVID-19 vaccination. If we are to avoid the backfire effect (Hanmer-Lloyd, Nov. 26, 2020), then we might consider adopting this empathetic approach aiming to answer questions without judgement. Perhaps health messaging can hone in on the need for more scientific evidence, while avoiding the use of confusing scientific jargon. Also, according to

respondents, information about the history of mRNA research and its part in developing the COVID-19 vaccine was majorly influential to the level of trust they developed for the vaccine.

CHAPTER 6 LIMITATIONS AND FUTURE RESEARCH

The main limitation of this study was the difficulty of recruiting participants (1) during a pandemic and (2) for such a heated topic. Another notable limitation in this study was the inability to remain completely anonymous from the PI herself. Some potential participants indicated their unwillingness to speak with the researcher for fear of being identified, particularly when connected with individuals (or more accurately, usernames) on Reddit. Future research should consider new ways to interview participants that would prevent even the PI from identifying their voice, face, or name. This would also require participants to yield their right to a consent form. This was not a feasible or approved measure for this study, but perhaps in the future these could be taken into consideration. While this was not as much of a concern on Facebook, it would also be interesting to also study the hesitancy of group moderators to allow recruitment to such studies in their vaccination groups.

As the researcher proceeded through the analysis, she began to consider how young mothers, who were not necessarily raised anti-vaxx, became enraptured by the anti-vaxx "mommy-sphere" (a termed used by Participant F) and proceeded to diverge from their own preconceived notions to become anti-vaxx. It would also be interesting to investigate the reverse sample of those referenced in this study- individuals who were raised pro-vaxx, but decided against vaccinating their own children or proceeding with any other potential vaccinations for themselves. Lastly, specifically pertaining to COVID-19, it would also be useful to study the effectiveness of various incentive programs, such as the vaccine passport.

CHAPTER 7 CONCLUSION

This study delved into understanding the meaning of narratives established by the anti-vaccination community, and those of adults diverging from the community when it comes to vaccinating themselves and/or their own children. The results indicated that vaccine hesitancy is still deeply rooted in religion. Naturopathic behaviors also made a significant appearance in parental decisions. From this study, it is suggested that future health strategies aim to: (1) establish trust of medical institutions, (2) validate parental decisions, rather than judge them, and (3) encourage independent research (especially outside of social media).

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APPENDICES

Appendix I. Semi-Structured Long Interview Guide

1. Growing up in your home, what was your experience related to health issues, just generally?
    a. Were there any discussions in your household regarding vaccinations as a child?
    b. Did your parents get vaccinations as children?
    c. In the extended family, was there any discussion or awareness of vaccination?
    d. What was the community you lived in like, especially pertaining to vaccination?
2. Since not being vaccinated as a child, did you experience any positive or negative experiences related to your family decision regarding vaccination?
    a. As a child, did you have any opinion or feelings about vaccinations?
    b. As a child, were you aware of the role of vaccination related to your health?
3. Can you share with me your choices regarding your own children and vaccinations?
    a. What are your thoughts on vaccinating your own children?
    b. How did you come about those choices?
    c. Can you consider what influenced you, beyond your family's decision, regarding your choice of whether vaccinating your children is appropriate?
    d. Any media influences, bloggers or other online sites that may have played a role?

Appendix II. IRB Approval

January 06, 2021

Shelby Cole Luttman,

UTK - College of Communication and Inf - Advertising/Public Relations

Re: UTK IRB-20-06192-XP

Study Title: How Divergent Risk-Characters Rewrite the Anti-Vaccination Narrative

Dear Shelby Cole Luttman:

The UTK Institutional Review Board (IRB) reviewed your application for the above referenced project. It determined that your application is eligible for expedited review under 45 CFR 46.110(b)(1), categories 6 and 7. The IRB has reviewed these materials and determined that they do comply with proper consideration for the rights and welfare of human subjects and the regulatory requirements for the protection of human subjects. Therefore, this letter constitutes full approval by the IRB of your application (version 1.3) as submitted, including the following study documents:

- Luttman_ConsentForm v. 1.3
- Recruitment materials v. 1.1
- Interview Questions v. 1.0

Approval of this study will be valid from January 06, 2021 to 01/05/2022.

In the event that subjects are to be recruited using solicitation materials, such as brochures, posters, web-based advertisements, etc., these materials must receive prior approval of the IRB.
Please note that restrictions are in place due to the COVID-19 pandemic, and all in-person contact with research participants is on hold until further notice.

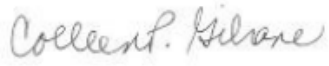
- Newly-approved studies with in-person interactions may not begin enrollment until further notice from the IRB/HRPP.
- Newly-approved studies with no in-person participant interaction may begin after receiving IRB approval.

Please monitor the COVID-19 Updates at https://www.utk.edu/coronavirus/faq/ for the latest information. Human Subjects Research updates are being filed under Information for Instructors/Research.

Any revisions in the approved application must also be submitted to and approved by the IRB prior to implementation. In addition, you are responsible for reporting any unanticipated serious adverse events or other problems involving risks to subjects or others in the manner required by the local IRB policy.

Finally, **re-approval** of your project is required by the IRB in accord with the conditions specified above. You may not continue the research study beyond the time or other limits specified unless you obtain prior written approval of the IRB.

Sincerely,



Colleen P. Gilrane, Ph.D.

Chair

Institutional Review Board | Office of Research & Engagement
1534 White Avenue Knoxville, TN 37996-1529
865-974-7697 865-974-7400 fax irb.utk.edu

Appendix III. IRB-Approved Informed Consent

Consent for Research Participation

Research Study Title: How Divergent Risk-Characters Rewrite the Anti-Vaccination Narrative

Researcher(s): Shelby Luttman, Graduate Student, University of Tennessee, Knoxville

We are asking you to be in this research study because you are over the age of 18 and displayed divergent behavior from your family of origin regarding vaccinations. The information in this consent form is to help you decide if you want to be in this research study. Please take your time reading this form and contact the researcher(s) to ask questions if there is anything you do not understand.

Why is the research being done?
The purpose of the research study is to understand why adults diverged from their family of origin and how their narrative shifted regarding vaccinations. This study is being conducted by a graduate student at the University of Tennessee, Knoxville.

What will I do in this study?
If you agree to be in this study, you take part in a virtual interview via Zoom. The questions ask about your experiences and preferences regarding vaccinations. You can skip questions that you do not want to answer.

Can I say "No"?
Being in this study is up to you. You can stop up until the interview is complete, as it will then be identified by letter for the duration of the study.

Are there any risks to me?
You will not experience any more risk than what you experience in everyday life.

What are the potential benefits for taking part in this study?

The potential benefits for taking part in this study include providing your story regarding vaccinations. This research also has the potential to inform future research. Lastly, there may be feelings of nostalgia of the participant's childhood.

What will happen with the information collected for this study?
During the process of each interview, the researcher will first ask if they can record the session to later create a transcript. Post each interview, the researcher will transcribe the interview. Interviewer's recordings and transcriptions are to be saved in a secure drive on a computer in which only the researcher has the password, and that computer will be stored behind a locked door for the protection of interviewees identities.

Information collected for this study will be published and possibly presented at scientific meetings. No identifying information will be included.

What will happen to your data in the future?

Your data will be transcribed within 48 hours of the interview. At which point, the entire recording will be permanently deleted. The transcription will be assigned a letter and will be henceforth identified as such. These recordings will not be released in any form. Any identifiable information from the transcript will not be used.

Will I be paid for being in this research study?
There will be no monetary compensation for taking part in this study.

Who can answer my questions about this research study?
If you have questions or concerns about this study, or have experienced a research related problem or injury, contact the researcher, Shelby Luttman, shelby.luttman@gmail.com , 704-930-9814.

For questions or concerns about your rights or to speak with someone other than the research team about the study, please contact:

Institutional Review Board
The University of Tennessee, Knoxville
1534 White Avenue
Blount Hall, Room 408
Knoxville, TN 37996-1529
Phone: 865-974-7697
Email: utkirb@utk.edu

How will this consent form be stored?
This consent form will be stored on a USB drive in a locked drawer on UTK's campus. This drawer will be behind a locked door, in which only the PI has the key. The consent forms will be kept for three years as per the requirements of the UTK IRB. Once the principal investigator graduates, arrangements will be made to keep these consent forms on the same USB locked on campus behind a locked door of one of the members of the PI's committee. This is a requirement by the university that consent forms cannot be stored at any private residence. After three years, the consent forms will be permanently deleted.

Statement of Consent
I have read this form, been given the chance to ask questions and have my questions answered. If I have more questions, I have been told who to contact. By consenting in writing before the interview, I am agreeing to be in this study. I can print or save a copy of this consent information for future reference. If I do not want to be in this study, I can end contact with the researcher.

Participant signature: _____ Date: _____

Appendix IV. Example of Transcript

Participant C

SUMMARY KEYWORDS

vaccinated, remember, vaccines, vaccinations, colds, talking, siblings, community, chickenpox, adamantly, understand, kid, caught, families, trust, discussions, disease, parents, consequential, questions

PI: And you... you sent me over the consent form. Do you have any questions about anything on there? Or am any concerns?

R: No, no, no questions yet about the form.

PI: Okay, then I guess we'll just hop right in. Let me pull up my questions.

R: Sure.

PI: So growing up in your home, what was your experience related to health issues? Just generally?

R: Just generally, we had a… when I was younger, I mean, we had a pediatrician, older primary doctor that we would see, for colds lasting longer than a couple to a few days. I mean, depending on severity of the cold, my mom tended to um… she tended to try homeopathic remedies: homeopathy, teas, vitamin C. So, she tended to try that kind of stuff first. Or if things were mild. Yeah, first. Um…

PI: Perfect. Um. Were there any discussions in your household when you were a kid about vaccinations that you can remember?

R: Only, uh only between parents, between like my parents and other parents. So I definitely picked up on and then when we went through um… so in like the 2000s, we think my siblings had Pertussis, whooping cough. And so there were a lot of discussions then that I overheard about, like vaccines in general. So I mean, it was, you know, the kind of thing like it's better to have natural immunity. Anyway, oh, these diseases are treatable. And this is, you know, 30 years ago, this these ideas going around. Um. It is, you know, not natural, having vaccines are not natural. They're putting things into your body that, you know, that aren't meant to be their um…ideas like that. And I remember repeating that I had, I did not catch chickenpox until I was 18. So, it was always quite severe. At that age, it's not a good idea to get Chicken Pox at 18. But even after chickenpox, I mean, I missed my high school graduation, while I was home, delirious with fever, that I was struggling, they're struggling to control with Tylenol, and our primary doctor was saying, “Can I take pictures and document your daughter's case? Because you just don't see cases like this anymore?” *Because people are vaccinated by that point, right*. But I remember even after that,

somebody telling me, “Oh, I bet you wish you'd been vaccinated for chickenpox.” And I remember telling them, “Oh, no, it's so much better that I have natural immunity. Now, that will last a lifetime.” I remember like adamantly believing that in the early 2000s.

PI: And do you know if your parents were vaccinated, and they decided to not vaccinate you or?

R: Yes, they both would have been vaccinated. Yeah.

PI: Okay. In your extended family, was there any discussion or awareness of vaccination, especially pertaining to yours?

R: Not that I know of.

PI: Okay.

R: Yeah.

PI: And can you tell me a little bit about what your community was like growing up, especially pertaining to vaccination, but also just generally,

R: Oh it was a homeschool community of a lot of the families didn't vaccinate either. Yeah.

PI: And was that in any… Was there any religion that played into that or any other beliefs that might have played into that or…?

R: No, I think I was talking to a friend and she said our parents were crunchy before crunchy was a term. (laughing) that’s what she said, so they, you know, ate organic food did all… you know, I don't think elderberry syrup became a thing in recent years, but they used echinacea tea and homeopathic remedies and um did their best to be healthy, organic and all of that and it all was almost part of the lifestyle. Like uh um it was not religious for any of the people that I knew. Although they may have used religious exemptions to get away with it (laughing).

PI: And since not being vaccinated fully as a child, did you experience any positive or negative experiences related to that decision? Anything that other people might have said to you or uh any stipulations of that nature?

R: Oh, the only negatives really were catching preventable diseases. Those are the only negatives I can think of. I didn't… like I never had anyone who was rude to me, or it usually simply didn't come up.

PI: And do you remember, obviously, this is all as a kid…it's hard to remember everything. But do you remember having any opinions or feelings at a young age about vaccinations?

R: Well I-I mean, I remember talking to my friends about it and just saying, “You know, yeah, we don't vaccinate. It's- it's just natural that way. You know, and if we, and we never get sick” - which wasn't true, we got caught colds here and there, and then eventually more serious cold stuff. But um, yeah, I remember just saying, “Oh, yeah, this is natural. We're not, you know, we don't inject um things into our body that we don't need to.” And uh that -just that kind of thing. Um I remember having that type of conversation through like, maybe my early, maybe my like my late teens. Yeah.

PI: And kind of related to that. How aware were you of the role of vaccinations? Did you know what they were intended to do? Or um I guess…

R: Yeah. I understood, I understood that they were meant to prevent disease. Yeah.

PI: And so you shared at the beginning that you do have a kid, so I was going…

R: Yeah.

PI: Can you share with me your choices regarding vaccinating your own children?

R: Oh, yeah, fully. He's fully vaccinated on schedule.

PI: Okay uh and how did you come about those choices? What made you want to do something that your parents didn't do for you?

R: Uh I think it was a gradual process. I don't know that it was any one thing. Um it was, it was in college that I really started to think about things and understand like, um and understand vaccines more fully. And I …and probably trust more in the scientific community. You know, these are just average people that don't want to hurt anyone else. Like there's- there's not some conspiracy theory out there either. That was part of it from my mom, too- she's doesn't trust the CDC. But she still will bring up occasionally I just don't trust the CDC, she doesn't understand herd immunity. That is something that I understood later. So I think I think it was a gradual thing. And then also talking to my siblings who had a very serious, very serious illness in the winter of 99 through early to 2000. That we believe was pertussis although they were not tested for it. But they were um extremely ill I mean, like the level of like bed rest. Ill for months, my sister, I remember my mother screaming at me in the middle of the night to go with the phone call 911 because my sister couldn't breathe because of the mucus in her lungs. And then in and out of… and then the and… then they had chronic lung damage for uh where they were on medications, daily medications. Where looking back on that and talking to them, like we think the best immunity is- is the one where you don't have to suffer to get it. I remember one of my brothers saying that and be like yeah That's, that's really true. And there's this fear of uh- there's -and it's just hard to sort through, I think. Because there's so much misinformation out there. And people trust their friends. And so if their community and their friends are saying, Oh no, there are risks to getting the vac- getting vaccines, and that's who you believe. And you don't know what actually going through the disease is going to be like um, I think it's just really hard to navigate that as a person who doesn't have background. So kind of reflecting on our experiences and saying, this is something we want to avoid for

ourselves and our kids and… trusting- building, I guess, trust. I mean, I was I was in undergrad at that point, but- but I'm the first person in my family to receive a college degree, like beyond a two-year type degree. Yeah, I think it was a combination of personal experience, education, and understanding science better. For me.

PI: Were there any media influences or bloggers or online sites or anything like that, that might have played a role in that decision? Either?

R: No I mean, I got myself, I started the process to get myself vaccinated in college in maybe 2008. And I wasn't aware of any, any bloggers… or Facebook was, I was not a member of Facebook, that wasn't a thing yet. I was just beginning to be, but you had to have a college email, and it was just you know. Um so I don't- I don't know if the communities that you see now that I'm on social media were a thing then but they weren't when- or at least I was not aware of them. When I was- yeah- making a decision to get myself vaccinated. Yeah.

PI: This is um kind of a question that makes the study a little bit more timely. But I guess I'm wondering, what are your thoughts on the COVID vaccine?

R: Oh I'm on 100% for it. Yeah. 100%. Um…in- yeah, definitely we'll get it as soon as we have the opportunity for it.

PI: And once uh they create a vaccine that is safe for children, would you give that to your child as well?

R: Oh, absolutely. Yeah. 100%

PI: Well, those are my- end to my direct questions, but I like to leave it open at the end, kind of just asking, Is there anything else that you'd like to share that I didn't touch on? Anything like that?

R: Um, I don't know. I think it's really cool that you're doing this study. Because I do- I still see people. And now it drives me crazy. But, but I still see people making the same arguments that were made 30 years ago, that didn't go well for us. Or even like the whole vaccines causing autism thing, which has been disproven again and again and again. That people still believe um- it just, it just drives me- now it just drives me nuts because I understand how to read a paper and look at data and it seems clear. But um, but I still know people that I grew up with that are adamantly anti-vaccine. And it is almost like their cause that they've decided, they're- that they see danger in vaccines. It's almost like a cause to them to convince other people not to vaccinate. I don't know how- where it becomes a cause. Like, uh um…but…it's, yeah- or how to- because, because it just it hurts because it's the kids who suffer when they get sick. It's not the parents. So yeah, especially after having my own, I feel bad for those families that- that I mean, enough people are vaccinated now that it will probably be okay, at least for us for a while it was okay. Every year that oh, we haven't caught something miserable- um convinces you that it's going to continue to be okay. But then when things do go around, it's the kids who suffer. And I don't. I, I - I feel like it's- I just feel

bad for those families that that don't come around before something like that happens. Have you? Have you found many people for your study yet? Or are you just getting started?

PI: That was actually um kind of something I was going to talk about. It's a very niche community.

R: Yeah.
PI: And it's a very sensitive topic.

R: Yeah.

PI: So I've had- I've had about probably about half the interviews that I would need.

R: Yeah.

PI: Um, but I was gonna say if you know of anybody feel free to give them my email, send them my way.

R: Okay yeah.

PI: Anything helpful?

R: Yeah. Okay. I will- I will think about that. I might know a couple people, if they're, but if they're willing to participate. It's not a question, but I'll ask, and like my siblings to I'll check in with them. Because they might be. They might be willing.

PI: Yeah that'd be great

R: Yeah, yeah. I don't know if it is helpful from the same family. But um…

PI: Anything is helpful.

R: Yeah

PI: Well, thank you so so much for being willing to talk to me and reaching out. It's so helpful and I hope that I can provide some results are consequential in a good way.

R: Yeah. Yeah. And best of luck to you. Yeah. I think it's a really interesting area.

PI: Thank you so much.

R: You're welcome.

PI: All right. Have a good day.

R: You too.

PI: Bye.

VITA

Shelby Luttman grew up in North Carolina. After high school, she attended Appalachian State University and received a Bachelor of Science degree in Public Relations. She chose to attend the University of Tennessee, Knoxville to pursue a Master of Science degree in Communication and Information with a concentration in crisis and health communication. Her research interests include health crises and environmental activism. She owes all she has done to her family and friends who supported her along the way, especially the strong women who taught her resilience. She would like to specifically thank her mom Alice for always showing up for her, leading by example, and teaching her that empathy and strength do not need to be mutually exclusive. This is the philosophy in which she plans to live her life.