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‘It’s Been a Huge Stress’: An In-Depth, Exploratory Study of Vaccine Hesitant Parents in Southern California

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‘It’s Been a Huge Stress’: An In-Depth, Exploratory Study of Vaccine Hesitant Parents in Southern California

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy in Anthropology
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TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

ABSTRACT

In 2015, the US experienced a widespread measles outbreak that originated at Disneyland, California and spread to six other states, Mexico, and Canada. That year, California passed Senate Bill 277 (SB 277), which eliminated the personal belief exemption for vaccinations required for school entry; California became the third state in the country to eliminate nonmedical exemptions. In 2019, Washington, Maine, and New York followed suit eliminating all nonmedical exemptions amid the largest measles outbreak in the US in 25 years. Many countries, including the US, are experiencing a rise in vaccine preventable diseases due, in part, to increasing vaccine hesitancy, a fluid and context- and vaccine-specific phenomenon broadly defined as the delay or refusal of vaccine services despite availability. Through in-depth interviews with vaccine hesitant parents in Southern California, this dissertation explores the underlying factors that shape vaccine hesitancy and examines how the passage of SB 277 impacted vaccine-related strategies, decisions, and behaviors. Applying a political economic framework through a feminist lens, three major themes are presented, 1) highly individualized processes of risk assessment and management around vaccines, informed by neoliberal ideologies, 2) institutional distrust that drives parents to challenge biomedical authority and demedicalize their approaches to health, and 3) the gendered processes of vaccine hesitancy that disproportionately burden women and mothers. Findings suggest that efforts aimed at addressing falling vaccination rates and subsequent vaccine-preventable disease outbreaks would benefit from in-depth, qualitative research that considers multiple socio-ecological levels of influence, including interpersonal, socio-cultural, and political economic.

CHAPTER 1: INTRODUCTION

Research Rationale

In 2015, the United States (US) experienced a widespread measles outbreak, originating in southern California and spreading to six other states (i.e. Arizona, Colorado, Nebraska, Oregon, Utah, Washington), Canada, and Mexico (Centers for Diseases Control and Prevention [CDC] 2015). Between January and April 2015, 159 people were reported to have measles, most (111 [70%]) directly linked to Disneyland, a popular amusement park located in Anaheim, California, about 25 miles southeast of Los Angeles (CDC 2015). The widespread and highly publicized nature of this vaccine-preventable disease outbreak triggered a strong response from both medical and public health communities, concerned parents, and state representatives regarding falling vaccination rates in California, the state that harbored the highest number of infected individuals (CDC 2015). In February 2015, as the outbreak continued to grow, California State Senators Richard Pan, a physician, and Ben Allen, an attorney, co-authored Senate Bill 277 (SB 277), which proposed the elimination of the personal belief exemption for vaccinations required for school entry (California Legislative Information [CLI] 2015). The bill maintained the allowance for medical exemptions, which can be granted by any licensed physician in the state of California; home-based education programs or homeschool was the only option available for parents who wanted to refuse or delay vaccinations for their children (CLI 2015). The bill quickly passed through both Education and Health Committees and was signed into law by California Governor Jerry Brown on June 30, 2015, a mere six months after it was first introduced; the law went into effect on July 1, 2016 (CLI 2015).California is one of only five states that do not allow nonmedical exemptions, including personal, philosophical, or religious belief exemptions, for childhood vaccinations required for school entry. Vaccine hesitancy, defined as a “delay in acceptance or refusal of vaccination despite availability of vaccination services,” is a complex and context-specific behavior that varies across time, space, and vaccines (McDonald et al. 2015, 4165). Vaccine hesitancy is associated with increases in disease outbreaks, transmission, morbidity and mortality, particularly of highly contagious infectious diseases such as measles and pertussis (whooping cough) (Atwell et al. 2013, CDC 2015, Gahr et al. 2015, May and Silverman 2003, Omer et al. 2008). California is one of many states experiencing an increasing number of vaccine hesitant parents, with personal belief exemptions for compulsory vaccinations tripling from 0.77% to 2.37% between 2000, when measles was declared eliminated from the US, to 2016, prior to enforcement of SB 277 (CDC 2015a, California Department of Public Health [CDPH] 2016a, Los Angeles County Department of Public Health [LACDPH] 2015) (Figure 1). This dissertation explores underlying factors shaping vaccine hesitancy and vaccine-related behaviors among vaccine hesitant parents following the elimination of the personal belief exemption.

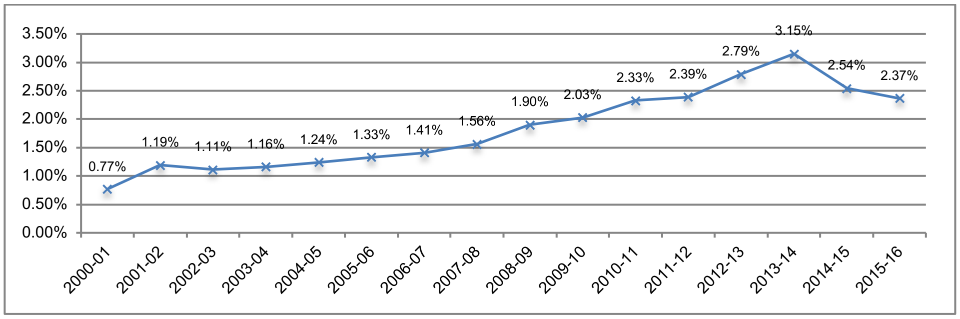

Figure 1. Percent of kindergarten enrollees in California who are exempt from school immunization requirements due to their personal belief exemptions, 2000-2016. California Department of Public Health Department, Immunization Assessment Reports, 2000-2016.

Research Objectives

The overall objective of this study was to identify underlaying factors that influence vaccine hesitancy, and understand how state vaccination laws shape vaccine-related decisions, behaviors, and strategies among vaccine hesitant parents in Southern California. The specific objectives were:

1. To identify underlying factors shaping vaccine hesitancy
    a. To determine how vaccine hesitant parents conceptualize vaccines, i.e. as individual health intervention vs. community/population-level health intervention
2. To document how the elimination of the personal belief exemption (SB 277) shaped vaccine-related decisions, behaviors, and strategies among vaccine hesitant parents with preschool-age children
3. To determine the social and cultural impacts of SB 277 on vaccine hesitant parents

Overview of Chapters

In chapter 2, I provide a brief history of vaccine legislation and the origin of anti-vaccine sentiment in the US, with an overview of vaccination requirements and exemptions. I summarize the Disneyland measles outbreak, the catalyst for SB 277, and provide an overview of ongoing explanatory debates of vaccine hesitancy in anthropology, social sciences, and public health literature.

In chapter 3, I discuss relevant anthropological theories and perspectives applied in analyzing vaccine hesitancy among Southern California parents, and present a theoretical model that draws connections between the theories.

In chapter 4, I describe the methods and provide a discussion of ethical considerations and limitations for this study. I describe the field site of Los Angeles County, California and explain the methods I used for recruitment, data collection, and analysis, and my rationale for each method. Here, I present participant demographic information.

In chapter 5, I discuss the theme of individual risk assessment and management that emerged from in-depth interviews with vaccine hesitant parents. I present the analysis through theories of risk and the individualization of risk. Using their words, I demonstrate how parents internalized vaccine risks as vulnerabilities and mitigate risk through individual actions.

In chapter 6, I discuss how the environment of institutional distrust drives vaccine hesitant parents to challenge authoritative biomedical knowledge and engage “natural” approaches to health. I analyze these processes through the theories of relational trust.

In chapter 7, I discuss the ways in which vaccine hesitancy is gendered, disproportionately involving and impacting women and mothers. I summarize major points from my interview with State Senator Richard Pan and present an analysis of the political process and consequences of SB 277 through a gendered lens. I discuss how trends toward intensive mothering feed into existing gender norms and expectations that exacerbate gender inequity and disproportionate social, emotional, and mental burden on vaccine hesitant mothers in this study.

I conclude with chapter 8 with a discussion of the theoretical and applied implications of each of the themes presented in previous chapters. I provide a summary of the immediate aftermath of SB 277 in California, and a snapshot of vaccine legislation in the US. I outline other important factors of vaccine hesitancy to consideration for future research. Finally, I provide examples of tools and interventions that have been developed to assess and address vaccine hesitancy, and recommendations.

CHAPTER 2: BACKGROUND

Introduction

In this chapter, I provide a brief history of vaccine legislation and anti-vaccine sentiment, and an overview of vaccine requirements and exemptions. I summarize the timeline of the Disneyland measles outbreak the subsequent Senate Bill 277 and provide an overview of ongoing explanatory debates of vaccine hesitancy in anthropology, social sciences, and public health literature.

History of Vaccine Legislation and Opposition in the US

Compulsory vaccinations in the US date back to 1809, when Massachusetts enacted the first vaccination law mandating the smallpox vaccine for individuals over the age of 21. Later, in 1827, Boston's school committee ordered all teachers to require all students entering public schools to present evidence of vaccination (Diekema 2014, Omer et al. 2009). By 1855, Massachusetts became the first state to enact a compulsory vaccination law for school entry (Hinman et al. 2002). With the increasing availability of vaccines in the late 19th century, compulsory vaccination laws spread across the US and Western Europe, and from the beginning, there was opposition. In the US, anti-vaccination sentiments against the smallpox vaccine were associated with so-called "irregular physicians" who were considered the "advocates of unorthodox medical theories;" they often called on the Bible to discredit the efficacy of the vaccine (Kaufman 1976, 464). Despite opposition, the vaccine was widely accepted, and smallpox incidence began falling dramatically. As most of the population became immune to smallpox, the disease all but disappeared from view and vaccine use started to diminish. Smallpox reappeared in the 1870s and quickly spread through the unvaccinated, susceptible population in epidemic proportions (Kaufman 1967). As many states scrambled to pass new vaccination laws or enforce those that were already in place, opposition arose again (Omer et al. 2009). This time, the "anti-vaccinationists" of the era, with their focus on vaccine safety, were successful in repealing vaccination laws in several states, including California.

In the United Kingdom, the anti-vaccination protestors in England were primarily drawn from a politically active working class that viewed the legislation as a violation on their bodies, an act of political tyranny from an already interventionist state (Durbach 2000, 2002). Additional ancillary policies, such as the Anatomy Act and the New Poor Law in 1930s England, allowed state-paid health officers and public vaccinators to prosecute parents who did not comply with the compulsory vaccination laws. Employers could dismiss those who were deemed "non-compliant," which mobilized labor advocates and middle-class reformers into action (Durbach 2000). While individual citizens exerted their liberties by resisting the vaccinations, organizations like the Anti-Vaccination Society of America (est. 1879) in the US and the *Bond ter Berstijiding van Vaccinedwang* (Association to Oppose Compulsory Vaccinations, est. 1881) in Holland formalized their collective anti-vaccination efforts (Blume 2006, Durbach 2000).

By the turn of the twentieth century, most of the vaccination mandates, at least in the US, were written into law and enforceable by the state through local school boards and public health institutions. In 1905, the US Supreme Court endorsed states' rights to pass and enforce compulsory vaccination laws in the landmark case, *Jacobson v. Massachusetts*, which is foundational for all public health laws in the US (Gostin 2000, Omer et al. 2009). This ruling was based on the idea of protecting the greater good, heavily influenced by the concept that there is a social contract in place wherein individual citizens hold duties and responsibilities to each other and to society as a whole (Gostin 2000, Khalili and Caplan 2007). In this context, compulsory vaccinations were found to be a reasonable exercise of police power by states to ensure the health of the broader population, even at the expense of individual freedoms (Gostin 2000).

Significant efforts were taken during the late 1960s to eradicate measles in the US, and by the 1970s, studies showed that states with compulsory vaccination laws for school entry had measles incidence rates 40-51% lower than those without similar laws (Hinman et al. 2002). Periodically outbreaks of measles and other VPDs encouraged parents and states, alike, to support expansion of school vaccination laws, particularly since schools were well known as active sites for disease transmission and major sources of community-wide outbreaks (Diekema 2014, Hinman et al. 2002). For example, Alaska experienced a sustained measles outbreak in 1976, despite vaccination laws for school entry and free measles vaccines offered in public and private schools (Orenstein and Hinman 1999). It forced public health officials to start enforcing the existing laws to contain the outbreak, ultimately leading to the exclusion of 7,417 students (8.3%) from schools across the state for failing to provide proof of vaccination (Orenstein and Hinman 1999). Similarly, in early 1977, a measles outbreak was detected in Los Angeles County, California, which resulted in two deaths, three cases of encephalitis, and multiple hospitalizations due to measles-related pneumonia within a span of two months (Orenstein and Hinman 2002). On March 31st, the County Director of Health Services ordered all children without proof of vaccination be barred from attending school by May 2nd. Prior to the exclusion deadline, vaccination clinics were set up in schools with extended hours, and by the May deadline, thousands of students had been vaccinated. However, approximately 50,000 students (4%) still lacked proof of measles vaccination and were subsequently excluded from school (Orenstein and Hinman 2002). Within days of the exclusion being enforced, most of the children were back in school with their proof of vaccination. This case set the precedent that strict enforcement of school vaccination laws, with exclusions, even in a county as diverse and large as Los Angeles County, was accepted by the majority of community members, indicating that school vaccination laws could be implemented and enforced essentially in any state (Orenstein and Hinman 1999).

Persistent concerns over vaccine safety continue to act as major catalysts for the re-emergence of anti-vaccination sentiments, especially following highly publicized incidences of vaccinations-gone-wrong. In 1975, Japan suspended pertussis (whooping cough) vaccinations for infants following two widely publicized deaths that were purportedly linked to the vaccine (Baker 2003). It was later re-introduced as a scheduled vaccination for toddlers at age two, but only after a dramatic rise in pertussis infections, peaking in 1979 with a major outbreak involving 13,000 cases in that year alone, including 40 infant deaths from pertussis infection (Baker 2003). In the US, a 1982 WRC-TV documentary called *DPT: Vaccine Roulettte* emphasized the risks posed by vaccines without addressing the dangers of whooping cough (pertussis) and sparked widespread negative publicity toward vaccines, which ramped up anti-vaccination sentiment, particularly among parents active in vaccine victim advocacy groups. The American Academy of Pediatrics protested the documentary in a letter to the then-President of NBC, the parent company of WRC-TV, stating that the film's "distortion and total lack of balance of scientific fact" was "unfortunate and dangerous" (Hilts 1982). This film confirmed the suspicions of one parent, Barbara Loe Fisher, whose son suffered an adverse reaction to the diphtheria-pertussis-tetanus (DPT) vaccine. Fisher and other parents went on to form the lobbying group Dissatisfied Parents Together (also known as DPT), and later co-founder of the National Vaccine Information Center (NVIC), one of "the most powerful [anti-vaccine] advocacy groups in American history" (Offit 2015 , 21); it is still active today.

While the mobilization against vaccines in the 1980s did not significantly impact vaccination rates, due in large part to the counter-campaigns by medical and public health associations, it did dramatically increase the number of litigations against pharmaceutical companies that produced vaccines. In 1986, a jury awarded over one million dollars to a child whose lawyers claimed became paraplegic as a result of vaccine injury related to the DPT vaccine (Berezin and Eads 2016). Lederle Laboratories, the vaccine producer and defendant in the case, discontinued vaccine production after the judgment, which threatened the country's vaccine supply (Berezin and Eads 2016, Baker 2003). A series of Congressional hearings followed, resulting in the passage of the National Childhood Vaccine Injury Compensation Act of 1986, which established no-fault compensation for injuries related to vaccines to secure the vaccine supply, and the creation of a federal reporting system, the Vaccine Adverse Events Reporting System, to monitor vaccine injuries and settle legal issues (Berezin and Eads 2016, Baker 2003).

The most recent controversy that has sparked yet another wave of anti-vaccination sentiment is the vaccine-autism controversy of the late 1990s, derived from the infamous, and later retracted study by Wakefield and colleagues, which erroneously linked the measles-mumps-rubella vaccine (MMR) with the onset of enterocolitis and behaviors associated with autism (Wakefield et al. 1998, retracted). While the Wakefield study was disproven and discredited numerous times by hundreds of peer-reviewed studies,[1] it resonated with parents of autistic children and those with concerns around vaccine safety. Unlike most research publications, it garnered sensational media attention and support from autism advocacy groups and celebrities

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[1] Select references include Chen et al. 2004, Elliman and Bedford 2001, Farrington et al. 2001, Godlee et al. 2011, Honda et al. 2005, Kaye et al. 2001, Miller and Reynolds 2009, Mrozek-budzyn et al. 2010, Uchiyama et al. 2007.

(Poland and Spier 2010). Misconceptions and fears around the MMR vaccine and autism continue to persist today and play a role in shaping contemporary vaccine hesitancy (discussed further, below).

Vaccination Mandates and Exemptions in the US

In the US, every state has vaccination requirements for specific communicable diseases as a condition for school enrollment. Each state establishes its own vaccination laws as well as the exemptions and the requirements for the exemption application process. Furthermore, there are additional implications for those exemptions during outbreak situations, and the process of exemption varies between states. For example, some states (i.e. Arkansas, Georgia, Wyoming) expressly allow for the exclusion of students with vaccination exemptions from school during an outbreak, while others (i.e. Hawaii, Kentucky, North Dakota) simply do not recognize exemptions during public health emergencies and may even requiring immunization at the discretion of the health department (CDC 2015b). To regulate the exemption application process, some states (i.e. Delaware, Iowa, New Jersey) make clear the distinction between religious and philosophical/personal belief exemption by including statements such as, "[t]his belief is not a political, sociological or philosophical view of a merely personal moral code" (CDC 2015b, 3). While the legal definition of "religious exemptions" used in policies has not been shown to have a significant effect on the rate of nonmedical exemptions, states that allow nonmedical exemptions or have simpler exemption procedures were found to have higher exemption rates, some more than twice as many, compared states with more complex and restrictive policies and procedures (Blank et al. 2013, Bradford and Mandich 2015, Thompson et al. 2007, Yang et al. 2015). To address this issue, some states, including Alaska, Minnesota, and Virginia, have incorporated additional requirements in their exemption procedures, such as notarization, affidavits, or counseling by a health professional, to create additional barriers to obtaining nonmedical exemptions (Blank et al.

2013, CDC 2015). Furthermore, medical exemptions tend to decrease as philosophical exemptions are introduced, suggesting that medical exemptions were used in the past to avoid vaccinations when nonmedical exemptions were not available (Thompson et al. 2007). As of 2020, Mississippi, West Virginia, California, Maine, and New York are the only states that do not offer nonmedical exemptions for vaccinations required for school entry. All other states offer personal, philosophical, and/or religious belief exemptions (National Conference of State Legislatures [NCLS] 2020).

The Disneyland Outbreak

In early January 2015, an 11-year-old child was hospitalized with measles in California, with rash onset on December 28, 2014; the child was unvaccinated. On the same day, the California Department of Public Health (CDPH) received four additional reports of suspected measles in California residents, and two more in Utah residents. All of these patients had visited Disneyland during December 17-20, 2014. By January 7, seven cases of measles were confirmed in California, and CDPH issued a press release notifying other states of the outbreak: “Measles transmission is ongoing” (CDC 2015b). Disneyland had become the epicenter of large, multi-state measles outbreak. Between January and April 2015, 159 cases in 18 states and the District of Columbia were reported to have measles, most of whom (111 [70%]) were directly linked to Disneyland (CDC 2015b). The majority of the cases associated with the 2015 outbreaks were unvaccinated (71 [45%]) or had unknown vaccination status (60 [38%]), and 28 (18%) were vaccinated. Among the US residents who were unvaccinated, 29 (43%) cited philosophical or religious objection, 27 (40%) were ineligible due to age (i.e. too young) or medical contraindication, three (4%) were attributed to missed opportunities for vaccination, and nine (13%) cited other reasons (CDC 2015b, see Figure 2).

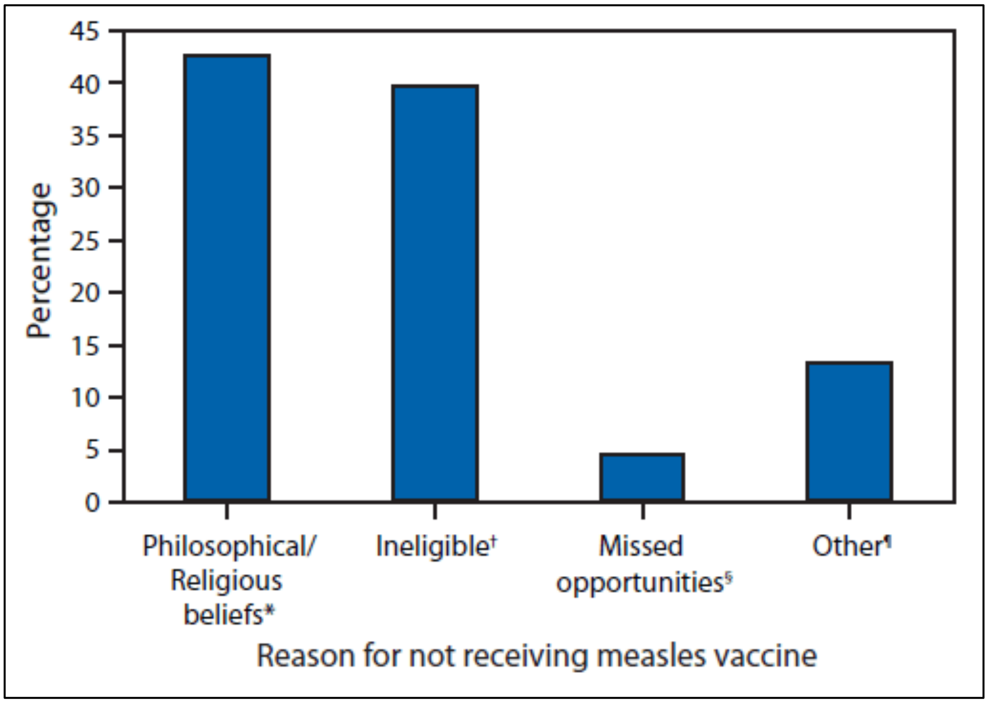

Figure 2. Percent of US residents with measles (2015 Disneyland measles outbreak) who were unvaccinated (n=68), by reason for not receiving measles vaccine- US, January 4-April 2, 2015 (CDC 2015b) *Includes those who were unvaccinated due to their own or parent's beliefs

The widespread and highly publicized nature of this outbreak triggered a strong response from medical and public health communities, concerned parents, and state representatives regarding falling vaccination rates, particularly in California; the average rate of vaccination for kindergarteners for 2014-15 was 90.4% (86.6% for private schools, 90.7% for public), and the state harbored the highest number of infected individuals (CDC 2015b, CDPH 2015c). In February 2015, as the outbreak continued to grow, Senators Ben Allen and Richard Pan, a physician, co-authored Senate Bill 277, which proposed the elimination of the "personal belief" exemption, including religious exemption, for vaccinations required for school entry (CLI 2015). The bill maintained the allowance for medical exemptions, which can be granted by any licensed physician in the state of California (CLI 2015). The bill quickly passed through both Education and Health

Committees and was signed into law by Governor Jerry Brown on June 30, 2015, a mere six months after it was first introduced; the law went into effect on July 1, 2016 (CLI 2015). California became one of only three states, with Mississippi and West Virginia, that do not allow personal belief, including religious, exemption for childhood vaccinations.

After the law passed, local and national organizations have taken action against the law. In September 2015, opponents collected approximately 228,000 signatures on petitions supporting a referendum to overturn the measure, with Los Angeles County alone receiving about 43,000, the most signatures collected of any county. The efforts fell short of the 365,880 signatures needed for a measure on the ballot in November 2016 but indicated a large number of parents in opposition to the law (McGreevy 2015). On July 1, 2016, the day the new law went into effect, the nonprofit organization Education 4 All with a group of parents filed a suit to overturn the law in US District Court in San Diego, claiming that the law "violates California children's right to an education under the state's constitution" (Karlamangla 2016). Federal Judge Dana Sabraw declined to put the new law on pause, denying the injunction request filed by parents wanting to continue claiming personal belief exemptions during an ongoing legal fight. In doing so, Judge Sabraw cited over 100 years of legal precedents that have protected states' rights to require vaccinations for the protection of the population at large (Sisson 2016). Local and national groups have organized protests and "Health Freedom Rallies" across California and the country.

Broader Health and Policy Context

Vaccinations are a core component of preventive health services and are attributed for saving 33,000 lives, preventing 14 million cases of disease, and saving $33.4 billion in indirect costs every year in the US (Office of Disease Prevention and Health Promotion [ODPHP] 2016). Despite advances in health care and delivery, an estimated 42,000 adults and 300 children die of complications related to vaccine-preventable diseases each year in the US, and communities with pockets of *under*vaccinated and *un*vaccinated populations remain vulnerable to outbreaks[2] (ODPHP 2016). One of the goals of Healthy People 2020, a national initiative focusing on health promotion and disease prevention, is the increase of vaccination rates and reduction of preventable infectious diseases (ODPHP 2016). In general, Americans only receive about half of the preventive services that are recommended by national health guidelines (Koh and Sebelius 2010). The 2010 passage of the Patient Protection and Affordable Care Act was an historic step toward comprehensive healthcare reform and addressing the critical gap of preventive services in the US (Koh and Sebelius 2010). One of the major strategies in improving access to preventive services is to remove cost as a barrier, for example, by requiring healthcare plans to cover a range of preventive services, such as vaccinations, at no cost to the patient (Koh and Sebelius 2010). The US has markedly high levels of healthcare expenditures, ranking first in expenditures among the Organization for Economic Co-operation and Development (OECD) countries, and last in healthcare coverage (Lorenzoni et al. 2014). Research suggests that the prices of service, rather than volumes, significantly shape higher spending in the US (Lorenzoni et al. 2014).

While the goals of Healthy People 2020 and the implementation of the Affordable Care Act (ACA) aim to "close the gap" in preventive healthcare, vaccine hesitant parents do not necessarily fall into the same target population. In the US, *under*vaccinated children, defined as those who have missed opportunities to obtain vaccination services, tend to be black, live in households near the poverty level, have young mothers who are not married or do not have a college degree, and live in urban, city environments (Smith et al. 2004). Low-income children

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[2] Here, I define *under*vaccinated as those who have not received vaccinations or not completed a vaccine series due to lack of access, whereas *un*vaccinated refers to those who choose, or whose parents choose, not to vaccinate, delay vaccination, or do not follow recommended vaccination guidelines and do not intend to (i.e. vaccine hesitant).

were more likely to complete their vaccinations if they had higher spatial accessibility to a vaccine provider, such as primary care providers (Fu et al. 2009). In contrast, *un*vaccinated children who have submitted personal belief exemptions (PBE) for school entry are most likely white and come from higher income households (Yang et al. 2016). While both *under*- and *un*vaccinated populations are vulnerable to vaccine preventable diseases, the consequences of their susceptibility to VPDs vary significantly due to their differential levels of privilege and access to appropriate healthcare services. In Los Angeles County, conditional entrants account for 8.2% of kindergarteners in 2015-2016 (prior to SB 277), much higher than the incoming students with personal belief exemptions (1.5%) (CDPH 2016a). These are students who are missing one or more vaccine doses required for school entry (without exemptions) but are admitted on the condition that they will complete their remaining doses "when they become due"; conditional entrant provisions are also offered to homeless students (LACDPH 2011). Both *under*- and *un*vaccinated students, and their potential overlap, are important considerations to equitably address public health not only in California but also in other areas with low vaccination rates.

Homeschooling Trends and Vaccination Issues

With the passing of SB 277 into law, the only way that school-aged children in California can refuse or delay vaccinations is to enroll in a home-based educational program, or homeschool (CLI 2015). The home has always been utilized as an educational space, for various pragmatic, political, and ideological reasons (Kunzman and Gaither 2013). In the 19th century, nearly all children received formal education through large-scale public and private school education systems until the 1970s, when parents turned back to home-based education as a deliberate act of political protest to reject institutional schooling; this shift is often dubbed the "homeschooling movement" (Gaither 2009, Kunzman and Gaither 2013).

Between 1999 and 2016, the percent of children between 5 and 17 years of age[3] enrolled in homeschool in the US rose consistently, from an estimated 1.7% to 3.3% (NCES 2018). Exact data regarding the homeschool population is difficult to find, since there is no central registry and mandated school attendance and reporting vary between states. For example, Oklahoma, Mississippi, and Texas require no registration for homeschool and homeschooled children are not monitored or regulated by the state, whereas Illinois requires vaccinations for homeschooled children, but does not have a system of enforcement (Choi and Manning 2010, Johnson et al. 2013, Khalili and Caplan 2007). Homeschooled children in North Carolina are required to follow the same vaccination and exemption rules as public and private schools (Khalili and Caplan 2007). In California, a child enrolled in homeschool or independent study is required to file private school affidavit to the state's Department of Education but is not subject to vaccination laws unless their curriculum includes some classroom-based instruction. Classroom-based instruction is not clearly defined by the law, however, and is open to interpretation (California Department of Education [CDE] 2019). If the student received a personal belief exemption prior to January 1, 2016, the student is considered "grandfathered in" and is exempt for the remainder of his or her grade span (i.e. preschool/daycare; K-6th grade; 7th-12th grade) (CLI 2015).

An estimated 10% of homeschool families in the US participate "underground," meaning they do not comply with state laws that require reporting to state and/or local education authorities (National Home Education Research Institute [NHERI] 2020). With the passing of the new vaccination law in California, the parallel rise in both homeschooling and vaccine hesitancy over the past decade makes this intersection critically important (CLI 2015, Thorpe et al. 2012). The haphazard regulation of homeschool makes regulating and monitoring vaccinations within the

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[3] Students of kindergarten through 12th grade are considered ages 5-17 years old.

homeschool population even more difficult. It is important to note that not all homeschool parents are vaccine hesitant, and not all vaccine hesitant parents will choose to homeschool their children. In fact, Thorpe and colleagues found that the majority of homeschool children in their study were partially vaccinated (56%), with 36% fully vaccinated, and only 6% not vaccinated at all (2012). Only about 4% of parents reported "desire not to vaccinate children" as their reason for homeschooling their children (Thorpe et al. 2012). In a nationally representative sample, Cordner found that homeschoolers had lower levels of healthcare utilization rates, including annual preventive medical and dental care compared to their public schooled counterparts (2012). Homeschoolers had lower rates of vaccination for Tetanus (77%) and HPV (6%) compared to public school students (Tetanus 85%; HPV 19-85%) (Cordner 2012).

Ongoing Explanatory Debates of Vaccine Hesitancy

Anti-vaccination sentiments among the population have existed since the vaccine was invented over 200 years ago (Diekema 2014). Contemporary vaccine hesitancy is characterized by concerns of vaccine safety and risk; trust in biomedical institutions and the state; personal choice and individual responsibility; and shaped by social relationships.

Vaccine Safety and Risk: Thiomersal and MMR-Autism Controversies

As with most pharmaceutical products, vaccines carry some risks and can result in negative health consequences. While the alleged link between autism and the measles-mumps-rubella vaccine (MMR) (Wakefield et al. 1998) has been repeatedly disproven and discredited,[4] the highly publicized controversy brought risk around all childhood vaccines and potential "vaccine injuries" to the forefront of parents' minds. The decreasing prevalence of antiquated childhood illnesses

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[4] Select references include: Chen et al. 2004, Elliman and Bedford 2001, Farrington et al. 2001, Godlee et al. 2011, Honda et al. 2005, Kaye et al. 2001, Miller and Reynolds 2009, Mrozek-budzyn et al. 2010, Uchiyama et al. 2007.

(e.g., polio, mumps), increasing public distrust and animosity toward pharmaceutical companies, and fear around chemical components of vaccines contribute to heightened perceptions of risk which in turn influence health-related decisions and behaviors (Brownlie and Howson 2006, Kata 2012).

Lillvis and colleagues state, “fears regarding the MMR vaccine that emerged from the Wakefield paper… mark the start of a unique period in the history of US vaccine politics,” one that is defined by low prevalence of vaccine-preventable diseases, increasing numbers of recommended childhood vaccines, high levels of opposition to vaccine mandates, combined with increasing vaccine hesitancy and use of nonmedical exemptions (2014, 476). While the effects of the 1998 Wakefield study were widespread, England’s vaccine coverage rates were the most dramatically affected; in England, where there are no vaccination requirements (National Health Services [NHS] 2016), MMR rates fell from 92% in 1995-96 to 80% in 2003-04, and as low as 58% in London (Burgess et al. 2006). Media coverage in England about the rumored link between the vaccine and autism produced levels of parental concern higher than the usual anti-vaccine sentiments, due in part to a failure of effective risk communication (Burgess et al. 2006, 3921). While the media covered each side of the debate equally, a more narrative and emotive response was required from the scientific community to be more effective in counteracting the panic and subsequent decrease in vaccination rates (Burgess et al. 2006). Vaccination rates in England did not start improving again until 2004-2005, eight years after the Wakefield study was published (Burgess et al. 2006).

In the US, autism began its rise into public awareness in the 1980s as more children were diagnosed with the condition and related neurodevelopmental disorders (Kaufman 2010). This was due, in part, to the expansion of the autism criteria in 1987 to what is now known as autism spectrum disorder (Zeldovich 2018). Parents of children with autism began to suspect that vaccines caused or were somehow related to their child's development of the condition. In 1997, the US Food and Drug Administration (FDA) determined that the cumulative amount of *ethyl*mercury found in childhood vaccines might exceed the agency's guidelines for *methyl*mercury, the chemical form found in fish and toxic environmental contamination. This revelation took parents and vaccine experts by surprise and caused a considerable level of concern among parent advocacy groups in the US. In 1999, the American Academy of Family Physicians and the US Public Health Service jointly called for a voluntary removal of thimerosal, the ethylmercury-containing preservative, from vaccines but due to uneven policies and procedures, it wasn't until 2006 that it was completely eliminated from childhood vaccines in the US; it is still present in some influenza vaccines (Kaufman 2010).

Following thiomersal concerns, the controversy around the 1998 Wakefield study swirled through British and American media, and the association between the MMR vaccine and autism, regardless of whether it was confirmed, denied, challenged, or disavowed, was solidified in the minds of every parent (Kaufman 2010). By the next year, Kaufman notes, "a generation of well-educated, middle-class adults with infants and young children was already risk aware and skeptical" (2010, 22). The formal retraction of the article by Wakefield and colleagues by the *Lancet* twelve years after it was originally published did not have much impact on counteracting widely circulated and persistent fears around the MMR vaccine; the damage had been done (Kaufman 2010). Kaufman draws on Beck's (1992, 2006) and Giddens' (1990, 1991) theories of risk to make an example out of the vaccine-autism connection as "an emergent example of the contours of 'risk society,'" in the way that risks represent a way of knowing and risk assessment as a "technique for living," both of which constitute modernity and a way of life in postindustrial society (2010, 9). In both vaccine controversies, the FDA and the *Lancet*, the experts, failed to provide sufficient risk assessment models, therefore creating an environment in which risk calculation [based on these models] became obsolete. Kaufman argues that self-reliance, through self-assessment and risk reduction, becomes mandatory, in this case self-assessment of vaccine safety and subsequent decisions and behaviors (2010).

Institutional Distrust

The deterioration of trust in authority is another factor shaping contemporary vaccine hesitancy. Trust in healthcare providers, biomedical systems, vaccine technologies, and governments are prominent in environments with high levels of vaccine acceptance (Lee et al. 2016). Among new mothers in their sample drawn from a Connecticut hospital, Benin and colleagues found that relationships of trust were the main determinant in their vaccine-related decisions, suggesting that information dissemination must also be paired with trust building between parents and healthcare providers (2006). Mothers were also found more likely to accept the HPV vaccine for their children if they trust doctors; likewise, mothers who distrust public health authorities were less likely to perceive vaccines favorably (Dube et al. 2016, Marlow et al. 2007). Public distrust in government also influences how parents seek information about vaccines and how much they trust or distrust particular sources (Lee et al. 2016). Within vaccine hesitant populations, Lee and colleagues found that individuals with low governmental trust (i.e. nonwhite, lower income, less religious) were more likely to seek out information from alternative, "unofficial" sources, such as blogs, social media, friends, and family (2016). While there was no difference in their levels of access to scientific vaccine information between trusting and distrusting parents, there was disparity in how trustworthy they perceived those sources to be (Lee et al. 2016). For example, even when presented with scientific evidence supporting the safety of vaccine, vaccine hesitant parents were not convinced to vaccinate their children (Nyhan et al. 2007).

Sensationalized media coverage that focuses on worst case scenarios damages the trust-building work of healthcare providers and relations of governmentality, engendering uncertainty and distrust in the authoritative information about vaccines produced by biomedical and governmental institutions (Brownlie and Howson 2006). In the context of risk and trust, if institutions cannot definitively state that vaccines pose no harm, then lay people "must live as though [these risks] were a fact, as though vaccines could cause harm" (Kaufman 2010, 22). Vaccine critical groups indirectly depend on trust and step to fill the knowledge gap, not necessarily by presenting themselves as experts but by re-focusing the message on encouraging parents to educating themselves so they can trust their own knowledge and therefore make the best decisions for their children, in neoliberal form (Hobson-West 2007).

Personal choice and individual responsibility

Social scientists examine personal choice and responsibility related to health, such as vaccinations, within broader socio-cultural or political economic contexts. For example, Anthropologist Poltorak and colleagues examined the social phenomenon of "MMR talk" in the United Kingdom, a way for parents to engage with each other around vaccine decisions and anxieties, and expose their own values and beliefs, scientific knowledge, views on parenting, and even their position amongst their friends (2005). They found that "MMR talk" also worked to build confidence among parents making decisions about vaccines, particularly within the National Health Services agenda promoting "patient choice" and active citizenship (Poltorak et al. 2005, 717). Broader trends toward personalized medicine, combined with wider access to parental support groups and a new focus on disease genetics create an environment that encourages individual choice and personal responsibility in avoiding health risks (Poltorak et al. 2005).

In a political economic climate favoring neoliberal and libertarian views of individual responsibility, the idea of choice has extended beyond market relations to become part of the dominant language in public health (Brennan 2016, Briggs and Hallin 2007, Hobson-West 2003, Reich 2014). In an environment where risks are conceptualized on an individual basis, it is rational to conceive of vaccines, and the associated risks, as an individual choice (Hobson-West 2003). In a recent study among pregnant women, most women conceptualized vaccines in terms of their individual child, rather than through a universal, public health perspective (Dube et al. 2016), disregarding vaccines contributions to community health and herd immunity. In further investigation of the language of choice in the context of "neoliberal mothering," Reich notes "the emphasis on individual choice reflects the rhetoric of the women's health movement," harkening back to reproductive health campaigns advocating "My body, my choice" and encouraging women to challenge to mainstream medical advice (2014, 5). Reich found that mothers blended "science and intuition" when engaging in empowered, individualized consumerism [of healthcare] in their conceptualization of vaccine refusal as "choice" (2014, 12). In this sense, by rejecting the "one size fits all" schedule of vaccinations for their children, mothers reinforce individualized model of healthcare and individualized consumption of healthcare (Reich 2014).

Decision-making and Social Relationships

With greater access to information, support groups, and social networks than ever before, parents have seemingly infinite, and often contradicting, sources of information to consult when making vaccine-related decisions. For most parents, their first source of information about vaccines are healthcare providers, and there are missed opportunities in which pediatricians can educate parents who lack basic knowledge about vaccines, many of whom are potentially more vulnerable to misinformation (Benin et al. 2006, Downs et al. 2008). However, simply increasing education efforts will not fully or effectively address the various social factors that shape vaccine hesitancy. Brunson found that social networks strongly influence parents' vaccination decisions, with the number of people in parents' networks recommending nonconformity being the best predictor of their decisions (2013a). In a related study, Brunson also found that parents who are in the process of making vaccine-related decisions generally fall into three general groups, 1) acceptors, 2) reliers, and 3) searchers (2013b). There are factors that mark different stages of parents' decision-making processes 1) pre-decision making, 2) awareness, 3) assessing, with each group engaging at different levels during each stage. For instance, acceptors' assessing stage is minimal, almost non-existent, since they tend to follow broader social norms about vaccinations (i.e. physician recommended schedule), whereas reliers are very active during the assessing stage and are highly aware of the social norms within their own social networks. For reliers, their perceptions of others' decisions therefore significantly impact their own decisions around vaccinations. In contrast, while searchers are active and highly involved during the assessment stage, broader social norms and the norms within their social network have little impact on their decisions (Brunson 2013b). Brunson's research suggests that the "one size fits all" approach to vaccination interventions would not be effective since parents' assessment of vaccines and their decision-making processes vary (2013b).

Dube and colleagues confirmed Brunson's findings that one's social network has profound influence on vaccine-related decisions (2016). Among vaccine hesitant mothers who had doubts about vaccines, those who ultimately decided against vaccinating their child reported that their decisions were triggered by negative stories they had heard or advice against vaccines they received from people they respected. On the other hand, vaccine hesitant mothers who decided to follow through with vaccinating their child reported positive influences from friends, family, partners or spouses (Dube et al. 2016).

Examining vaccine refusal in a southern California Waldorf (Steiner) school, Sobo found that social relations are critical drivers of vaccine delay and refusal (2015). Waldorf schools focus on experiential learning with a strong emphasis on the arts; they are typically thought of as a private "alternative" to the conventional public school system (Petrash 2002, in Sobo 2015). Within the school, where many parents' perceived themselves as part of a "special community with particular lifestyle expectations," Sobo found social mechanisms that reinforced vaccine delay and refusal, including the institutionally supported skepticism of government and corporate interest, generally in line with the principle of independent thinking encouraged at the school. Social pressures against "mainstream practices," such as vaccination, were reinforced by prejudice against mainstream or allopathic medicine (Sobo 2015, 393). The school's "social fabric" encouraged high PBE rates as non-vaccination is equated to independent thinking; this is demonstrated by the decreasing trend in vaccinations for families' younger children and rates of PBE increasing with time; PBE rates for kindergarteners were 51%, and 71.5% for 7th graders (Sobo 2015, 393).

Public Health Construct of Vaccine Hesitancy

The World Health Organization (WHO) established the Strategic Advisory Group of Experts (SAGE) on immunization in 1999 to develop guidelines and advise WHO regarding global immunization strategies and policies, encompassing research and development, immunization delivery, and linkages to related health interventions (WHO 2016). WHO convened the SAGE Working Group on Vaccine Hesitancy, hereafter referred to as the Group, which published a report (2014) and a series of papers (2015) defining "vaccine hesitancy," describing its scope and determinants, and providing tools and strategies for how to address its global rise. The Group agreed upon the following definition:

> Vaccine hesitancy refers to delay in acceptance or refusal of vaccination despite availability of vaccination services. Vaccine hesitancy is complex and context specific, varying across time, place and vaccines. It is influenced by factors such as complacency, convenience and confidence (MacDonald and SAGE 2015, 4163).

The Group describes vaccine hesitancy as a continuum occurring between "high vaccine demand" and "complete vaccine refusal" (MacDonald and SAGE 2015, 4162) (Figure 3). The Group incorporated the "3 Cs" model in their definition, which was developed by the WHO EURO Vaccine Communications Working Group in 2011, which utilized three concepts of 1) *confidence*, defined as trust in the safety and effectiveness of the vaccine itself, the system that administers them including healthcare providers and policy-makers, 2) *complacency*, generally accompanied by the perception of low risk of vaccine-preventable diseases, and 3) *convenience*, as in the availability, affordability, and accessibility of vaccination services (MacDonald and SAGE 2015, 4162-3). This model can be applied to identify determinants of vaccine hesitancy and target specific areas of intervention.

The Group also developed a Vaccine Hesitancy Determinants Matrix, which includes determinants identified in the literature as well as those identified through the Group members' field experiences and discussions with vaccine experts (MacDonald and SAGE 2015, 4163). The determinants of vaccine hesitancy differ from the social determinants of health in that some characteristics may be associated with both increased and decreased vaccine acceptance. For example, higher levels of education may be associated with both vaccine acceptance and hesitancy; in contrast, in terms of broader health outcomes, education is generally associated with better outcomes (MacDonald and SAGE 2015). The matrix was not primarily intended to serve as a practical tool, but rather to provide researchers with information to improve research tools, such as surveys and interview guides. The Group ultimately concluded that the factors that influence vaccine hesitancy are complex and various, and therefore higher levels of vaccine hesitancy require strategies that not only address factors related to personal/community behavior choices, but also factors that drive decreasing vaccine demand.

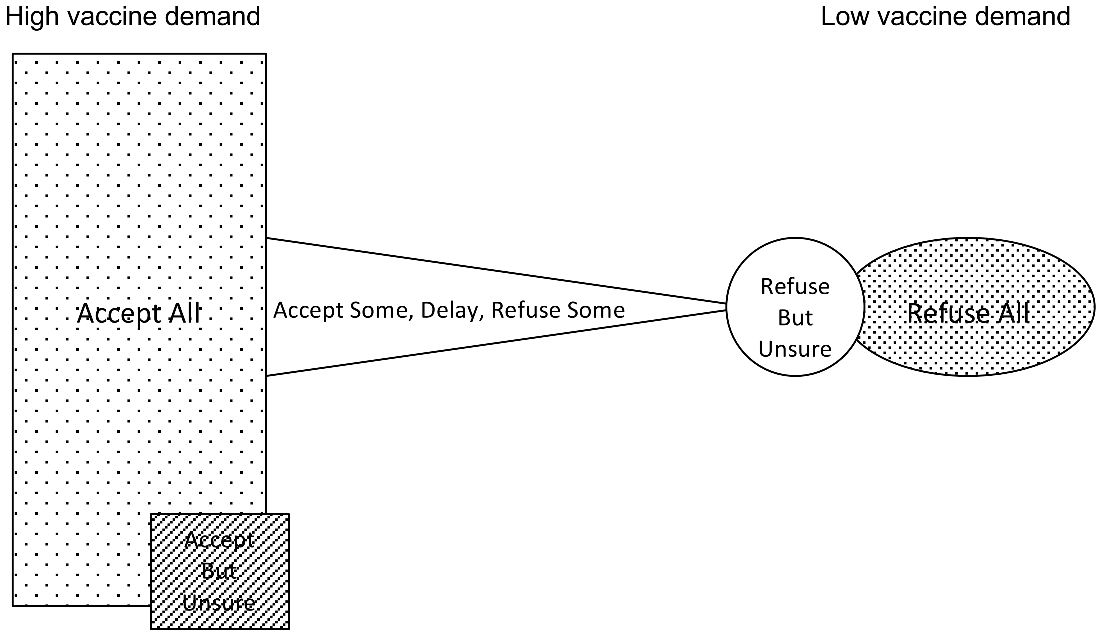

Figure 3. Vaccine hesitancy continuum

The recent literature reflects the idea of vaccine hesitancy as a continuum or process, highlighting the heterogeneity in its expressions and interpretations. Benin and colleagues identified a "continuum of attitudes" that characterized vaccinators and nonvaccinators, ranging between acceptors, vaccine-hesitant, late vaccinators, and rejecters (2006). The researchers found that the attitudes among the *vaccine-hesitant* mothers and the *late vaccinators*, the two middle groups, were similar in their interest and approach to obtaining vaccine-related information, but their outcomes ultimately differed (i.e. *vaccine-hesitant* mothers accepted vaccinations but had major concerns, and *late vaccinators* delayed or only accepted some vaccines). The researchers compared the sources of vaccine-related information between the groups and found that vaccine acceptors preferred to obtain information from their pediatricians, whereas the *vaccine rejecter*s preferred homeopathic or naturopathic sources, the Internet, and parenting magazines (2006). While the two middle groups had information sources in common, the *accepters* and *rejecters* had no overlap in their sources. Furthermore, mothers who ultimately chose to vaccinate reported that their children's pediatricians answered their vaccine-related questions in detail and spent time with them. In contrast, mothers who chose not to vaccinate reported that their children's pediatricians did not answer their questions about vaccine controversies, could not spend time with them, or treated them condescendingly (Benin et al. 2006). The researchers concluded that mothers who fall in the middle of the continuum, the *vaccine-hesitant* and *late vaccinators*, should be the targets of vaccine intervention programs since they may be more amenable to improved contact and relationships with physicians and public health providers (Benin et al. 2006). This study shows that the decision-making process is fluid and shaped by many external factors, with potential points of intervention among some sub-groups of parents.

During this decision-making process, it is important to note that the decision flow is not necessarily unidirectional. Parents who are for and against vaccinations may reconsider their decisions at different points in the process (Brunson 2015). Brunson examined the decision-making process in order to identify points where parents may be especially amenable to receiving vaccine-related information and advice from healthcare providers. The initial decision-making process that takes place during their first child is formative, with many parents "[sticking] with those decisions" even with their subsequent children. However, some parents continued to assess vaccinations years after the births of their children, presenting healthcare providers with opportunities to intervene during this process. Healthcare providers must therefore be able to recognize these processes and be willing to engage with these parents and their particular concerns.

Brunson concludes that due to the complexity of vaccine hesitancy and parents' decision-making processes, healthcare providers must be willing and prepared to "tailor their pro-vaccination conversations to the needs of individual parents" should they become open to vaccine-related information (2015, 6).

In their study examining the use of vaccination services among pregnant mothers, Dube and colleagues focused particularly on those who were vaccine hesitant, who fall "in the middle of the continuum between vaccine acceptance and refusal" (2016, 411). In following with the idea of vaccine hesitancy as a continuum, the researchers divided the participants into three groups 1) *favorable*, for the women who were confident in vaccines and expressed intention to vaccinate their child, 2) *unfavorable*, for those who expressed serious concerns and indicated they would refuse vaccinations for their child, and 3) *hesitant*, for those who were unsure and undecided about whether they would vaccinate their child. The participants were divided again into groups according to their vaccination decision, 1) *accept all*, 2) *refuse, delay*, for those who refused or delayed one or more vaccines, or both, and 3) *refuse all* (Dube et al. 2016, 413). The study findings indicated that vaccine-hesitant mothers, regardless of their final vaccination decisions, reported that they were "not entirely comfortable with their decisions and could change their minds at any time" (2016, 421). Further demonstrating the dynamic nature of vaccine hesitancy, vaccine hesitant multipara mothers made different vaccination decisions for their newborns as they did for their previous children (Dube et al. 2016, 421).

The authors also point to discrepancies in the literature around which behaviors and characteristics qualify as falling under the "umbrella of 'vaccine hesitancy'" a term which has been used to describe those who refuse or accept specific vaccines, those who delay any recommended vaccines, those who choose to fully vaccinate but still harbor significant concerns related to vaccines, and also parental knowledge gaps regarding vaccines (Benin et al. 2006, Downs et al. 2008, Dube et al. 2016, 411, MacDonald and SAGE 2015, Rees and Madhi 2011). While the WHO refers to the newly defined vaccine hesitancy as a continuum, the Group continues to situate "vaccine hesitancy" in opposition to "vaccine acceptance" (Dube et al. and SAGE 2015, 4190), reinforcing the dichotomous framework of "pro- versus anti-vaccination" we are trying to move away from.

From an applied perspective, it is important to examine and identify the various levels of vaccine hesitancy to determine if individuals are open to pro-vaccine messages, since many vaccine hesitant parents are actively seeking out information and taking a participatory role in vaccine decision-making (Benin et al. 2006, Brown et al. 2010, Brunson 2013, 2015, Dube et al. 2016, Wheeler and Buttenheim 2013). It is also important to determine particular concerns around specific vaccines. Are parents accepting specific vaccines but not others? Are parents delaying some vaccines but not others? Differential rates of vaccination between the childhood vaccines have implications on the community's susceptibility to communicable diseases, since vaccine preventable diseases have differential levels of contagiousness and severity. Vaccination rates for the DTP, polio, and MMR vaccines are consistently lower than the rates for the Hep B and varicella vaccine, particularly for private schools (CDPH 2016).

In California, vaccination rates at private schools was lower than rates at public schools for all vaccines required for school entry (CDPH 2016). With the passage of SB 277, no new PBE can be filed unless the student enrolls in homeschool, but students with exemptions filed prior to January 1, 2016 will remain exempt until they enter the next grade span. The average percent of kindergarteners with PBE in Los Angeles (LA) County was 2.2% prior to SB 277, resembling the state's average; however, the percent of kindergarteners in LA County's Service Planning Area

(SPA) 5 was 9.4%, the highest in the county (LACDPH 2014). In fact, in Santa Monica (located in SPA 5), there were six kindergartens that reported vaccination rates ranging between 40% and 80%, with PBE rates ranging from 13.8% to 60% (LACDPH 2016). Several other schools in the area were reported as "vulnerable," vaccination rates between 80-95% (LACDPH 2016). This differential rate of PBE in this area of LA County is an important point of investigation.

The 2014-2015 measles outbreak that originated at Disneyland may have raised awareness of the risk of measles and other vaccine-preventable diseases, impacting vaccination rates in the state (CDPH 2016). At the time, 20 (34%) counties in California had vaccination rates below 90% for all required vaccines for kindergarteners, and 31 (53%) counties have fewer than 95% of kindergarteners reported as having both doses of MMR, which is the approximate threshold to maintain herd immunity (CDPH 2016). Vaccine hesitancy is not monolithic; the concept is only useful when it is contextualized, when the particular levels, specificities, vaccine context, origins, and contributing factors are identified.

CHAPTER 3: THEORY

Introduction

In this chapter, I discuss the main anthropological theoretical perspectives I applied in examining vaccine hesitancy, 1) political economy, specifically the impacts of neoliberalism on health, 2) risk, in the context of individualization and trust, and 3) gender and feminist anthropological perspectives. I incorporate the social ecological model (SEM), a public health framework, and present a theoretical model that connects the theories together.

Political Economy

The political economic approach is a family of approaches defined as "the methodology of economics applied to the analysis of political behavior and institutions" (Weingast and Wittman 2008, 1). In other words, the approach focuses on macro-level structural factors, such as political and economic systems and institutions, and their impact on particular societies and cultures. In the context of critical medical anthropology, Baer, Singer, and Johnsen (1986) called for the deliberate recognition that "disease, illness, and treatment occur within the context of the capitalist world system" and are "intimately related to hegemonic ideologies and patterns outside of medicine" (95). That is, rather than examining health solely at the individual, family, or community levels, the focus of inquiry should be broadened to encompass the socio-economic and political environment that shape disease, illness, and health constructs (Baer et al. 1986).

Neoliberalism and Health

The political economic approach can be applied toward examining the influence of neoliberalism on health-related behaviors and healthcare policies. Neoliberalism, the theory of political-economic practice characterized by individual freedoms within an institutional framework valuing private property rights and free trade (Harvey 2005, 2), has extended beyond market relations and into aspects of everyday life, including public health and health care (Brigg and Hallin 2007, Coburn 2000). In the neoliberal environment of the US, for example, the "actively responsible individual" (Rose 2007) is made to thrive at the expense of social cohesion and the welfare state.

The impacts of neoliberalism on vaccine hesitancy can be examined within a political economic framework (Casiday 2007, Hobson-West 2003). Vaccines function in two ways, by 1) protecting individuals directly from infectious diseases through acquired immunity, and 2) contributing to the protection of the entire population, including those most vulnerable such as newborns, the elderly, and immunocompromised individuals, through herd immunity (Diekema 2014, NIH 2010). In the US, health decisions are made within a neoliberal political economy wherein [public] health responsibilities fall primarily on the [private] individual (Coburn 2000, Hobson-West 2003). Burns and Davies examine discourses of health and wellbeing in relation to an HPV vaccination program in Australia, drawing on Foucauldian governmentality to argue that "'health-as-wellbeing' is mobilized as a modality of neoliberal government" (2015, 71). With the development and wide adoption of the concept of "wellbeing," which extends ideas of health from biomedicine into every other aspect of life, the pedagogies of health-as-wellbeing produces a "systemic surveillance process" in which behaviors, lifestyles, health practices, and even ideas about "healthy living" are monitored (Burns and Davies 2015, 74). Within neoliberal political economies, the "discourses of choice and freedom are conflated within a market economy as *freedom of choice*" (2015, 79, original emphasis). "Wellbeing" is commodified and consumed in the marketplace by individuals who are positioned as free-choosing agents, responsible for reducing their own health risk through consumption. Choosing to vaccinate against HPV is then framed as a "right to choose," reinforcing neoliberal virtues of choice and personal responsibility, assuming the individual as an "autonomous rational economic agent who makes choices between competing goods and services based on price and value, cost and benefit" (Burns and Davies 2015, 79).

Reich examines the gendered discourse of vaccine refusal within a neoliberal context wherein the rhetoric of choice, again, is prominent and drives the prioritization of individual over community health (2014). Women's individual efforts to "define themselves as good mothers [through good choices], and thus, good women" are encouraged by two neoliberal ideologies of 1) governmental and economic systems that value competition, self-interest, and decentralization, and 2) active self-management of risks through informed decision-making (Reich 2014, 4). In combination with choice, these neoliberal ideologies undermine community health by emphasizing individual health outcomes and risks, contradicting principles of public health which promote greater population health. The rejection of vaccines, one of the cornerstones of modern public health, by women privileged enough to do so are facilitated by gendered claims of maternal expertise ("a mother's intuition"), class privilege, and neoliberal concept of the empowered consumer (2014, 6, 12). This trend toward neoliberal, intensive mothering and the laser-focus on their own individual children enable mothers to allow their children to benefit from other children's vaccinations while ignoring how their unvaccinated children might put others at risk. These neoliberal healthcare choices reflect a broader trend in parenting, where parental investments are made to the individual child, at the expense of the security and development of children as a whole (Reich 2014).

To contextualize, when SB 277 was introduced in 2015, the average kindergarten vaccination rate (for school-required vaccinations) in California was relatively high (92.9%), though still falling below the CDC's target rate of ≥95% (CDC 2011, CDPH 2015). The vaccination rate among children in private schools in California was lower (88.2%) than public schools (93.2%), with corresponding personal belief exemption rates for private (4.93%) and public (2.16%) schools; medical exemptions accounted for a tiny fraction (0.17%) of unvaccinated children in the state's school system (CDPH 2015). Here, the tension between social responsibility [to contribute to herd immunity through vaccinations] and individual freedoms [to forgo vaccinations] is evident, divided along public and private lines. Historically, the primary actors of the Victorian-era anti-vaccination protests in England were drawn from a politically active working class that viewed the legislation as a violation on their bodies from an already interventionist state (Durbach 2000, 2002). At the time, employers could dismiss those who were deemed "non-compliant," which further mobilized labor advocates and middle-class reformers (Durbach 2000). In contrast, the current trend of vaccine hesitancy in California is primarily among the wealthier families. For example, the Service Planning Area (SPA) 5 of the Los Angeles County Public Health Department had the highest average household income ($86,572) and the highest rate of personal belief exemption (9.4%), compared to the average household income of $61,302, and average PBE rate of 2.7% (LACDPH 2014).

Political economy is an integral, if not defining, component of Critical Medical Anthropology. In the debates over SB 277 California, both sides invoked the American ideals and neoliberal ideologies of freedom, choice, and individual autonomy. Those in favor of SB 277 emphasized the social contributions of vaccines to herd immunity and protecting children's freedom to attend schools without fear of infectious disease. Those opposed to SB 277, on the other hand, argued that the law would impede their freedom to make individual health choices, including those regarding childhood vaccinations (CLI 2015). While individual and community level factors that influence vaccine hesitancy are important to consider, the political economic perspectives recognizes the broader context within which health-related decisions and processes play out. The political economic framework is also critical in examining macro-level trends within the areas parenting, education (e.g. homeschooling), and healthcare (e.g. individualized and personalized healthcare) that, in turn, shape micro-level behaviors and trends.

Neoliberal Governance and Health

Many theorists employing a political economic and critical medical anthropological approach have elaborated particularly on Michel Foucault's concepts of governmentality and biopower (1973, 1979, 1991). The concept of governmentality was defined by Foucault as the "art of governance," referring to various formal and informal processes and "technologies of domination" that seek to monitor, train, modify and manage individual bodies and populations, usually guided by particular expert knowledges (Brownlie and Howson 2006, Clarke 2003, Foucault et al. 1988, 17). The state and its social institutions shape human behavior as the means to secure the "welfare of the population [and] the improvement of its condition" (Foucault 1991, 100 in Li 2007). This is achieved through the use of both 1) apparatus forms of control, such police and surveillance, and state and social institutions, and 2) self-administration (self-governing) (Foucault 1977, Lupton 1995).

Governmental interventions, from a Foucauldian perspective, are deployed by assemblages rather than singular, monolithic entities; this recognizes the various parties and institutions involved in creating the regulated conditions in which we live (Foucault 1988, Li 2007). Power, closely tied to knowledge, also does not rest in a single bureaucratic apparatus; rather it is diffused in various locales across all areas of social life, some of which are constituted as authoritative agents of knowledge, and therefore power, while other domains and bodies are defined as governable (Dean 1999, in Li 2007, Lupton 1995). From this perspective, public health can be conceptualized as a governmental apparatus seen as a network of experts dispensing knowledge toward the improvement of health through self-regulation (Lupton 1999). For example, to protect the individual and the population from infectious diseases, medical and public health experts recommend that individuals become properly vaccinated. In this context, the discipline of the body [by the self] and the regulation of the population [by public health] can be understood as "the two poles around which power over life is deployed"; the body is thus the object of power (Foucault 1978, 136-139). In the case of vaccine-preventable diseases, the body, rather than the disease, becomes the target of intervention through vaccination campaigns and mandates. Once individuals and populations internalize particular expert knowledge and act upon it themselves, control is achieved from within [through self-discipline], without the need for external imposition or coercion. This is referred to as biopower (Foucault 1973, 1977, 1978).

While governmentality is distinct from discipline, which seeks to manage and reform deviant individuals and populations (Foucault 1979, 141; Li 2007), both exist within relations of power. In order for deployment of biopower to be most effective, it must be imposed on disciplined, or "docile," bodies, able to be "subjected, used, transformed and improved" (Foucault 1977, 136). Deborah Lupton applies theories of risk and governmentality in the context of public health and the regulation of the body, recalling the capitalist ideologies behind the "modern" public health movement (1995). Government investment in population health served primarily to combat the potential loss of worker productivity, and therefore profits, due to ill health and premature death. Through the use of authoritative systems of knowledge, in this case public health, privileged subjects, or ideal bodies, are constructed, normalized, and serve as an axis around which normal and deviant subjects and behavior are measured, defined, and corrected (Foucault 1977, Lupton 1995).

Nonetheless, in relations to compulsory vaccinations, even the earliest mandates of the smallpox vaccine (1853 in England, 1855 in the US) were met with resistance (Blume 2006, Durbach 2000, 2002, Lupton 1995). Vaccine mandates were seen as direct government intervention on individual bodies and as a violation of personal liberty and individual rights (Durbach 2000, Lupton 1995). This new “doctoring state” (Wohl 1983 in Lupton 1995) demonstrates the interaction of state and biomedical power as deployed through public health intervention. For example, in examining measles and vaccination campaigns in New Zealand, Drew (1999) locates mass vaccination programs within the dynamics of biopower. In 1995, “mandatory choice” became law in New Zealand, requiring parents to produce immunization certificates indicating whether their child has been vaccinated or not if they enrolled in childcare or school (Drew 1995). In this case, it was not the vaccination that was mandatory but the choice and corresponding documentation. This requirement caused tensions among parents and between parents and education workers who are an extension, in this context, of biomedical hegemony. The regulation of biological processes, such as immunity, extended from the health sector into the education sector, creating a new form of power and giving rise to new political struggles (Drew 1995). The social and political pressures to conform situated parents [who did not vaccinate their children] as the threat to population health rather than the virus itself, in the same way that bodies are the target of vaccination campaigns, rather than the infectious agent (Drew 199). Drew argued that to oppose vaccines is to oppose the state and biomedical science, and “as the state develops more intricate strategies of the control, the sites of resistance [will] multiply” (Drew 1999).

Much of the contemporary literature around governmentality and vaccines addresses the human papillomavirus (HPV) vaccine. Engels (2016) presents a Foucauldian analysis of the vaccine debate around the HPV vaccine among adolescents. Engels recounts Foucault’s analysis of the concepts of *case*, *risk*, *danger*, and *crisis*, which developed during the 19th century smallpox epidemic (2007, in Engel 2016, 302, original emphasis). In the context of HPV, the most common sexually transmitted infection in the US and worldwide, Engel applies Foucault’s concepts of *case*, *risk*, *danger*, and *crisis* to argue that the HPV vaccine is a form of biopower and a strategy for “normalization,” that is, the vaccine has the potential to establish new medical and behavioral norms (2016, 310). First, the mandatory vaccination seeks to establish the elimination of HPV in both the individual and population as the norm. Second, the mandate establishes the vaccinated individual as the norm, and therefore unvaccinated bodies as abnormal (2016, 307). The third form of normalization focuses on behavioral norms established by the vaccine mandate, that is, the normalization of sexual activity among adolescents (Engels 2016, 307). Since communication with parents and family members was vital in the uptake of the smallpox vaccine, in the same way that parents and healthcare provider recommendations are critical in the HPV vaccine uptake today (Gilkey et al. 2016, Kessels et al. 2012, Rosenthal et al. 2016), Engels highlights the effects on parental autonomy and adolescent decision making, and the parent-child relationship the vaccine mandates would have (2016). Here, Engels applies Foucault’s argument that “relationships exist only though various power mechanisms and strategies of biopower are necessarily intertwined within familial relationships” (2016, 308). Engels demonstrates the HPV vaccine as a strategy of biopower that effect individuals, communities, and society at various levels (2016).

Connell and Hunt also examine HPV vaccination campaigns, this time in Canada. The authors argue that the HPV vaccine is “a moral regulation project aimed at both the self and others,” drawing on Foucault’s central theory of governmentality and the linkage between the self-governance and government of others (2010, 65). Connell and Hunt highlight the transition that occurred in the 18th century when the focus of discipline moved from the individual to the population as a whole, characterized as biopolitics, usually through institutions working closely with the state, such as public health (2010). Public health of that era focused on improving the broader population, with programs such as sanitation and infrastructure, although these had individual effects as well. The authors situate the HPV vaccination campaigns as a population-based biopolitical effort to control HPV within the female population, rationalized through expert knowledge of the public health and medical institutions and financially supported by the state (Connell and Hunt 2010). Extending the normative power of this rational, expert knowledge toward the improvement population health ultimately leads to the further expansion of institutional mechanisms of control. Furthermore, concerns around health and sexuality are often invoked by moral regulation, in this case addressed through discourses of HPV risk, which itself encourages self-governance and self-discipline (Connell and Hunt 2010). By analyzing the Canadian vaccination campaign through a Foucauldian lens, the authors highlight the role of traditional modes of authority, of the state and medical professions, which are, in this case, mobilized by resources provided by the pharmaceutical industry. These apparatuses of control work together to legitimize the vaccination program, and reinforcing self-governance by encouraging schools and parents, particularly mothers, to accept the HPV vaccine and support vaccine mandates (Connell and Hunt 2010).

Vaccines, perhaps more than other biotechnologies, highlight the relationship between the state, public health institutions, and its citizens, conjuring debates about the links between government, corporate interests, family constructs, and social control (Wailoo et al. 2014). Concepts of governmentality and biopower are relevant in examining vaccine hesitancy in California, particularly in the context of the new vaccination laws in the state. Arguments against an interventionist state persist among vaccine hesitant individuals and communities in support of individual rights and freedom (to choose not to vaccinate). As parents oppose the new vaccine and position themselves against "technologies of control" and institutional authorities (of the state, public health, education), they may begin to conceptualize themselves in new ways, shaped by social and political forces seeking to establish new behavioral norms. This framework is also applicable when exploring how the role of the government (state and local) and public health are changing in relation to health decision-making and subsequent health behaviors, particularly in an increasingly neoliberal political economy (and health care system).

Theories of Risk

Theories of risk are principally drawn from the critical structuralist perspectives of Beck (1986, 1995, 1999) and Giddens (1990, 1991). Both Beck and Giddens address concepts of risk in the context of late modernity, however their perspectives differ on the reflexive nature and origins of risk. Beck argues that individuals living in Western industrialized societies are confronted with risks that are altogether different, and at unprecedented levels, than to those that existed before; this is an outcome of modernization (1986). In the context of reflexive modernization, wherein modernization becomes "its own theme," concerns over the economic and political management of risks related to modern technologies supersede the development and implementation of technologies themselves (1986). Industrialized "wealth-distributing" societies thus become "riskdistributing" societies, wherein the risks associated with modernity are constantly being managed and addressed (Beck 1986).

In contrast, Giddens defines modernity as a "risk culture" (1990, 3), arguing that the modern concept of risk is not based on a quantifiable increase in risks, rather that society's sensitivity and focus on risk has increased (1990). In this context, reflexive citizens, involved in continuous monitoring of one's own behavior and context, rely on experts and "expert systems," above local knowledges, to conceptualize and manage risks perceived in their daily lives (Giddens 1990, Lupton 1999). Giddens argues that trust is intertwined with risk; this argument is a central theme in his work, in contrast to Beck's. When the expert systems fail, certainty and trust in them decreases, which have far-reaching repercussions beyond the local context. Trust in global expert systems are therefore characterized by uncertainty (Lupton 1999).

Both Beck's and Giddens' seminal theories of risk are important in situating vaccines and vaccine hesitancy within late modernity and modern biotechnologies. Beck and Beck-Gernsheim's theories of individualization of risk, expanded on further below, can be applied to examining risk perception of vaccines and strategies of risk management in neoliberal political economic contexts. Gidden's perspective can also be applied to analyzing the changing contexts and perceptions of risk, first around infectious diseases and then the vaccines themselves. Gidden's inclusion of trust as a central theme is also important in examining the current context of vaccine hesitancy, particularly at the intersection of the state, political actors, biomedical and public health institutions, and the corporate interests of the pharmaceutical industry (Livingston et al. 2014, Lupton 2013).

Casiday (2007) reviews the effects of the MMR controversy in the United Kingdom through several theoretical streams of risk perception, including cultural theory of risk. Casiday

(2007) applies Douglas' theory that risks threaten both individual well-being as well as the maintenance of social order (1966) to analyze parental decision-making around vaccinations for their children. Parents consider the individual risk of vaccine-preventable disease and adverse reactions to vaccines against the social risk of appearing to be a bad parent (Casiday 2007). Casiday examines the interplay between the individual-level health risk and the population-level social risk, underscoring the tension between the individual and state public health interests through the cultural theory of risk (2007). This framework is useful in acknowledging and understanding the multiple perceptions of risk that influence parents' decisions around vaccinations.

Individualization

Beck and Beck-Gernsheim's theories of "individualization" [of risk] are also relevant, wherein individuals take it upon themselves to assess and manage the risks posed by both infectious diseases and vaccines (Beck and Beck-Gernsheim 2001). Individualization is the neoliberal iteration of Marx's concept of atomization, the social mechanism that reduces collective units, such as families, unions, socio-economic classes, into separate units made up of single individuals (Boykoff 2011, Marx 1976). In a world risk society, in which radical uncertainty is ubiquitous (Beck 2006), Beck and Beck-Gernsheim note that the defining characteristic of individualization is that "society tells us to seek biographical solutions to systemic contradictions" (2001, 2). In other words, risks that were formerly considered collective and universal are to be assessed and managed by the individual. Individualization is propelled by neoliberal capitalism, which values hyper-individualism and privatization above all else. In this context, causality, state institutional accountability, and social responsibility are set aside to allow the rational, atomized citizen can express individual freedoms and agency through consumption (Beck and Beck-Gernsheim 2001, Boykoff 2011).

Beck uses the term “tragic individualization” (2006) to describe the futility of individual efforts to negotiate collective risks, especially in neoliberal capitalist environments in which traditional systems of expertise and risk management have eroded.

> The individual must cope with the uncertainty of the global world by him- or herself. Here individualization is a default outcome of a failure of expert systems to manage risks… The individual is forced to mistrust the promises of rationality of these key institutions. As a consequence, people are thrown back onto themselves, they are alienated from expert systems but have nothing else instead… (Beck 2006, 336)

The concept of “tragic individualization” provides a frame for analyzing the individualized process of risk assessment and management strategies and the context of perceived institutional failure and distrust.

Applying individualism, Hobson-West (2003) highlights the ineffectiveness of mass vaccination campaigns that have a social focus on the benefits of community immunity in neoliberal environments, since individuals prioritize their own health over the community’s overall health. While this perspective is closely tied to perceptions of risk (individual vs. population; infectious disease vs. vaccines), Hobson-West emphasizes the influence of the “[dominant] language of choice, empowerment and individual responsibility in the current public health discourse,” shaped by the libertarian and neoliberal ideals of individual autonomy and responsibility. These, in turn, impact health decision-making processes and behaviors (2003, 277). In this context, vaccines are conceptualized as individual health interventions with individual health outcomes, and vaccines’ social contributions to herd immunity and population health are deemphasized, if considered at all.

Harm Reduction

Mark Nichter (2003) draws on the work of Beck and Giddens in describing the concept of harm reduction, situated within larger anthropological themes of risk, vulnerability, and responsibility. While theories of reflexive modernity (Beck 1986) and risk culture (Giddens 1990) focus on individuals assessing and managing exposure to risks from occupational or environmental sources, harm reduction practices are rooted in perceptions of individual vulnerability, which are derived from feelings of susceptibility to illness or injury due to variety of factors, including personal traits; seasonal (climatic) or life-stage status (infancy, pregnancy, old age); preexisting health conditions; or an accumulation of negative exposures over time (to toxins, germs, etc.) (Nichter 2003). Nichter argues that harm reduction is practiced on an individual level as an expression of agency toward both reducing the sense of vulnerability and also enhancing perception of self-control (2003).

In the context of vulnerabilities, in contrast to risk, Nichter (2003) argues that, within the harm reduction model, responsibility falls on the individual to take the appropriate expert-recommended actions to address their own vulnerabilities, rather than risks introduced from outside sources (Beck 1986, Giddens 1990), to maintain health. Public health interventions based on the harm reduction model are aimed at individuals who are deemed vulnerable, or "at risk," of illness or disease; risk management, decision-making, and choice, which are contingent on access to appropriate advice or information, are central to the harm reduction model (Owczarzak 2009). Interventions aimed at "risk groups" also define and reinforce boundaries around those who are "at risk," contributing to perceptions that individuals can also fall outside those boundaries and, therefore, are not vulnerable (Owczarzak 2009, Schiller et al. 1994). However, members of a "risk group" may not necessarily perceive their vulnerability through the same rationale or cultural context (Nichter 2003). Furthermore, individuals or behaviors labeled as "at risk" or "risky" suggests blame and stigma constructed within specific social and cultural contexts, which implicates members of "risk groups" as a threat to the well-being of the rest of the population (Farmer 1994, Owczarzak 2009, Schiller et al. 1994).

While still controversial due to its potential to reinforce and exploit negative stereotypes, strategies utilizing the harm reduction model have become more common in public health interventions (i.e. syringe exchange programs, etc.), and are relevant in political-economic analysis of neoliberal public health program and policy development and implementation. While vaccinations are not theoretically considered harm reduction, this framework offers a way to examine how vaccine hesitant parents analyze the vulnerability of their children and internalize the perceived risks posed by vaccines.

Precautionary Consumption

Mackendrick applies theories of risk to analyze how mothers apply the precautionary principle on an individual level through the practice of "precautionary consumption," a form of vigilant consumption in efforts to mediate individual exposure to environmental chemicals (2010, 2014). It is a strategy of self-protection and expression of individual control and agency over chemical exposure (MacKendrick 2010). The concept stems from the Precautionary Principle in public health, based on the old adage "better safe than sorry" (Chaudry 2008, MacKendrick 2014, Marchant 2001). It originated in the field of environmental health and was fueled by environmental crises such as the Love Canal tragedies (1970s) and the Chernobyl nuclear catastrophe (1986). Incidences such as these and books such as *The Silent Spring* (Carson 1962) led to increasing public awareness of the dangers of environmental toxins (Chaudry 2008). In the neoliberal era characterized by deregulation and privatization of producers of synthetic chemicals and toxic waste, the onus to protect the public's health from everyday exposure is diverted from the state onto the individual. While MacKendrick does not apply the concept of precautionary consumption to vaccines in her research (2010, 2014), the concept is relevant to this study. Parents' vaccine hesitance can be viewed as one of many forms of precautionary consumption that parents practice to protect their children from external and environmental risks. The concept can also be applied to analyze how parents individualize risk and their risk avoidance strategies through consumption practices, particularly in the context of deregulation.

Theories of risk are relevant to examining the logics of risk, modes of reasoning, and meanings of risk that influence risk perception and decision-making related to health, including childhood vaccinations. Parents negotiate between their child's risk of contracting a vaccine-preventable disease against the risk of vaccine injury, in addition to the social risk of appearing to be a "bad parent" (Casiday 2007). The interplay between the individual- and population-level risk underscores the tension between individual freedoms and the "right to choose" at the individual-level versus the interest of the state and public health at population-level health (Casiday 2007). This dynamic also reflects the tension between the biomedical model and public health, between individual health and community health.

Risk and Trust

In the context of modern risk societies, perceptions of risk are intertwined with institutional trust (Beck 1992, Beck, Giddens, and Lash 1994, Giddens 1991, Meyer et al. 2008, Peretti-Watel et al. 2015). Beck and Gidden's central thesis of reflexivity[5] suggests that individuals understand and respond to risks based on expert knowledges. In other words, we trust and rely on the experts

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[5] Reflexivity, generally defined as the way citizens apply knowledge to govern (assess, monitor, inform) their behavior in response to risks in a modern risk society (Beck 1992, Beck, Giddens, and Lash 1994, Giddens 1991).

to analyze and communicate technical knowledge that is then consumed and applied by everyday people in their everyday lives (Giddens 1991). In environments of institutional distrust, expert institutions and authoritative knowledge are contested and challenged (Beck 1992, Beck, Giddens, and Lash 1994, Giddens 1991, Horlick-Jones 2005, Tulloch and Lupton 2003, Lupton 2013, Wynne 1996). While expert institutions shape universalized perceptions of risk, lay perceptions of risk are individualized, localized, and contextualized, and shaped by informal logics of risk that are constructed through individual experiences, collective memories and evaluations of institutions themselves (Lash and Wynne 1992, 7, in Tulloch and Lupton 2003). Those evaluations of institutions, in terms of trustworthiness, are based on "pre-established knowledge of how relevant industries and regulatory bodies have tended to deal with risks in the past" (Lupton 2013, 148).

On a systems level, Luhmann's theory of relational trust analyzes institutional trust through relationships and mutual interactions between social systems (e.g. medical system, political system, etc.) (Luhmann 1979, Meyer et al 2008). Trust or distrust in one social system impacts trust or distrust in others; from a structural-functional perspective, trust is the "glue" that holds the system [as a whole] together (Meyer et al. 2008, Pearson et al. 2005). This dynamic also applies to actors and institutions within the same system; if, for example, either the medical providers or the medical institution is unable to create a relationship or environment of trust, it can undermine the public's trust in the system as a whole (Meyer et al. 2008).

Trust plays an important role in vaccine decisions for parents (Attwell et al. 2017, Benin et al. 2006, Casiday et al. 2006, Dube et al. 2015, Glanz et al. 2013, Hobson-West 2007, Sobo 2015). In general, highly publicized controversies around vaccine safety, such as concerns around TDAP-thimerosal in the 1980s and MMR-autism in the late 1990s, contributed to the erosion of trust in vaccines among parents (Dube et al. 2015). On an interpersonal level, trust or lack of trust in their pediatricians is critical in vaccine decision-making among new mothers (Benin et al. 2006). For new mothers, feeling satisfied with their discussions about vaccinations with their pediatricians led to higher levels of trust in them, and the subsequent trust in their pediatrician was found to be a promoter of vaccination (Benin et al. 2006).

In terms of relational trust, Casiday and colleagues found that the distrust that parents in the United Kingdom felt toward the government and their ability to regulate risks around vaccines following the widely publicized Wakefield-MMR controversy undermined individual health providers' ability to provide vaccination advice to their patients (2006). If parents thought the government was directly involved in promoting vaccinations, it negatively impacted their belief that providers could be impartial in their vaccine recommendations. However, parents were generally happy with the information provided to them by their individual providers, indicating that there are opportunities for providers to foster trusting relationships with parents by acknowledging and respecting parents' primary goals of protecting their children's health (Casiday et al. 2006).

Perceived conflicts of interest between systems can also impact dis/trust in each system involved and the system as a whole. Attwell and colleagues found that perceptions of profit motive and distrust in pharmaceutical companies had a negative impact on trust in research, healthcare providers, and the government (2017). Parents viewed vaccine recommendations for their children were in conflict with their best interests, even when the recommendations came from individual representatives, such healthcare providers, that were not "tainted" by conflicts of interest (Attwell et al. 2017). Relational trust perspectives are relevant in analyzing how institutional dis/trust and perceived conflicts of interest between social systems impact vaccine hesitant parents and their decisions about vaccinations for their children in this study.

Gender and Feminist Anthropological Perspectives

The second-wave feminism of the 1970s ushered in the rise of feminist scholarship in the discipline of anthropology. The seminal works of Michelle Zimbalist Rosaldo and Louise Lamphere (1974) and Rayna Rapp (1975) were foundational to feminist anthropology, supporting, and supported by, the era's institutionalization of feminist and gender studies publications and journals, national associations and societies for women and women of color, and the first United Nations World Conference on Women (1975). Critical feminist scholarship intersects with critical medical anthropology in the ways these approaches challenge traditional gender norms and androcentric hierarchies of power; contest patriarchal, neoliberal frameworks; and, emphasize the intersectional view that political and social constructs of sex and gender privilege some while disadvantaging others along the lines of race, class, sexuality, and gender (Abu-Lughod 1987, Davis and Craven 2016, Disch 2015, Lupton 2012, Martin 1994, Romero-Daza et a. 2003, Sheper-Hughes 1992, Whiteford 1997).

In the context of vaccines, anthropologists, public health, and social scientists have examined the human papillomavirus (HPV), HPV vaccine, and related policies through the lens of gender (Burns and Davies 2015, Caspar and Carpenter 2008, Daley et al. 2010, Mamo et al. 2010). The HPV vaccine Gardasil was first clinically trialed and FDA-approved for females in 2006 due to its causal association with cervical cancer at the time. While HPV is not gender-specific, Daley argues that the "accidental synergy" of the known science, initial female-only FDA approval, and historic sexism in public health, biomedicine, and US culture in general promoted the narrative that HPV was a "woman's problem" and reinforced the overidentification of HPV with females; this is referred to as the "feminization of HPV" (Daley et al. 2010, Daley et al. 2016). In the absence of broad HPV vaccination requirements in the US, the public health system is still working against this feminization and gender parity in vaccination rate. Though evidence suggests the gap is closing, boys continue to have lower vaccination rates than girls (48.7% versus 53.7%) (CDC 2018a, Jenco 2019).

The HPV vaccine has been theorized as a site of cultural, social, and political contestation involving constructs of gender, sexuality, cancer, family, the role of the state, and the influence of the pharmaceutical industry (Burns and Davies 2015, Daley et al. 2010, Daley et al. 2015, Daley et al. 2016, Daley et al. 2017, Engels 2016, Reich 2016, Wailoo et al. 2010). Due to its common mode of transmission of intimate contact, the HPV vaccine is inextricably linked with sexuality. Parents' neoliberal approaches to the HPV vaccine are informed by their future goals and expectations of sexuality and sexual citizenship for their children. Parents are more likely to consent to vaccinating boys for HPV than girls, suggesting a gendered process of assessing necessity, risk, and sexuality (Reich 2016). This bias toward vaccinating girls centralizes the risk of HPV and the meanings of risk and sexuality on girls' bodies. The rejection of the vaccines can be viewed as parents acting as responsible consumers in their individual assessment of need and risk, and their consideration for the future sexual citizenship of their children (Reich 2016).

The gendered dynamics of childhood vaccinations and vaccine policies has not been examined to the same extent as the HPV vaccine, even though women have a long history of being the primary vaccine decision-makers for their households. Historically, women "antivaccinators" of late-1800s Victorian-era England linked their cause to other feminist issues of the time, such as female enfranchisement and women's property rights which were based on the assertions of "political manhood" (Durbach 2002). At the same time, women were fighting for their right to legal parenthood to claim a certificate of conscientious objection for vaccination for their children, since by law it was the father who held custody of a "legitimate child." Even then, while men were viewed as heads of household, women were the primary health decision-makers when it came to vaccines; ninety-five percent of applicants for the conscientious objection certificate were women (Durbach 2002).

The critiques of childhood vaccines in the more recent 1970s and 80s also followed the trends of feminist and women's health movements in their critical view the medical system. The congenital effects of many vaccine-preventable diseases, such as rubella, solidified vaccines as a mother's responsibility, not only to protect their children but to protect the mother themselves. As more women entered the wage-earning labor force, vaccine-preventable diseases were presented as a possible interference to women's and mother's economic stability, suggesting that if children fall ill to vaccine-preventable diseases, they would be primarily responsible for, and expected to, stay home and care for them; this once again reinforced vaccines as a mothers' responsibility (Conis 2013). Mothers were situated on either side of the polarized issue of vaccines. On one hand, mothers were viewed as resources available in mobilizing vaccination campaigns; on the other hand, mothers who refused vaccinations for their children were viewed as uneducated and irresponsible (Conis 2013). This dual pressure is still evident in the vaccination "debate" in the 2000s.

The Natural Birth Movement and Authoritative Knowledge

Seminal works of feminist anthropology feature cross-cultural studies of childbirth (Davis-Floyd 1992, Jordan 1997, Martin 1992, Riessman 1983). As childbirth in the US became increasingly medicalized with the ascension of biomedical authority starting in the early twentieth century, the natural childbirth movement emerged in the 1960s as a way for women to take back control over the labor process and experience and assert their authoritative knowledge in the arena of childbirth. The vertical biomedical hierarchies of knowledge were turned on their side as mothers claimed equal authority with other members of community, family, and medical providers in the arena of childbirth (Davis-Floyd 1992). Critical perspectives of the natural childbirth movement, however, question the total rejection of biomedical interventions, including analgesics and anesthetics, as further constraining women's choices (Lupton 2006, Martin 2003). Others suggest that focusing on the natural-ness of childbirth moralizes the "natural," promoting ideologies around "good" mothers and essentializing women and birth as "natural" (Cohen 2006). This calls back to the historic, patriarchal views around women as instinctive, simple, and one with nature, and men as rational, scientific, and creators of culture (Brubaker and Dillaway 2009). The natural childbirth movement reclaimed the misogynistic alignment of women with nature to assert and empower authoritative knowledge of women. Feminist perspectives of authoritative knowledge, and challenging biomedical hierarchical knowledge, can be applied to examine how vaccine hesitancy plays in environments of institutional distrust, and the ways it impacts, or is impacted by, other aspects of their approaches to health.

Intensive Mothering

Neoliberal ideologies shape parenting norms and expectations in gendered ways. Hays (1995) first described "intensive mothering" practices as a labor, time, and resource demanding form of motherhood that has become the norm in Western industrialized countries. The rise of intensive mothering practices coincided with the wave of neoliberal policies that expanded privatized, commodified modes of parenting at the expense of social and structural support for children and families. This transformation further reinforced mothers' primary and exclusive responsibility toward their children. On the growing trend toward intensive mothering practices, Green states a consensus among scholars of women's and gender studies which is that regardless of how mothers identify, "the ideology of intensive mothering serves the interests of neo-liberal, white supremacist, capitalist patriarchy. And, it harms most people in the process" (Green 2015, 199). The mid-century "feminine mystique," when a woman's primary aim was to keep a happy marriage, has transitioned into the "motherhood mystique," which is centered around raising welladjusted children in a clean and happy household (MacDonald 2013). The prioritization of the mother-child relationship above all else, regardless of whether the mother works outside of the home or not, undermines women's happiness while at the same time, keeps the focus on private problems rather than on public, structural issues that promote and exacerbate gender inequities, such as the lack of paid family leave, universal childcare, and quality public education (MacDonald 2013). Intensive mothering ideologies interplay with vaccine hesitancy through neoliberal gender norms and cultural views of health as "highly individual, controllable, and requiring informed consumers to be self-efficacious" (Crawford 1980, in Reich 2014, 21).

Gender "Mainstreaming" in Health Policy

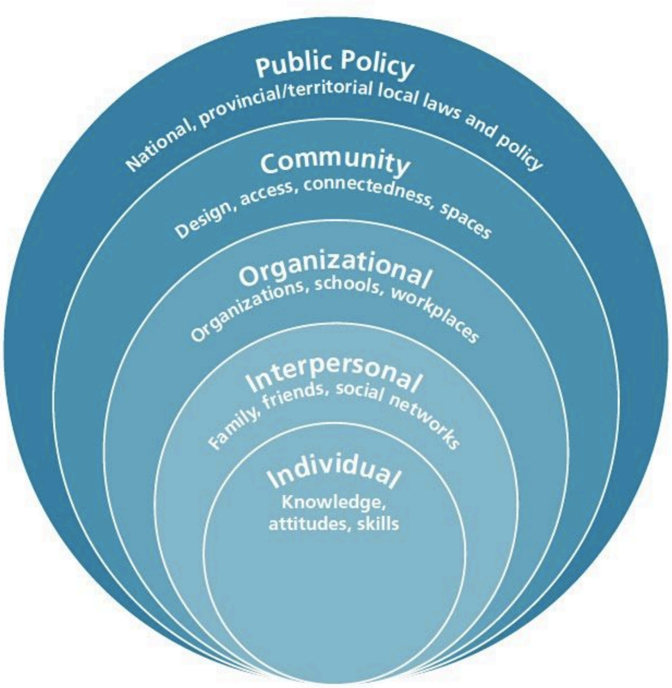
Feminist policy and critical policy scholars are actively challenging domination and marginalization, revealing and remedying gender inequity, and incorporating reflexivity in policy analysis with the goal of gender "mainstreaming" (McPhail 2003, Paterson and Scala 2015). In the context of health policy, movement toward gender mainstreaming promotes the visibility of gender in health policies and interventions, particularly in areas that are not typically considered gendered, such as diabetes, smoking, and childhood vaccines (Amin et al. 2014, Paterson and Scala 2015). While research around the HPV vaccine and related policies brings to light gendered social, economic, and political issues, there is a dearth of research examining the gendered processes and impacts of policies around the seemingly "gender neutral" childhood vaccines, with a few exceptions (Conis 2013, Durbach 2002, Reich 2015, 2016).

Through a feminist theoretical lens, I analyze how women challenge authoritative knowledge and the patriarchal power structure of biomedicine through vaccine hesitancy. I also examine the ways in which the process around SB 277, from support to opposition to the political consequences, was gendered.

Social Ecological Model

Strong evidence supports the notion that the application of social and behavioral theories and models are important in developing effective public health and health promotion interventions. The social ecological model, or socioecological model (SEM), emphasizes multiple levels of influence that impact behaviors that in turn shape, and are shaped by, social environments (Glanz and Bishop 2010; see Figure 4). While there are various adaptations of the SEM, the constructs generally include individual, interpersonal, organizational, community, and public policy levels (Glanz and Bishop 2010). The four core principles of ecological perspectives, such as SEM, are 1) the focus on multiple levels of factors that influence health behaviors, 2) the emphasis on the interaction between influences across levels, 3) the promotion of multi-level interventions toward effective behavior change, and 4) the focus on a specific behavior (Glanz, Rimer, and Viswanath 2008).

While I do not explicitly utilize the SEM to guide my research, the SEM lends itself well to analyzing the interrelated and multi-level factors that shape vaccine hesitancy, for example, individual beliefs and behaviors related to vaccines (*individual*); provider-parent relationships and parents' social networks (*interpersonal*); schools and community-based organizations (*organizational*); relationships between social systems and institutions, e.g. public health and schools (*community*); and state and federal vaccine-related policies and agencies (*policy*). Theoretically, the findings of this study guided by the anthropological framework of political economy and theories of risk, trust, and gender can be integrated into the various levels of the SEM.



A Social-Ecological Model for Physical Activity - Adapted from Heise, L., Ellsberg, M., & Gottemoeller, M. (1999)

Figure 4. Social ecological model

Summary

The overarching framework of political economy encompasses the theoretical perspectives of neoliberal health and governmentality, and connects with theories of risk, relational trust, and gender (Figure 5). Through this theoretical model, I analyze the micro- and macro- level factors that shape vaccine hesitancy.

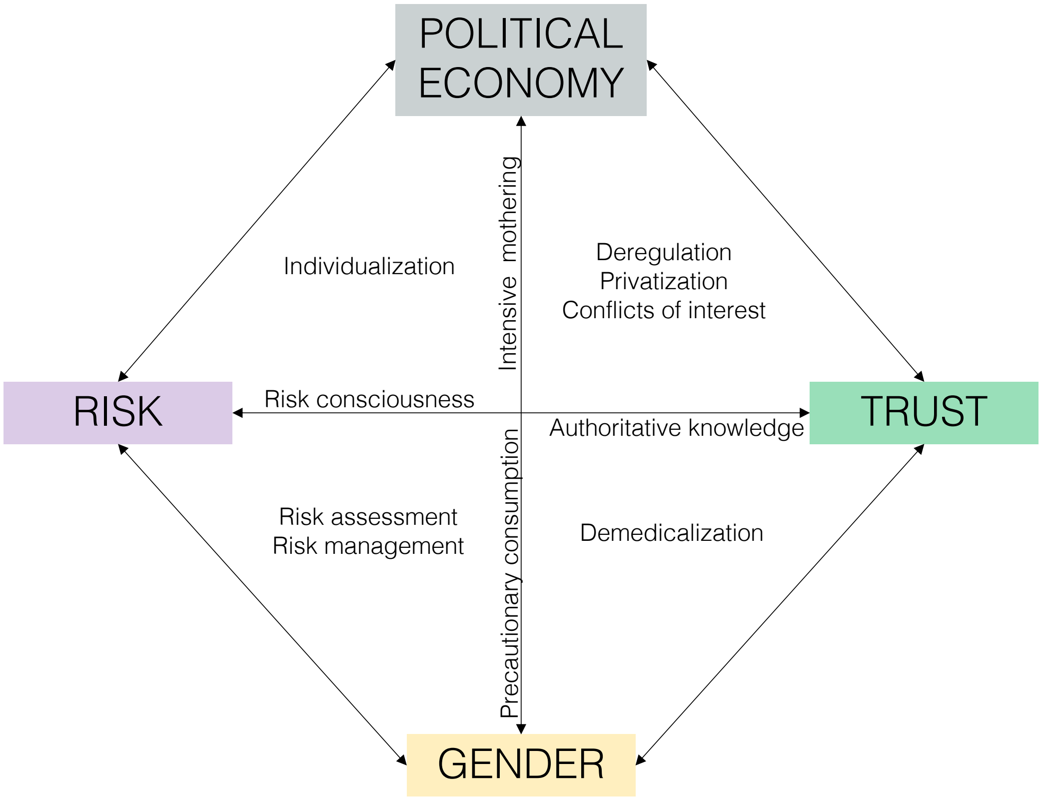


Figure 5. Theoretical model

CHAPTER 4: METHODS AND ETHICAL CONSIDERATIONS

Introduction

In this chapter, I provide an overview of research methods employed by this study. This includes a description of the field site, participant recruitment, research design, and interview and survey methods. I conclude with a discussion of the limitations and ethical considerations.

Field Site

The field site was Los Angeles County, California. In the state, during the 2014-2015 school year prior to the proposal of Senate Bill 277, 20 of 58 (34%) counties had rates of fully immunized kindergarteners below 90% (CDPH 2016d). In Los Angeles County, 90% of kindergarten entrants received all required vaccine doses, leaving 10% still vulnerable to vaccine-preventable diseases commonly spread in schools (CDPH 2016d).

Los Angeles County (LAC) [officially the County of Los Angeles] is one of the largest and most diverse metropolitan areas in the US. An estimated 10.4 million people live in the county, with over 70% of the population belonging to a racial and/or ethnic minority group (LACDPH 2017). The demographic breakdown by race and ethnicity of LAC is 45% Latino, 31% White, 12% Asian, 10% Black, and 0.8% Native American, Alaska Native, Native Hawaiian and other Pacific Islander (County of Los Angeles [CLA] 2020). LAC is separated into eight Service Planning Areas by the Los Angeles County Department of Public Health (see Table 1). In SPA 5, located on the west side of LAC, is 64% White, 16% Latino, 14% Asian, 6% Black, and 0.3% Native populations (LACDPH 2014). This SPA has the highest median income and the highest rates of personal belief exemptions (PBE) in the county, which is consistent with the literature regarding the demographics of vaccine hesitant parents.

Table 1. Los Angeles County Department of Public Health Service Planning Areas, including regions, cities, median household income (2014), and personal belief exemption (PBE) rates for kindergarten (2013-2014), prior to SB 277.

Service Planning Area (SPA)	Region and Cities	Median Household Income (2014)	PBE Rate in Kindergarten (2013-2014)
1	Antelope Valley: Acton, Agua Dulce, Gorman, Lake Hughes, Lake Los Angeles, Lancaster, Littlerock, Palmdale, Quartz Hill, and others	$57,423	3.5%
2	San Fernando Valley: Burbank, Calabasas, Canoga Park, Canyon Country, Encino, Glendale, La Cañada-Flintridge, San Fernando, Sherman Oaks, Sun Valley, Van Nuys, Woodland Hills, and others	$69,909	3.3%
3	San Gabriel: Alhambra, Altadena, Arcadia, Azusa, Baldwin Park, Claremont, Covina, Diamond Bar, Duarte, El Monte, Glendora, Irwindale, Monrovia, Monterey Park, Pasadena, Pomona, San Dimas, San Gabriel, San Marino, Temple City, Walnut, West Covina, and others	$68,417	1.7%
4	Metropolitan Los Angeles: Boyle Heights, Central City, Downtown LA, Echo Park, El Sereno, Hollywood, Mid-City Wilshire, Monterey Hills, Mount Washington, Silverlake, West Hollywood, and Westlake	$47,173	1.3%
5	West: Beverly Hills, Brentwood, Culver City, Malibu, Pacific Palisades, Playa del Rey, Santa Monica, and Venice	$86,572	9.4%
6	South: Athens, Compton, Crenshaw, Florence, Hyde Park, Lynwood, Paramount, and Watts	$36,400	0.3%
7	East: Artesia, Bell, Bellflower, Bell Gardens, Cerritos, City of Commerce, City Terrace, Cudahy, Downey, East Los Angeles, Hawaiian Gardens, Huntington Park, La Habra Heights, Lakewood, La Mirada, Los Nietos, Maywood, Montebello, Norwalk, Pico Rivera, Santa Fe Springs, Signal Hill, South Gate, Vernon, Walnut Park, Whittier, and others	$57,726	0.9%
8	South Bay: Athens, Avalon, Carson, Catalina Island, El Segundo, Gardena, Harbor City, Hawthorne, Inglewood, Lawndale, Lennox, Long Beach, Hermosa Beach, Manhattan Beach, Palos Verdes Estates, Rancho Dominguez, Rancho Palos Verdes, Redondo Beach, Rolling Hills, Rolling Hills Estates, San Pedro, Wilmington, and others	$66,794	1.9%
	Average	**$61,302**	**2.7%**

As of January 1, 2016, with the passage of SB 277, children are required to complete all recommended vaccinations in order to attend private or public school (Table 2). Medical exemptions, provided by a licensed physician in California, are still in place. Medical exemption rates in California have risen dramatically, from just 0.2% three years ago to almost 1% since the passage of SB 277 (CDPH 2018).

Table 2. Vaccinations required for kindergarten students in CA at ages 4-6 years (CDPH 2016b)

Vaccine	Required Doses	Special Instructions
Diphtheria, Tetanus, and Pertussis (DTaP, DTP, or DT)	5	4 doses OK if one was given on or after 4th birthday
Polio (OPV or IPV)	4	3 doses OK if one was given on or after 4th birthday
Hepatitis B	3	N/A
Measles, Mumps, and Rubella (MMR)	3	Both given on or after 1st birthday
Varicella (Chickenpox)	1	N/A

The vaccination mandate for public and private school entry do not apply to students enrolled in home-based private school or an independent study program without classroom-based instruction (i.e. homeschool) (CLI 2015). Homeschooling has been on an upward trend in the US in the past decade, with rates across the country increasing by 61.8% between 2003 and 2012, with approximately 1,773,000 enrolled in home-based schools, about 3.7% of the school-aged population (NCES 2012). In California, there was a three-fold increase of children attending home-based kindergarten who were un- or under-vaccinated, from 0.5% in 2016 (before SB 277) to 1.5% in 2017 (After SB 277). Los Angeles County is one of six California counties (i.e. Los Angeles, San Diego, Fresno, El Dorado, Sutter, and Placer) that are attributed to 90% of the increase in un- or under-vaccinated children enrolled in home-based independent or virtual school (CDPH 2018).

Research Design

In this exploratory study, I had originally intended to use both qualitative and quantitative data collection and analysis methods. I conducted unstructured, in-depth, individual interviews with vaccine hesitant parents in order identify and explore defined and undefined domains of vaccine hesitancy, and identify underlying factors that shape vaccine hesitancy and subsequent vaccine-related decisions and behaviors, particularly in the wake of the elimination of the personal belief exemptions in California (Schensul, Schensul, and LeCompte 1999, 122). Research methods evolved organically following the grounded theory orientation and the opportunities and constraints I encountered during my time in the field. My overall theoretical framework of political economy also shaped the selection of methodologies, as my interactions with participants occurred soon after the highly contested and publicized passage of SB 277.

I intended to include the Parent Attitudes about Childhood Vaccines (PACV) survey, developed and validated by Douglas Opel and colleagues at University of Washington School of Medicine (2011a, 2011b). The original aim of the survey was to provide a tool for healthcare providers to identify "vaccine-hesitant parents," assess parental vaccine hesitancy, inform strategies to improve provider-parent communication around childhood vaccinations, and ultimately increase vaccination rates (Opel et al. 2011a). I worked with key informants to recruit survey participants through social media. However, after the first week, I was unsuccessful and discontinued collection of the PACV survey (discussed further, below).

Healthcare providers (MD and DO) were later interviewed after parents and key informants recommended that I speak to their own and other "vaccine friendly" providers for additional context and information.

The ultimate focus of this dissertation on the in-depth, ethnographic analysis of vaccine hesitant parents allowed me to give priority to parents' voices, experiences, and daily practices.

This created space for parents' vacillation and responsiveness to legal and socio-cultural changes to be revealed in a theoretically nuanced and contextualized anthropological and public health framework.

Recruitment of Study Participants

To take part in this study, participants were required to (1) be 18 years of age or older, (2) be a resident of Los Angeles County, (3) have at least one child enrolled in preschool, including public, private, and home-based schools, and (4) have delayed or refused one or more of the vaccines required for school entry in California for at least one child.

I used criterion-based selection of a purposive sample (Bernard 2006, 190, Schensul, Schensul, and LeCompte 1999, 235), targeting parents with at least one child enrolled in public, private, and home-based preschool at the time of recruitment. Parents of children enrolled in preschool would not have been eligible to submit an exemption for the kindergarten through 6th grade span by the January 1, 2016 deadline, since students could only submit an exemption for the grade span they were enrolled in at the time. Based on the new requirements of the vaccination law (CLI 2015), this method was chosen under the assumption that parents with preschool-enrolled children were, or soon would be, in the process of making vaccine- and school-related decisions prior to enrolling their child in kindergarten (Poland and Brunson 2015).

I used the snowball method to recruit vaccine hesitant parents for in-person interviews. This nonprobability, chain referral method is commonly used to reach hidden populations for which no sampling frame exists, and for whom privacy is a major concern due to involvement in socially stigmatized, controversial, or elicit behaviors (Heckathorn 1997, 174; 2002). Chain referral methods are widely used and recognized by public health and social science researchers as an effective tool for collecting data from hard-to-reach populations (Des Jarlais et al. 2009, Hathaway et al. 2010, Johnston et al. 2008, Magnani et al. 2005, Malekinejad et al. 2008, McCreesh et al. 2012).

In this study, members of my indirect social network in Los Angeles acted as "seed" participants to recruit vaccine hesitant parents into the study. Each participant was then asked to refer members of their own social networks (i.e. friends, family members) who met the inclusion criteria. Some participants recruited more than others into the study; three parents who were recruited were not vaccine hesitant and therefore did not meet inclusion criteria. The sampling frame was saturated after 14 participant interviews, meaning no new themes or relationships between themes were being discovered (Bernard 2006, 501; Schensul, Schensul, and LeCompte 1999, 261).

Survey participants were recruited purposively via social media. I worked with key informants to identify to 38 local and national Facebook groups that were actively participating in discussions about childhood vaccines and vaccine policies. One key informant posted the link to the PACV survey on the group's page or reached out to moderators 15 of those groups, and members of only seven of those groups interacted with the survey (Table 3).

Table 3. Facebook Groups (names redacted for privacy purposes).

Group Name (Survey Posted)	Theme	Region	Members /Likes (4/24/17)	Key Informant Status
[redacted]	Choice	CA	19,764	Member
[redacted]	Choice	National	4,396	Member
[redacted]	Choice	CA	967	Member
[redacted]	Mothers/Parents	National	59,774	Member
[redacted]	Mothers/Parents	National	1,856	Member
[redacted]	Choice	CA	12,734	Member
[redacted]	Choice	CA	2,717	Member

Table 3. (Continued)

[redacted]	Parental Rights/Freedom	National	812	Member
[redacted]	Choice	National	270	Member
[redacted]	Advocacy	CA	3,481	Member
[redacted]	Health	CA	271	Member
[redacted]	Mothers/Parents	National	871	Member
[redacted]	Mothers/Parents		327	Member
[redacted]	Parental Rights/Freedom		1,002	Member
[redacted]	Advocacy	National	48,248	Member
[redacted]	Advocacy	National	192,526	Member
[redacted]	Mothers/Parents	National	20,164	Member
[redacted]	Mothers/Parents	National	191	Member
[redacted]	Choice	CA	8,151	Member
(Survey Not Posted)				
[redacted]		National	48,248	Non
[redacted]		Internat'l	22,847	Non
[redacted]		National	50,440	Non
[redacted]		National	14,664	Non
[redacted]		National	8,103	Non
[redacted]		National	4,386	Non
[redacted]		National	30,154	Non
[redacted]		Nation	11,493	Non
[redacted]		National	2,107	Non
[redacted]		National	6,954	Non
[redacted]		CA	1,130	Non
[redacted]		CA	63	Non
[redacted]		CA	649	Non
[redacted]		CA	249	Non
[redacted]		CA	829	Non
[redacted]		National	4,784	Non
[redacted]		CA	1,979	Non
[redacted]		CA	2,195	Non
[redacted]		National	20,033	Non

Key Informant Interviews

Key informants are members of the target population or community who are considered "insiders" and recognized as subject matter experts (Schensul, Schensul, and LeCompte 1999, 74). They understand the information the researcher is trying to obtain and are willing to obtain that information for the researcher (Bernard 2006, 199). Key informants are critically important for ethnographic research involving hidden populations for their ability to provide context, guidance, and assistance in recruiting participants. For this study, three key informants were selected based on their (1) intimate knowledge of vaccine-related concerns and practices among parents, (2) inclusion in or familiarity with social networks of vaccine hesitant parents, and (3) knowledge and experience with the broader effects of vaccine-related policies. Key informants included two parents and one policy maker.

I consulted with two parent key informants on a regular basis over the course of my fieldwork, meeting with them at their homes or coffee shops every week during the first few months in the field. Both parents are mothers of one preschool-aged child; one identified as self-employed, and the other is a practicing midwife; their children were completely unvaccinated. I stayed in continuous contact with each of them via text messages and phone calls and continued to meet with them 1-2 times per month, depending on their availability, as my fieldwork progressed. They assisted with participant recruitment for interviews and the PACV survey, identified popular beliefs and sources of information for vaccine-hesitant parents, referred me to "vaccine friendly" healthcare providers, and provided information regarding common practices and concerns among vaccine hesitant parents. Field notes were taken during meetings and conversations; some conversations were voice-recorded, with consent, for reference.

I interviewed California State Senator Dr. Richard Pan as a key informant to gain insight into the political process and context of Senate Bill 277. Senator Pan represents California's 6th

Senate district, including parts of Sacramento and Yolo counties, and co-authored[6] SB 277. He is also a practicing pediatrician in Sacramento, CA. Senator Pan gained notoriety among the anti-vaccine community for his involvement in SB 277 and his pro-vaccine advocacy. During that process, Senator Pan received a number of death threats and racist messages and was physically assaulted by an anti-vaccine activist in 2019 (Gutierrez 2019). Senator Pan introduced Senate Bill 276 in 2019 as a follow-up bill to SB 277, tightened California's school immunization laws by allowing the state's public health department to review, and potentially reject, existing and future medical exemptions (CLI 2019). Following negotiations with California Governor Gavin Newsom and amendments, SB 276 passed the Senate and Assembly along party lines (with Democrats supporting the bill) and was signed into law in September 2019 (CLI 2019). I interviewed Senator Pan in-person in his capitol office located at the California State Capitol building in Sacramento. The interview was voice-recorded, with consent, and transcribed verbatim.

In-depth Interviews (n= 18)

Parents (n= 14). In-depth, unstructured interviews were conducted with parents. The interviews ranged from 30 to 150 minutes, with interviews lasting an average of 90 minutes. Face to face interviews were conducted in the participant's home, office, or location of their choosing; two interviews were conducted by phone. Follow-up interviews were offered as a way for participants to add provide additional information and were conducted if possible (n = 5). These follow-up interviews were transcribed and combined with the participant's first interview. All interviews took place between January 2017 and July 2017, audio recorded with consent, and transcribed verbatim. Parent interviews were conducted with those who were involved in vaccine- and school-related decisions for children in the household. (Three additional interview participants

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[6] with Senator Ben Allen, who represents California's 26th district, which includes cities located on the west side of Los Angeles County (https://sd26.senate.ca.gov/district) (https://sd06.senate.ca.gov/district)

who were referred by other participants did not delay or refuse any recommended vaccinations for their children and therefore, did not meet inclusion criteria for this study; did not know until I was already interviewing them; not included in the sample size [n] or the analysis)

Providers (n= 4). In-depth, unstructured interviews were conducted with providers (3 MD, 1 DO) that were referred to me by parents and key informants and identified as "vaccine friendly." "Vaccine friendly" is a contradictory term used among vaccine hesitant parents that refers to providers who are open to allowing a modified vaccination schedule for children, including delay or omission of some or all vaccines, and will consider broadly-defined family medical histories when providing medical exemptions for childhood vaccinations; sometimes referred to as "vaccine flexible." I reached out to 15 providers via direct email or messaging through their practices' websites and followed-up by phone to request an interview. Four providers agreed to be interviewed. Two interviews were audio-recorded and transcribed verbatim; two providers asked not to be recorded. Notes were taken during each interview.

Parental Attitudes Around Childhood Vaccines (PACV) Survey (N=36)

The Parent Attitudes about Childhood Vaccines (PACV) survey was administered online using Qualtrics. The PACV survey contains a total of 18 items divided into four content domains of (1) immunization behaviors, (2) beliefs about vaccine safety and efficacy, (3) attitudes about vaccine mandates, and (4) trust (Opel et al. 2011a). I had originally planned to use the survey to compare relevant domains identified by Opel and colleagues with themes discovered during the in-depth interviews. The survey was also intended to recruit additional participants for in-depth interviews. However, I was unable to successfully recruit sufficient number of survey participants through social media to produce a statistically representative sample, nor was I able to successfully recruit additional interview participants. I decided not include analysis of these surveys because, as themes emerged from the in-depth interviews, it became clear how limited the content domains of the PACV survey were. It became clear that the surveys offered an incomplete picture of the underlying concerns and reasons that impacted parents' vaccine-related decisions for their children. Therefore, they are excluded in the analysis presented in this dissertation.

Parent Demographics

A total of 14 self-identified vaccine hesitant parents participated in unstructured, in-depth interviews. Three additional participants were referred to the study; however, I discovered during their interviews that they were not vaccine hesitant and therefore did not meet the inclusion criteria for this study. Their data were omitted in the analysis.

The average age of participants was 37.2 years old. The sample was predominantly women (13, 93%) and married (13, 93%). The man who was interviewed was the spouse of one of the participants; their household information (income, number of children, preschool enrollment status, vaccination status of preschool-age child) was combined and recorded as one participant. The majority of parents had a four-year college degree (4, 29%) or higher (7, 50%). Most of the participants were of higher socioeconomic status, with the majority of annual household incomes in the categories of $50,000-75,000 (4, 31%) and greater than $100,000 (6, 46%). Parents identified as white (10, 72%), Latino or Hispanic (3, 21%), and Asian (1, 7%). About a third of participants had one child in their household (5, 38%), and the others had two children (9, 62%). Three (3, 23%) parents decided to homeschool their child for preschool; all others (10, 77%) enrolled or planned to enroll their children in a preschool or transitional kindergarten (TK) programs.

Of the participants' preschool-age children, six (46%) were partially vaccinated for the vaccines required for school entry, five (39%) were unvaccinated, and two (15%) were fully vaccinated. (See Table 4)

Table 4. Parent Demographics

Description	Category	n = 14 (individual) n = 13 (household*)	%
Average Age		37.2	
Gender	Woman	13	93%
	Man	1	7%
Parental Role	Mother	13	93%
	Father	1	7%
Marital Status	Married	13	93%
	Partnered/Living with Partner	1	7%
Education	Some college or 2-year degree	3	21%
	4-year college degree	4	29%
	More than 4-year college degree	7	50%
Household Income*	≤ $30,000	1	8%
	$30,001 - 50,000	1	8%
	$50,001 - 75,000	4	31%
	$75,000 -100,000	1	8%
	> $100,000	6	46%
Race	White	10	72%
	Latino or Hispanic	3	21%
	Asian	1	7%
Number of children in household*	1	5	38%
	2	8	62%
Preschool enrollment status*	Enrolled in Preschool or TK	10	77%
	Homeschooled	3	23%
Vaccination status of preschool-age child*	Unvaccinated	5	39%
	Partially vaccinated	6	46%
	Fully vaccinated	2	15%

Vaccination Strategies Post-SB277

Parents shared the vaccination decisions they made in the context of SB277. While all of the parents expressed hesitance around some or all of the routinely recommended vaccines, there were varying degrees of vaccination for their children. Six parents (46%) sought medical exemptions to avoid some or all vaccinations for their children. Among these parents, four were able to secure medical exemptions from their existing pediatricians based on family medical history or the child’s medical history; two selectively vaccinated their children based on their and their pediatrician's assessments of need, while the other two avoided all vaccines. One parent traveled hundreds of miles to visit a doctor that was known among vaccine hesitant parents to provide medical exemptions, and ultimately received one for their child. One parent was still in the process of obtaining a medical exemption but had not been able to secure one yet.

Two parents (23%) did not seek medical exemptions but decided to vaccinate on a delayed or modified schedule. Of these parents, one was in the process of completing all of the required vaccinations for school entry. The other parent was not intending to compete the remaining vaccinations so long as the child's school did not follow-up on his conditional entry (which was due to incomplete vaccination status).

Two parents (15%) told me that they submitted falsified vaccination records to their children's schools, since they were not able to secure a medical exemption in time to enroll their children in preschool. They said that their pediatricians did not believe that their family medical histories warranted a medical exemption for their children, and neither could afford to pay the out-of-pocket private practice fees of doctors who were known to provide medical exemptions to vaccine hesitant parents. In order to avoid vaccinations, one parent submitted an immunization card with "homeopathic doses" for the required vaccinations. The other parent forged the signature of their pediatrician who had died the year prior.

Two parents (8%) were not planning to vaccinate their children at all; they were homeschooling their children. One parent (8%) completed all routine vaccinations for their child based on their pediatrician's recommendations on the routine schedule.

Summary of Provider Perspectives

While there was a consensus between the four providers interviewed that vaccines have a beneficial effect on individual and community health, all providers prioritized the individual needs of the child, their parents, and families. Other salient themes that emerged from the provider interviews were 1) integrative approaches to health that incorporated perspectives, practices, and values of complementary, alternative medicine (e.g. naturopathic, holistic, and Chinese medicine), 2) consideration for the individual child's risk factors and family medical histories, and 3) allowance for families to deviate from the routine vaccination schedule. Providers also had diverse opinions, beliefs, and relationships with vaccines that were reflected their approaches to health and medical practice, and influenced the vaccine-related recommendations they made to their patients; this is an area for future research.

Thematic Analysis

All parent interviews were recorded, transcribed verbatim, and deidentified to protect participants' identities. Preliminary data analysis was performed by hand in the field in order to identify emergent themes and evaluate and ensure the data collected was relevant to the overall aims of the study. The deidentified transcripts were uploaded into MAXQDA for thematic analysis.

As an exploratory study, my broad aim was to identify themes related to the micro- and macro-level factors that influenced parents' vaccine hesitancy and their vaccine decisions for their children, in the context of SB 277. Exploratory analysis is a content-driven, inductive approach that emphasizes the information that emerges from the interactions between the researcher and the participants, in this case in-depth interviews (Guest, MacQueen, and Namey 2014). Using a grounded-theory approach, emergent themes were identified through inductive or “open” coding (Bernard 2011, Corbin and Strauss 2012, Glaser and Strauss 1967). A preliminary codebook was developed, including emergent themes and a priori themes from the domains drawn from the PACV survey and existing public health and social science literature on vaccine hesitancy. It became clear during the open coding process that the codes derived from the PACV survey were constraining; I consolidated the segments coded with PACV domains with emergent themes. I continued to analyze the data iteratively to redefine the code structure, organizing relevant themes into overarching codes and sub-codes. Using a finalized codebook, the interview data was analyzed using a political economic theoretical framework. Coded segments were retrieved using MAXQDA to illustrate themes for each chapter. Pseudonyms are used throughout the dissertation.

Limitations

Due to the controversial nature of vaccines and vaccine hesitancy, there were several limitations related to sampling and internet-mediated research. In the following sections, I summarize these limitations and situate them in the current literature.

Sampling

Vaccine controversies of the 1980s and 90s, first with thimerosal and then the Wakefield study, made vaccines a hot topic in the US once again. After the measles outbreak at Disneyland in 2014-15, popular media depicted vaccine hesitant parents as “dangerous” and “stupid,” and blamed them for the outbreak and the resurgence of measles in the US (Abrams 2015, Esquivel and Poindexter 2014, Hiltzik 2014, Merlan 2015). Meanwhile, the number of groups supporting vaccine hesitant parents and anti-vaccine activists continued to grow on social media, with “underground” anti-vaccine sources warning parents not to talk to scientists and researchers for fear that information shared with them would be used against them. A few weeks into my fieldwork, a participant recommended that I watch a newly-released series on YouTube called *The Truth About Vaccines,* a seven-part anti-vaccine docuseries. A few minutes into the first episode, an osteopathic doctor and anti-vaccine activist, Dr. Sherri Tenpenny, alerts viewers that the medical community has branded "vaccine hesitancy" as problematic and warns viewers that medical researchers and scientists were "combing information off of Facebook" to research anti-vaccine arguments and develop ways to convince parents to vaccinate. The first episode of the series was free; the other six parts were only available through the purchase of a digital download, for $149.

The controversy and stigma around vaccine hesitancy and the negative media coverage of vaccine hesitant parents in California, particularly in the wake of SB 277, made it difficult to recruit parents into my study. I used snowball sampling in an attempt to utilize in-person and online social networks to reach this savvy population of educated and engaged parents. This method does not employ probabilistic techniques to generate random samples. Therefore, the findings of this study are not generalizable to the broader populations. Criterion-based selection and snowballing are common for in-depth, qualitative research on special populations since purposive sampling is often required to obtain information that is specific to a particular community (Bernard 2006, 190).

Internet-mediated Research

In recent decades, the Internet has become an important tool and space for social science research. In addition to granting wider access to traditionally hard-to-reach populations and novel online communities, the Internet can also offer a bounty of information and data created through online communications and relationships. The virtual environment has proven suitable for both primary and secondary research, the former involving the collection of new, original data for analysis to answer particular research questions, while the latter is associated with the analysis of texts and bibliographic data available online (Hewson and Laurent 2008). With new opportunities, however, come new challenges and ethical considerations. The “field site” of the Internet is still relatively new territory and therefore the methods and tools associated with online research are still being explored.

As Internet-mediated research (IMR) began to expand in the mid-1990’s, one key issue was the representativeness of samples drawn from the Internet derived from biases in the Internet-using population (Hewson et al. 2016). In 1997, the early days of the Internet, there were approximately 16 million unique internet-accessible hosts worldwide (Hewson and Laurent 2008). A decade later, there were an estimated 433 million Internet-users in 2007, and by 2014, an estimated 3 billion users (Hewson and Laurent 2008, UNITU 2014). The population of Internet-users has changed dramatically over the last twenty years due in part to increasing access to the Internet and availability of facilitating technologies, such as computers and smartphones (Hewson et al. 2016). However, 60% percent of the world’s population still does not have regular access to the Internet, many of whom are located in underdeveloped countries/the Global South (Hewson and Laurent 2008).

While Internet-mediated research can be an effective way to target special populations, including those that are considered “hidden,” there are limitations in both recruitment and retention of participants. Hidden populations are typically characterized by two main features, 1) there is no sampling frame, and therefore the boundaries and the size of the greater population are unknown, and 2) members have strong privacy concerns since they are involved in stigmatized or illegal activities or behaviors (Heckathorn 1997, 174).

When examining hidden populations, online recruitment and sampling methods have become effective alternatives to traditional offline methods, i.e. word-of-mouth, flyers, etc., that often do not produce reliable samples since hidden populations are inherently difficult to access

(Heckathorn 1997). Individuals who are members of hidden populations have a lower response rate compared to the general population, as seen in this study for the PACV surveys, and are therefore more likely to be excluded from research using probability sampling frames (Barret et al. 2015). Therefore, it is recommended that limited probability samples of hidden populations be interpreted in conjunction with ethnographic methods and purposive samples that rely on the researcher's situated knowledge of the field and their relationships with members of the targeted group (Barrett et al. 2015).

Ethical Considerations for Internet-medicated Research

The new virtual "field site" of the Internet presents a host of new ethical challenges (Battles 2010, Driscoll and Gregg 2010, Flick 2016, Kitchen 2003, Sigiura et al. 2016). Traditional codes of ethics designed around human subjects research, such as those of the Society for Applied Anthropology (SfAA) and the American Anthropological Association (AAA), still apply to this new online paradigm. However, with the Internet's expanding global reach and rapidly changing nature, the use of traditional ethical guidelines for online research is contentious (Flick 2016, Sugiura et al. 2016). Social scientists, including anthropologists, are grappling with how to deal with new iterations of ethical dilemmas and how to operationalize traditional ethical guidelines when conducting research of and produced in online environments.

Many institutional codes of ethics were born as a direct response to major ethical failures of "scientific" studies that resulted in egregious human rights violations, particularly of socially, culturally, and politically vulnerable individuals and populations (Whiteford and Trotter 2008). They function, in general, to protect study participants from direct and indirect physical and social harm on the most basic level, and to encourage a transparent research process. Adhering as closely as possible to these guidelines allows both parties to make principled decisions throughout the research process, and to avoid unethical processes historically related to covert or clandestine research, including the intentional deception or manipulation of participants (AAA 2012). However, some researchers argue that ethical guidelines are defined rather narrowly and in methodological terms, functioning primarily to protect institutions and serving to justify the avoidance of human rights violations and the political oppression of the participants of their research (Bourgois 1990).

The idea that "ethical guidelines reflect and reify the cultures that produce them" is applicable to the culture of the Internet (Whiteford and Trotter 2008, 21). When "online networks," now known as the Internet, were introduced for broader public use in the early 1990s, researchers involved in "electronic" forms of research were confronted with issues derived from traditional ethical principles, such as privacy, representation, and protecting participants from harm. Researchers were confronted with new concerns specifically related to the Internet-mediated research, such as the dehumanization or "facelessness" of participants due to human-computer interaction, compared to face-to-face interaction; the "multiple and simultaneous nature of online interactions" and new forms of informed consent; and, the "virtual" and the "actual" social identities of potential participants (NCCIC 1999, Hewson et al. 1996, Frankel and Siang 1999, King 1996, Schrum 1995, Waskul and Douglass 1996). While the Internet was too new for there to be any certainty about Internet-mediated research (IMR) processes at the time, there was a clear recognition among early "tele-researchers" that methodologies and ethical considerations must adapted to new technologies and the expansion of the Internet and IMR (Hewson et al. 1996, Schrum 1995, Waskul and Douglass 1996).

In efforts to provide Internet-specific recommendations for researchers, institutions and organizations across disciplines developed, and are continuing to develop, specific guidelines on how to apply traditional ethical principles in an online setting. The Association of Internet Researchers (AoIR) published their first Ethical Decision-Making Document in 2002, which was a result of international and cross-disciplinary collaboration and extensive dialogue and debate among researchers and philosophers of the AoIR community (Markham and Buchanan 2012). A decade later, AoIR published a second document that responded to the advances in technologies and the continued global diffusion of the Internet (2012). The major IMR-related tensions addressed by AoIR include public vs. private domains, data (text) vs. persons, and top-down vs. bottom-up approaches (Markham and Buchanan 2012).

In addition to general guidelines, some scientific discipline have developed IMR-related ethical principles specific to their field and research processes. For example, the ethical guidelines for IMR of the British Psychological Society (BPS) are meant to supplement the Society's *Code of Human Research Ethics*, addressing the four main areas of 1) respect for the autonomy and dignity of persons, 2) scientific value, 3) social responsibility, and 4) maximizing benefits and minimizing harm (2013). In addition to general guidelines, BPS provides recommendations specific to research design in psychology including the level of researcher control, of the experimental environment, stimulus presentation, and monitoring participants' behaviors and reactions; use and anonymization of secondary data, such as online posts and discussion threads; scientific value; and, avoiding potential harm to participants (BPS 2013).

As with many ethical guidelines, the rules and principles are not static; rather, they reflect the complex, dynamic, and heterogeneous nature of the Internet itself and are meant provide a supportive framework for the researchers responsible for making ethical decisions (Markham and Buchanan 2012). As of this 2019, neither the American Anthropological Association nor the Society for Applied Anthropology has published ethical guidelines specific to IMR. However, many anthropologists have documented and discussed ethical issues they have confronted in their Internet-mediated research and the ways in which they have applied the traditional code of ethics in their IMR process. Here, I discuss issues related to (1) privacy, (2) representation, and (3) informed consent, as they relate to this study.

Privacy

An ongoing debate in IMR involves the blurring between public and private domains. While there is a general consensus among researchers that data gathered from traditionally defined broadcasts, such as television and radio, are situated within a public domain and therefore do not require the researcher to obtain informed consent to analyze the content (Herring 1997, Kitchin 2003, Walther 2002), there is no such consensus when it comes to the Internet. There are some researchers who believe that any communication that takes place online is generally considered public and available for research purposes (Basset and O'Riordan 2002, Sugiura et al. 2016).

The AoIR, in their 2002 ethical guidelines, urged researchers to consider, "the greater the acknowledged publicity of the venue, the less obligation there may be to protect individual privacy, confidentiality, right to informed consent, etc." (Ess and Committee 2002, 5). On the other hand, researchers acknowledge that there are expectations of privacy by Internet users, warning that accessible does not necessarily mean public (Henderson et al. 2013, Nissenbaum 2011, Sugiura et al. 2016). As Waskul observed early on, "what is 'public' and private' [on the Internet] is not always clear, in conception, experience, label or substance" (1996, 131). Internet users are able to "publicly" interact with others on the internet, via social media, blogs, discussion forums, etc., from the "privacy" of their home, workplace, car, etc.; this can promote a [sometimes false] sense of privacy (King 1996, Sugiura et al. 2016, Waskul 1996). Furthermore, participants of an online discussion, even in a public group, may not be "seeking public visibility" (Eysenbach and Till 2001). Since a publicly accessible website may be perceived as a private or semiprivate space, the expectation of privacy, and subsequent confidentiality, safety, and freedom is often illusionary since Internet users do not necessarily have control over who accesses and views the website (Frankel and Siang 1999, Munt et al. 2002, in Kitchen 2003).

The illusionary perceptions of privacy put researchers who are entering the virtual "field site" at risk being perceived as intrusive, especially by members of online groups addressing difficult social or medical circumstances (Battles 2010). Even in the highly public and participatory culture of the Internet, "people are not tolerant of intrusion into online lives" (Andrews et al. 2010, 187). One way a researcher can avoid this initial and irreparable loss of trust can be to choose a "field site" which one is already a member of (Battles 2010). For example, Battles (2010) conducted internet-based research about the attitudes and authority of older children and adolescents around vaccination decisions, specifically regarding the human papilloma virus (HPV) vaccine. Battles chose a website run by a non-profit organization geared toward adolescent and young adult women as her "field site," one which she was already actively engaged with (2010). She herself identified as a "long-time member of [their] message board" and was able to draw from her experience and knowledge with the environment to inform her research design and use of the data.

The rise in user-generated content through social media and social networking sites, such as Facebook, YouTube, and Twitter, marks the second stage of the Internet, Web 2.0 (O'Rielly 2005, Beer and Burrows 2007). Through these platforms, Internet users make up the participatory culture of Web 2.0, in which they are both "*creating* web content as well as *consuming* it" (Beer and Burrow 2007, 2, original emphasis). The environment of social media and social network sites (SNS), where many users voluntarily and publicly post private information about themselves, including their name, age, gender, geographic location, hobbies, etc., are ripe for ethical issues around privacy and IMR (Wilkinson and Thelwall 2011). Even though many SNSs have privacy settings that enable users to limit public access to private information, a significant number of members of SNSs have profiles that are completely public, either by choice or by accepting the default privacy setting (Wilkinson and Thelwall 2011). On the other hand, many SNS members employ a number of strategies to selectively protect their privacy in these public spaces, for example, by applying obscure tags to photos and videos to render their otherwise public posts private (Fileborn 2016). This kind of "publicly private" participation further challenges the dichotomous distinction between public and private as it relates to the Web 2.0, highlighting the notion that accessibility of information or content does not necessarily mean it was intended or perceived as public by its creator (Henderson et al. 2013, Lange 2008).

Representation

Another significant challenge researchers face in the virtual environment is representation. Considering the ease of anonymity associated with the Internet, the ability to verify information collected online is a concern particularly in research involving a stigmatized populations, controversial topics, and instances in which a involvement in a study poses a high risk to potential participants (Wittel 2000). In these situations, researcher must rely on the trustworthiness of the [online] participant, to a certain extent, as well as their own judgment (Wittel 2000). This uncertainty becomes especially problematic in a space, such as the Internet, that has become infamous for its infinite possibilities. As Wittel states, "to play with one's identity, to change one's real gender [age, race/ethnicity, ability, sexuality, etc.] for a virtual one and… becoming someone else… co-constitutes the attraction of the Internet" (Wittel 2000). While virtual spaces are often promoted and perceived as egalitarian, allowing for fundamentally new constructions of identity, online identities are just as negotiated, contested, and reproduced, as those in the so-called real world (Wilson and Peterson 2000).

When examining online communities, social science researchers have explored the ways in which virtual environments have provided additional public spaces for social interactions that could potentially replace existing settings, such as coffee shops, cafés, and community centers (Wilson and Peterson 2002). While there are distinctions between social interactions that occur in the online versus offline environments, the online/offline dichotomy is counter to how scholars have and continue to analyze concepts of online identities and communities (Wilson and Peterson 2002). The identities, social roles, and cultural ideologies that exist in the "real world" often play out, and are sometimes exaggerated, in online communities; further, online identities and communities are often influenced by and subject to power relations that exist in the offline world (Wilson and Peterson 2002).

Many anthropologists conduct research involving vulnerable populations. In a virtual environment, it becomes more difficult to determine whether an individual is part of a "vulnerable population," defined concisely as those having "diminished capacity to protect themselves" (Whiteford and Trotter 2008, 87). Representation of the researcher, i.e. how the researcher chooses to present his or her research goals and identity online, is also important to consider. According to the SfAA Code of Ethics, "to the peoples we study, we owe disclosure of our research goals, methods, and sponsorship" (2016). This principle mirrors the second of the AAA Statement of Ethics which implores anthropologists to "be open and honest about [one's] work," reiterating that "anthropologists should be clear and open regarding the purpose, methods, outcomes, and sponsors of their work," in order to fully satisfy the ethical requirements for openness, honesty, transparency and fully informed consent (2012, 5). Thorne argues, though, that ethnographers often rely on "partial truths" to gain access to the field (1980, in Bell 2014). Participant observation does not lend itself to constant announcements of one's status as a researcher, particularly when the integration of the anthropologist into the field often results in participants "forgetting" about the researcher's identity and goals (1980, in Bell 2014).

Issues of transparency, as it relates to representation, become particularly precarious when it comes to IMR. The negotiation and management of the researcher's own identity, online and offline, is an important precursor to navigating ethical dilemmas in the field. For this study, since I was not previously a member of any vaccine- or parent-related Facebook groups, I did not want to intrude on members perceived privacy [or misrepresent myself as part of the community] by requesting membership solely for the purposes of this study. Instead, I consulted with key informants to identify relevant Facebook groups that they themselves were already members of, and those that they regularly accessed for parenting or vaccine-related information.

Informed Consent

The American Anthropological Association states, "researchers working with living human communities must obtain the voluntary and informed consent of research participants" (2012, 7). Obtaining informed consent is considered an ongoing negotiation between the researcher and participants throughout the research process (AAA 2012). This process is a core ethical principle of scientific research, institutionalized internationally with the Nuremburg Code in 1947, after the unethical experimentation and torture of the infamous Mengela Experiments that took place in the Nazi concentration camps during World War II (Whiteford and Trotter 2008). Theoretically, ethical standards are easily applied to extreme examples, such as those that spurred the development of various institutional codes of ethics, however, their application in virtual environments and IMR are less concrete.

In this study, for the representation and privacy issues above and since my research did not involve content analysis, I did not "lurk" in any Facebook groups. Instead, I used contextual and topical information relayed to me by key informants to make decisions on where to post the survey, and had key informants post the survey link only to sites that they themselves were active members of.

As social media and SNSs amass personal information and text-based communications from their users, academics and market researchers are presented with publicly accessible data at unprecedented levels (Wilkinson and Thelwall 2011). Gathering and analyzing this secondary data does not necessarily require direct interaction with potential participants and therefore may institutionally qualify the research as free from human subjects, however, the research still has ethical responsibilities and the potential to cause harm. Researchers have argued that text that is posted or published on public websites, including social media, SNS, blogs, and personal websites, are considered electronic documents and therefore do not require informed consent to collect and analyze (Ess and Committee 2002, Eynon et al. 2009, Eysenbach and Till 2001). Others who are involved in analyzing data produced by vulnerable populations take additional precautions to anonymized the information and respect the content creators' expectations of privacy, while still upholding the precedent that collecting text does not require informed consent (McDermott et al. 2013). Wilkinson and Thelwall argue that seeking informed consent for text analysis "can be problematic because contacting content creators goes some way toward involving them in the research, hence triggering human subjects concerns" [which classically include informed consent, privacy, confidentiality, and anonymity] (2011, 395). I would argue that those "human subjects concerns" are triggered regardless of whether or not the population of interest is directly or indirectly involved in the research. It is always the obligation of the researcher to take measures to protect direct or indirect participants from potential harms.

Case Study: Facebook's Emotional Contagion Study

A recent study of "emotional contagion" in online social networks, conducted collaboratively by Facebook and Cornell University's Departments of Communication and Information Science (Kramer et al. 2014), triggered a massive debate around informed consent and the ethical standards of practice between corporate and academic research in the context of IMR (Boyd 2016, Flick 2016, Selinger and Harzog 2016, Shaw 2016). To summarize, researchers at Facebook manipulated the "newsfeeds" of approximately 689,000 randomly selected users for one week, and found that when positive expressions were reduced, users created fewer positive posts and more negative posts; reducing negative expressions had the opposite effect (Kramer et al. 2014). The researchers concluded that the results indicated "emotional contagion" on a massive scale outside of in-person interactions, i.e. via online social networks (Kramer et al. 2014).

In conducting this experiment, the Facebook researchers did not seek explicit informed consent nor provide the opportunity for users to opt out of the study (Flick 2016, Verma 2014). Within the industry and academia, the public debate about the ethics of the Facebook study focused on informed consent, the lack of corporate institutional review boards, ethical accountability, potential harm to participants, co-optation of user data for corporate purposes, and control of personal information, while acknowledging that as a private company, Facebook was at the time "under no obligation to conform to the provisions of the Common Rule" [as described by the US Department of Health and Human Services Policy for the Protection of Human Research Subjects] (Boyd 2016, Flick 2016, Kramer et al. 2014, Selinger and Harzog 2016, Verma 2014).

The debate continues over what the key focus of this ethical dilemma should be. Boyd argues that part of the public outrage around this experiment stems from the disconnect between "what people assume Facebook does and what it actually does" (1016, 10). That is, Web 2.0

emerged with a new (and not necessarily accurate) rhetoric of "democratization" and the idea of the "people's internet" wherein experts and amateurs alike can create and consume content in new collaborative and participatory ways (Beer and Burrows 2007).

In cases such as the Facebook study, Flick recommends an alternative approach to informed consent in a waiver of normative expectations (2016). It is common practice for online vendors and service providers to supply "terms of service" agreements that are overly lengthy and incomprehensible, with user-pertinent information buried so deeply amongst useless, irrelevant information that it is unrealistic to expect a lay person to read through it thoroughly (Boyd 2016, Flick 2016). Rather than accepting this impractical status quo, Flick suggests a waiver-based approach that shifts the focus from the consenting party to the consent-obtaining party, explicitly placing responsibility of setting threshold requirements for assessing users' autonomy and accurately communicating the potential for norm violations on the latter (2016). Conceptualizing the consent process as an ongoing transaction in which both parties are held accountable then requires the language used in a waiver disclosure to be easy to follow and relevant to the user, as opposed to a "flood of irrelevant or distracting – even if intelligible – information" that the consenter is unevenly responsible for reading and understanding (Manson and O'Neill 2007, 85, in Flick 2016, 19).

This case study is relevant to my research methods for a few reasons. First, one way parents in California, and nationally, have organized against (and in support of) the new vaccination law is through social media, specifically Facebook. In addition to national vaccine "choice" advocacy groups engaging in California's fight, there are smaller groups that specifically formed and organized against SB 277 and vaccination issues affecting Californians. Second, the ethically questionable, but legal, Facebook study and the ensuing controversy contribute to the public's growing distrust and discomfort of "big data" and researchers, in general. While I am not employed or associated with Facebook, aside from having a personal profile, I encountered apprehension and hesitancy by members of online groups to take part in research regarding a topic that is both deeply personal and highly controversial, evident in the low participation rate of the PACV survey.

Implications for the Study of Vaccine Hesitancy

As vaccine hesitant parents continue to organize in online/internet-mediated environments, these environments will become important "field sites" for medical anthropologists and anthropologists of media, science and technology, and other subfields. Issues of privacy, representation, and informed consent will continue to be of critical importance, particularly in the pandemic context when anthropologists, sociologists, and other qualitative scientists take to the internet and engage with online field sites and communities.

One additional ethical consideration that was relevant throughout my research process, from proposal development, to recruitment, to data collection, to analysis, and writing-up, was the divergence of my own beliefs and practices around vaccines with those of the majority of the participants in my study. Since my recruitment method was purposive and respondent-driven, participants were self-selected as individuals who were willing and able to participate and engage in research related to vaccine hesitancy; in other words, vaccine hesitant parents who were deeply skeptical and untrusting of researchers, or those who did not care to share their stories and processes with me simply did not communicate with me or participate in my study.

Through the entire data collection process, I was only asked by three participants what my personal beliefs/practices were around vaccines. I answered honestly and contextualized my responses in my background and experience in microbiology, infectious disease, public health, and global health. There were never any instances where I perceived changes in participants' demeanor due to our differing beliefs. Again, due to my method of recruitment, participants willing to share their opinions, beliefs, and stories with me. One possible way of addressing this limitation (i.e. of the exclusion of extremely vaccine hesitant parents) is to partner with healthcare providers and/or community-based partners that are interested in understanding and addressing decreasing vaccination rates within their practice or community that can identify and engage vaccine hesitant parents that may otherwise remain hidden to researchers.

Summary

In this chapter, I provided an overview of the research methods employed in this study and considered the limitations and ethical issues within the context of vaccine hesitancy and internet-mediated research. Demographic information and strategic decisions of parents, post-SB 277 were summarized; broad themes from provider interviews were also presented. In the following chapters, I present the analysis of several themes that emerged from the in-depth interviews with vaccine hesitant parents.

CHAPTER 5: INDIVIDUAL RISK ASSESSMENT AND MANAGEMENT

Introduction

As with most pharmaceutical products, vaccines carry some risks and can result in negative health consequences. While there is overwhelming scientific evidence discrediting the rumored link between autism and the measles-mumps-rubella vaccine (MMR), the highly publicized controversy brought risks around all childhood vaccines, evidence-based and rumored, to the forefront of parents' minds in the US.

In this chapter, I apply theories of risk to illustrate the ways the parents in this study individualized their processes of risk assessment and management related to vaccines. First, I show how parents conceptualized vaccines as an individual intervention, disregarding herd immunity and collective community health. Second, I describe parents' risk assessment processes and the way parents individualize and internalize their children's risks as vulnerabilities. Finally, I show how parents prioritized individual actions in their overall approaches to health, including vaccines, through responsible, precautionary consumption practices.

"Herd immunity is a myth"

Vaccines function in two ways, by 1) protecting individuals directly through acquired immunity, and 2) contributing to the protection of the entire population through herd immunity (Diekema 2014, NIH 2010). However, for nearly all parents in this study (13; 93%), when they talked about their thought process and decisions around vaccines, vaccines were conceptualized an individual intervention. Seven parents (50%) specifically brought up herd immunity and the social contributions vaccines make to community health, but it wasn't prioritized enough to convince them to vaccinate fully or on-time. Sofia, a 42-year-old writer/producer, talked about the potential risks that vaccines posed to children, so to protect her individual children, she opted to delay their vaccinations.

> *It's your child's body. I believe in community efforts to do what's best for the community. I don't think it's fair to force [the routine vaccination] schedule on people. It's going to be fine for most people, but there's gonna be a whole bunch it's not ok with for, and there's really not a great way to protect those kids. – Sofia*

This quote illustrates how Sofia has an understanding and expressed appreciation of vaccines' dual function. However, her support of "community efforts" stopped short of following the routine vaccination schedule for her own children. Tori, a 42-year-old stay-at-home mom with a background in biology, also acknowledged the positive contributions that vaccines make to society as a whole while, at the same time, she talked about how she was concerned about the safety of vaccines and their potential to cause harm. Her concerns were amplified by her general distrust in the pharmaceutical industry and vaccine research. As she explained:

> *[...] Obviously, I do think that vaccines do something for our society and there's the greater good in some ways of... Ok. Well, some people are unfortunately gonna have reactions to them, yes. But, why not make them better and do our best to study that instead of trying to cover all of that up and say, "Oh, no no no, they're perfectly fine for everybody." And that's just a ridiculous statement, you know. – Tori*

Tori believed that, in the absence of more rigorous institutional efforts to protect *all* children from the potential harms, the only way she could protect her children was to refuse vaccines altogether. This reflects the neoliberal idea that the responsibility of managing one's health, among other aspects of everyday life, falls onto the "actively responsible individual" at the expense of social cohesion and the welfare state (Rose 1996, 57-58, Scott 2007). This tension between the individual and community functions of vaccines mirrors the tension between biomedical and the public health frameworks in health, with the former focusing on individual health and the latter on the community and socio-structural aspects of population health.

Some parents challenged or rejected the functionality of herd immunity in individualistic societies like the US when they were explaining their decision to delay or refuse vaccines. Zoe, a 34-year-old lactation consultant who worked at a large public hospital, told me about a time in graduate school when she was told she need an MMR booster. She, too, acknowledged the social responsibility that people should have toward one another in society, but rejected it based on her perception of greater society's priority on individual self-interest. In her words:

> *It's not my body's job to protect [somebody else]… it's just not. I'm not you know, I'm not going to sacrifice, potentially sacrifice my children. My first job is to protect them, not anybody else's kids, not anybody else's sick grandma. Like, if you are so sick that you're that immunocompromised, you probably shouldn't be at school anyways. I'm sorry! That onus is not on me. And it's not to say that we don't hold responsibility for one another, but nobody holds responsibility for me. In some ways, this is our society. Like, you're kind of on your own in a certain sense, so my first priority, my first responsibility is to them [kids] with hopes that they're just so brilliant one day that they can fix everything and make things better. – Zoe*

Zoe was very passionate about her views about vaccines and her belief that they could potentially cause harm to her children. Her rejection of vaccines seemed to contradict other aspects of her life, which were more oriented toward community support and social advocacy. She talked about her own privilege and trying to work to give voice to those who are less privileged, which included her work as a lactation consultant and empowering women in the "98% Medi-Cal[7] reimbursed hospital" where she worked. She also spoke about taking advantage of the plethora of free community-based programs for children all over Los Angeles, at different museums and "forest school" in the area, many of which she participated in with her homeschooled children.

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[7] The California Medical Assistance Program (Medi-Cal), the state's Medicaid program

Rachel, a 40-year-old midwife, also expressed skepticism about the concept of herd immunity itself, which served to support her decision to forgo vaccines for their children. She explained:

> *That's the other thing that weird about vaccines is that everyone thinks that it's just kids that don't have the herd immunity but no grown up gets all their boosters. They just don't. So, I think that herd immunity is a myth. I do. I'm one of those people. – Rachel*

By disregarding and discrediting the concept of herd immunity, parents like Sofia, Tori, Zoe, and Rachel spoke directly in response to popular media and traditional public health messaging that promotes the broader population effects of vaccines and "doing your part" to support community health. However, this social focus does not resonate in highly individualistic, neoliberal environments. In neoliberal environments, vaccination campaigns emphasizing their social benefits are ineffective since individuals tend prioritize their own health over the health of community at large (Hobson-West 2003). In turn, neoliberal and libertarian ideals of individual autonomy and responsibility promote contemporary health discourse of choice and empowerment (2003). As illustrated by the parents in this study, vaccines' social contributions to herd immunity and community health, while acknowledged by some and refuted by others, were ultimately not a priority.

Assessing Individual Risks and Vulnerabilities

All 14 participants described some sort of risk assessment and management process related to infectious diseases and the vaccines themselves when making vaccination decisions for their children. Parents assessed risks based on internal and external risk, including vulnerabilities and behaviors associated with vaccine-preventable diseases, and conducted their own risk-benefit analysis around vaccines and vaccine-preventable diseases.

"I'm really sensitive to medication"

Eleven (79%) parents talked about their children's risks of potential adverse reactions to vaccines as something they could have passed down to their children. They internalized their own and their children's risks as vulnerabilities. Sofia suffered from ulcerative colitis that had gone misdiagnosed by conventional biomedical doctors for many years. After "doing her own research" and consulting alternative medicine practitioners, she was finally able to control her symptoms through acupuncture and a strict diet. When it came time to make decisions around her children's vaccines, she told me she was worried that they could be genetically predisposed to having adverse reactions to vaccines due to her autoimmune disorder, which she believed could have been caused by her own childhood vaccinations.

> *I was really concerned with my kids coming in with the same thing, and we don't really know what causes or triggers autoimmune inflammation. So I was very concerned about that. – Sofia*

Sofia was worried that she could pass down her autoimmune disorder and it could potentially impact the way her children responded to vaccines. Rachel also brought up about her own sensitivities and her spouse's family medical history when she talked about her concerns about her daughter's potential risk of adverse reaction to vaccines, which she believed included autism and other neurological disorders.

> *I started to have sensitivity to vaccines myself. I'm really sensitive to medication, I get hives with antibiotics, and I just tend to be more sensitive than most, the average person around me, to things like including the sun or, um, alcohol, caffeine. I have an intolerance to both of those[...] I didn't really research it, it's just [a] general feeling that I had. But then the person I'm married to, his dad has Parkinson's so now you have a neurological problem with a first degree relative. – Rachel*

Sofia and Rachel believed that their own vulnerabilities could be passed down and put their children at higher risk for adverse reactions to vaccines. Their children's risks were rooted internally, inherited from their parents, rather than introduced by external factors. Their decision to forgo their children's vaccines were expressions of individual agency in both reducing their sense of vulnerability and enhancing their perception of self-control (Nichter 2003). It was their responsibility, as parents, to assess their children's individual vulnerabilities, which originated from their own, and take action to reduce their risks.

"Why would you give a newborn a Hepatitis shot?"

> *I really kind of think that is kind of crazy that you're gonna give a newborn a Hepatitis shot. Why would you give a newborn a Hepatitis shot? I don't understand that. What's the thought process behind that. I mean, I'd really like to have been more informed why a kid, a newborn, a Hepatitis shot. He's not gonna be in a whorehouse anytime soon. I don't understand… or hopefully never for that matter (laughs). – Jen*

Jen, a chef at a local restaurant, delayed her son's Hepatitis B vaccine, which was recommended to her soon after her son was born, because she didn't think it was necessary or appropriate for a child so young. This was a common sentiment among parents in this study. More than half (9; 64%) of parents talked about refusing or delaying the Hepatitis B (HepB) vaccine, specifically. They were aware of the most common behavioral risk factors for HepB infection, such as injection-drug use and unsafe sex practices and, therefore, concluded that their newborns fell outside of the "risk groups" associated with those behaviors. Parents were especially concerned about how young their children were when they were expected to vaccinate for Hepatitis B. Jessa, a 34-year old stay-at-home mother who used to work in visual effects at a large production studio, talked about being worried about vaccinating her son so young. Lena, a 40-year-old preschool owner, also expressed concerns vaccinating her son for HepB so soon after birth, especially since she didn't believe her newborn son was in immediate danger of being exposed to HepB. In their words:

> *[…] Do we really need Hepatitis B, particularly in kids who are not engaging in drug-use or sexual activity? I just didn't feel comfortable, day one of birth, before we know their medical history, dosing them with a vaccine. That didn't make sense to me. – Jessa*

> *Especially, I don't understand HepB on the first day of life. That's always been like… Like of any of them, it's like what is the most, um, that a baby is most at risk of getting, and then I might be able to say within the first couple of weeks, Ok, I can get that if that… if meningitis were to be like a huge [threat]. Yeah. Then hey. But like, HepB? Like, Hey, welcome to this world! HepB. You know, it just feels weird. – Lena*

Based on their individual risk assessment, Jessa and Lena concluded that the potential risks posed by the HepB vaccine were higher than the risk of HepB itself.

This was also the case for Hannah, a 37-year-old marriage and family therapist, who had a four-year old son who was partially vaccinated and a six-month old daughter who was not vaccinated at all. Her daughter was born about one month early through emergency cesarean section; her and her husband had initially planned a homebirth for her, like they had done with their son. Hannah specifically mentioned the HepB vaccine as one that she strongly wanted to avoid since she believed her daughter was already very vulnerable due to being born prematurely. She believed the risks posed by the vaccine were greater than her risk of exposure to HepB.

> *[Our daughter], she's had nothing. Especially after her preemie crazy emergency birth, I was like, I'm not doing anything with her […] They want to do Hep B before you leave the hospital. I was like, No way. We're leaving with a five-pound baby. Which, she's not getting a sexually transmitted disease. It was a sketchy downtown hospital but whatever. Um, and I was like, No, we're not doing that. – Hannah*

Jen, Jessa, Lena, and Hannah all perceived their children's internal characteristics, in this case newborn age and premature status, as something that contributed to their vulnerability and increased risk of vaccine-related injury, especially since the external risks associated with HepB were not perceived as relevant at the time. This is despite the routine recommendation for the

HepB vaccine within 24 hours of birth (CDC 2019). The idea that the HepB vaccine is only necessary for those who are involved in "high-risk" injection drug-use and sexual behaviors reinforces socially constructed boundaries between those who are deemed "at risk" versus those who are not. It also reinforces the idea that individuals can fall outside of those boundaries and, therefore, would not vulnerable to HepB infection (Owczarzak 2009, Schiller et al. 1994). Individuals or behaviors labeled as "at risk" or "risky" promotes problematic stereotypes and suggests blame and stigma, implicating members of "risk groups" as a threat to the well-being of the rest of the population (Farmer 1994, Owczarzak 2009, Schiller et al. 1994).

Risk-benefit analysis

All but one parent (13; 93%) talked about their process of risk-benefit analysis for vaccine-preventable diseases. Based on their analysis, the risks posed by the vaccines was far greater than their children's risk of exposure or the risks posed by the diseases themselves. Both Jessa and Tori believed their children's risk of contracting a vaccine-preventable disease such as measles was negligible compared to the potential side effects of the vaccines themselves. In their words:

> *Basically, the risk to benefit ratio didn't seem like a risk I wanted to take for the benefits […] The risk of side effects to the vaccines to the benefit of not getting the disease. I personally feel like getting the side effects [of vaccines] was higher than getting… the risk of getting the disease. Particularly if you boost your own immune system. – Jessa*

> *But, I don't know, you have to kind of weigh, would I rather… what are the actual risks? Like, what are they? The actual risk that your kid could die from measles, compared to what are the actual risks that your kid could get some sort of neurological damage from [vaccines] because they had too many heavy metals in the system, whatever it was? – Tori*

These quotes illustrate the perception that their children are not at high risk of contracting diseases such as measles, compared to the risk of adverse reaction or negative health outcomes due to the vaccine itself, which is perceived as high. Allison and James also made additional assessments about the severity of particular infections, as well as their access to medical attention should they need it. As they explained:

> *[Measles] was a thing just like we view the chickenpox. You know, and everybody's like, Ooooooh! It's not… you're not, most likely, not gonna die from it. And what they're doing to these kids is pumping full of all this stuff when they're immune systems are really strong. – Allison*

> *If […] I don't vaccinate my children and they get the measles, I think that there's adequate healthcare to deal with the situation and it's gonna be fine […] – James*

Parents in this study performed mental gymnastics to build their case against vaccinating their children and, in many cases, the arguments that their children were at relatively low risk of death or severe injury from complications from various vaccine-preventable diseases held up, especially compared to resource-poor regions in the so-called Global South where vaccine-preventable diseases (VPD) still contribute to hundreds of thousands of deaths every year. Their argument, however, held up due to the fact that they were located in the Global North, where healthcare, hygienic living conditions, and vaccines are relatively easily accessible. The majority of parents in the US continue to routinely vaccinate their children, thus contributing to herd immunity and reducing the risk of infection for the community at large (Mellerson et al. 2018). This protection, however, is waning as evidenced by the incidence of measles in the US in 2019, the highest since 1992. The parents' risk calculus omitted the potential effects their children could have on community health should they contract a VPD. For example, individuals who contract measles, a highly infectious virus, are contagious about five days prior to the onset of the tell-tale rash and continue to be contagious for approximately four days after. An estimated 90% of people who are exposed to measles will fall ill if they are not protected by the vaccine (CDC 2018b). Their risk-benefit analyses accounted for perceived risks due to their children's vulnerabilities, the risk of exposure and severity of disease, and the vaccine, which were all centered around the individual.

“There's just these things that you can do to be healthier”

> *If you look into nutrition and you want to have nutrient dense foods and maybe organic foods, and you want to avoid GMOs, I mean… some people don't think that's true, but I do. You know, and I want grass-fed stuff and pastured stuff and, um, I'm trying to reduce the toxic load, the environmental toxic load. Like, if you eat crap or you live in a place with air pollution, there's just these things that you can do to be healthier. – Rachel*

For Rachel, like many parents in this study, vaccines were just one element in their overall approach to health and wellbeing, which encompassed the foods they ate, the environments they lived and played in, the household cleaning products they used, the doctors they saw, the schools their children attended or would attend in the future, and even their birthing and breastfeeding practices (discussed in further detail in Chapter 8). Their ability to achieve good health and secure a healthy future for their children was predicated on their ability to make good, healthy choices through responsible, healthy consumption. Eleven (79%) of the parents, including Rachel, talked about individual things they were doing to promote their family's and children's health, such as eating organic foods and using “natural” household products, even if it meant paying a premium. They practiced precautionary consumption, a vigilant form of individual consumption in efforts to avoid toxic exposure, particularly in the perceived [and real] absence of systematic, institutional protection from universal risks (MacKendrick 2010, 2014). The foods and products they curated for their household were contributing to their individualized approach to health, in the absence of vaccines.

Parents talked about consuming or avoiding specific foods based on their belief that it would impact their immune system. Ariana, a stay-at-home mom and doula-in-training, avoided giving her daughter sugar since she believed it would “poison” her body and negatively impact the development of her daughter’s immune system. For Ariana, avoiding sugar was one way of protecting her daughter from external toxins and supporting her daughter’s development of a healthy immune system.

> *The body has an immune system for a reason. And, yeah, really, like, I feel like some of these vaccines do what they’re trying to prevent. They’re harming the immune system and we’re trying to protect hers, you know, [with] nutrition. She’s the healthiest kid I ever met. Yeah, you know. We don’t, she doesn’t eat crap. We don’t do any sugar at all and a lot of parents are like, You’re depriving her of childhood-ness. And, you know, she doesn’t need, like, a poison that’s not gonna let her immune system develop. – Ariana*

Food was an important factor in maintaining good health for Zoe, too, who made an effort to provide “good quality” food to her children whenever she could afford it, which included “meats from Missouri” and cheese that was ethically sourced from cruelty-free farms, sarcastically referred to as “the $42 block of cheese.” She also avoided sugar, like Ariana, and drew parallels to avoiding vaccines in the pursuit of good health.

> *We’re very careful about making sure that, as much as we can, the food that they’re fed is really good quality food [...] It was like, we’re not going to vaccinate, and they’re not going to eat sugar, like, ever. – Zoe*

Rachel, Ariana, and Zoe practiced a form of precautionary consumption in efforts to avoid toxins, and this included vaccines. In the neoliberal era, of deregulation and privatization of producers of synthetic chemicals, pesticides, and toxic waste, the onus to protect the public’s health from everyday exposure was diverted from the state onto the individual. National agencies in the US and Canada report hundreds of synthetic chemicals, such as bisphenol A (BPA), phthalates, and brominated flame retardants, that are found in the human body in trace amounts (CDC 2009, Health Canada 2010, in MacKendrick 2014). Both men and women carry these chemical body burdens, and fetuses, infants, and children are considered most vulnerable since they absorb more relative to their body mass. Due to this, concerns about children's body burdens tend to be directed to pregnant women and mothers who, in turn, situate their children's chemical burdens within their own. Through precautionary consumption, they can mediate their exposures, and their families' exposures, to toxins in food, household products, and the environment (MacKendrick 2014). For parents in this study, vaccines and their ingredients were perceived as toxic and their decision to refuse or delay vaccinations for their children was one form of precautionary consumption in their overall approach to health through responsible consumption.

Summary

In this chapter, I illustrated how parents individualized their process of risk assessment and management around vaccines and vaccine-preventable diseases. Parents justified their refusal or delay of vaccinations for their children by disregarding or discrediting herd immunity and the community function of vaccines. Through their individualized risk assessments, they concluded that their children were more vulnerable to the risks posed by vaccines compared to the risk of contracting vaccine-preventable diseases, such as Hepatitis B. In lieu of vaccines, parents took individual actions to support their children's health, through responsible, precautionary consumption practices, upholding neoliberal capitalist values.

In the neoliberal environment of deregulation, and devaluation and decentralization of social welfare, parents are responsible to making informed, responsible decisions and taking individual actions to mitigate risks and promote health. Vaccines, like any other biomedical intervention, carry universal risks which are determined by biomedical research institutions and pharmaceutical companies. These risks are regulated and managed by state institutions, such as the CDC and the National Vaccine Injury Compensation Program, holding the state accountable for minimizing the any adverse effects caused by vaccines. Neoliberal ideologies encourage individuals to be accountable for assessing and managing internal and external risks and mitigating those risks themselves through responsible consumption. Parents in this study demonstrated these values through their consumption and avoidance of specific foods and products, including vaccines, as part of their overall individualized approach to health. Environments of institutional distrust further promote individualized perceptions of risk and reinforce individual actions toward health, which are discussed in the next chapter.

CHAPTER 6: INSTITUTIONAL DISTRUST AND DEMEDICALIZATION

Introduction

Health and healthcare in the US have changed dramatically in the last 50 years. Between 1960 and 2013, the cost of healthcare has more than tripled, from 5% of the US gross domestic product to 17.4%, while multiple health metrics of the American population have fallen far behind other industrialized countries (Catlin and Cowan 2015, Moses et al. 2013, Muennig and Glied 2010). In roughly the same time period, public trust in the medical institution has also declined sharply (Blendon et al. 2014). While patient satisfaction with their individual providers remains relatively high, public trust in physicians as a group ranks near the bottom, globally (Blendon et al. 2014). In the age of the internet, people are turning to "Dr. Google," online sources, and even social media in search of health and medical information. These trends leave medical and public health institutions contending with spreading misinformation, growing public distrust, and an increasing number of direct-to-consumer diagnostic tools, such as clinical blood tests, genetic testing, and allergy testing, that are easily accessible for use by the general public without any consultation from health professionals (Betsch et al. 2012, Eysenbach 2007, Tan and Goonawardene 2017, Yaqub et al. 2014).

In relation to vaccines, several studies have found that trust is an important factor in vaccine decisions for parents (Attwell et al. 2017, Benin et al. 2018, Casiday et al. 2006, Glanz et al. 2013, Sobo 2015). In this chapter, I describe the environment of institutional distrust that is driving the broader trends toward demedicalization among parents in this study. This trend extends from their general approaches to healthcare and childbirth and into the vaccination decisions for their children. I apply theories of relational trust in the context of risk to analyze 1) factors that contribute to institutional distrust and their impacts on parents' vaccine-related decisions, and 2) the ways parents evaluate and challenge biomedical authority.

Risk and Trust

"Lay" perspectives of risk are often different from "expert" perspectives, suggesting that perceptions of risk are products of competing knowledges about the world (Lupton 2013, 145). Often times, logics of risk that are counter to the dominant expert system are characterized as ignorant or "irrational" (Horlick-Jones 2005, Wynne 1989); however, these informal logics are based on rational judgements shaped by lay knowledges, experiences, and trust, or distrust, of expert systems (Lupton 2013, Wynne 1989). For example, the Centers for Disease Control and Prevention and the World Health Organization recommends that everyone over 6 months old receive the flu vaccine every flu season (CDC, WHO). However, only 62.6% of children and 45.3% of adults in the US received the flu vaccine during the 2018-2019 flu season (CDC). Regardless of expert advice, studies show that most adults, even those who work in healthcare, do not believe they are at high risk of flu, do not believe the vaccine is effective, and do not perceive flu as a serious enough illness to warrant an annual vaccination; these beliefs and perceptions are based on their knowledge and experiences with flu each season (Bednarczyk et al 2015, Kraut et al. 2011, Prematunge et al. 2012).

Judgements of experts and institutions, of their persuasiveness and trustworthiness, are informed by "pre-established knowledge of how relevant industries and regulatory bodies have tended to deal with risks in the past" (Lupton 2013, 148). In modern risk societies, risk and trust are intertwined (Beck 1992, Beck, Giddens, and Lash 1994, Giddens 1991, Meyer et al. 2008, Peretti-Watel et al. 2015). In environments of institutional distrust, expert and authoritative knowledges of risk are contested and challenged by lay knowledges and informal logics of risk. In this section, I focus on how parents in this study drew on their 1) knowledge of historic failures of the pharmaceutical industry and regulatory bodies, and 2) perceptions of conflicts of interest between the pharmaceutical industry and other systems involved in vaccinations to support their rationale that vaccines are not safe, and institutions are not to be trusted.

"Look back at the history of pharmaceuticals"

> *I'm not some conspiracy theorist getting into all the woo-woo stuff at all. And so, in fact, I studied biology when I was in [college] […] and so I'm very much like, "Yeah! Medicine!" Um, and so, I think that, what was it exactly, I started talking to one of my friends and she was doing the same thing. She was kind of questioning [vaccines] at that point, she has a son that's two years older than my daughter and she was questioning and I was just kind of like, you know, I should be informed on this stuff. So the more I started reading on it, I just started getting a little bit concerned that there weren't better studies out there and everything seemed to be funded by big pharma, which obviously has a big stake in the game and it makes you go [questioning face], and you know, it seems very paranoid to be like that I guess, in some ways, but you look back at the history of pharmaceuticals and even vaccines in the past and medicines that were given to people that should never been given to them and caused birth defects. So, it's not crazy to be wary of this stuff. – Tori*

When Tori was explaining some of her concerns about vaccines to me, she talked about not trusting pharmaceutical companies to be honest about side effects and risks, drawing from her general knowledge and collective memories of many of the industry's past failures in her construction of her logic of risk around vaccines. At the end of this quote, she referred to the fallout of Thalidomide, a drug that was widely used in the 1950s and 1960s to treat nausea and "morning sickness" in pregnant women that resulted in severe birth defects in thousands of children (Kim and Scialli 2011, Vargesson 2015). Her use of the Thalidomide tragedy as an example is especially pointed; to Tori, this was a cautionary tale about mothers who trusted the pharmaceutical companies and their products, which ultimately had severe and irreversible consequences on their children's health. Her perception of conflicts of interest (discussed further in this chapter) between the pharmaceutical industry and other scientific institutions further contributed to Tori's distrust in vaccines. She trusted her friend, a fellow mom, and followed her example of "questioning" vaccines and challenging the routine vaccination schedule.

Heather, a stay-at-home mom whose son is unvaccinated, also mentioned past failures of the pharmaceutical industry and their regulatory bodies, generally, when she explained her concerns around vaccines.

> *How many times do we have to see something that the FDA says is ok and then, oh shit, lawsuit! Not approved! People are dying! Sickness! And, how many people have to die in order for that to even become a thing? It's mind-blowing to me. – Heather*

These failures informed Heather's logics of risk around vaccines and laid the foundation for her rationale to refuse vaccines for her son. She explained to me that she didn't trust the "government" to apply the appropriate "checks and balances" to the pharmaceutical industry, highlighting conflicts of interest between the two systems. Heather talked about other contemporary examples of systemic institutional failures, specifically mentioning those with public-private linkages, which further supported her rationale for not vaccinating her son.

> *So, you're telling me I can trust you, but you're a privately-owned company that many people believe is a federal government issue, and it's not. There's not checks and balances. The checks and balances that we're told to believe in have been proven to be false. So until I know better, I will not put that [vaccine] in my kid [...] I mean, I feel that way about, sorry to get so off topic but just to kind of drive home the point, it's like, ok, we don't, we'll build pipes to run oil under drinking water, and people will say, "Wait, that doesn't make sense." And, then someone goes, "But it's mostly really safe. Technology's improved." Meanwhile, there's things bursting everywhere. "Oh, but they're old pipes… Oh, but they had sensors on them but we didn't get there in time." Or, "Oh no, we can't cap it." And "We're really concerned about our drinking water." But then these people that are supposed to say that everything is safe, we're supposed to line up and believe them? But I'm just saying, like, when people don't care about your drinking water… you can believe that. You know what I mean? – Heather*

Heather conflated several environmental crises that had garnered a lot of media attention, including Deepwater Horizon, Keystone Pipeline, and Dakota Access Pipeline, in citing a generalized example of institutional failures to protect the health of everyday people. Heather's logics of risk, informed by her knowledge around past pharmaceutical failures, conflicts of interest, and resulting distrust of government institutions, supported her belief that vaccines posed a threat to her son's health and were not safe.

When Lena, a pre-school owner, was explaining her concerns about vaccines, she talked about her own professional experience in biomedical research to support her rationale for delaying vaccines and her general distrust of the biomedical institution and pharmaceutical industry. Prior to her son's birth, she had worked for several years in a laboratory at a nearby university conducted research on cancer treatments.

> *I mean, I don't believe that doctors are all knowing [...] There were mistakes that happened all the time, and there's things that where, one of the studies that we had done was curing cervical cancer and there's a drug that was out, but the drug did so much harm in addition to, you know, it's like so many side effects and so they were trying to improve that. So, even just, even though it's helping, you know, it's also making you really sick, and there's, it was on the market for a decade before they were like, ok, now let's try to improve it and make sure that these people aren't having these horrific side effects in addition to the cancer. There's just so much of that in the medical world that, I don't know. Yeah. – Lena*

Lena projected her specific experience in biomedical research onto her overall concerns around vaccines. While she ultimately decided to have her son fully vaccinated so he could attend public school, she was extremely cautious with the process. She delayed his vaccines and gave her son homeopathic pre- and post-vaccine treatments that she believed would minimize the potential negative effects of each vaccine. These homeopathic treatments were recommended to her by her son's pediatrician, who Lena described as "very understanding and lenient" when it came to the routine vaccination schedule.

Heather, Tori, and Lena each drew from their individual knowledge and experience to construct their logics of risk to make rational judgements that supported their decisions refuse or delay vaccinations for their children. Their perspectives of risk differed from the experts'. For Heather, Tori, and Lena, their priority was to minimize their children's exposure to the risks posed by vaccines. For public health and medical experts, the risks posed by vaccine-preventable diseases to individual children and community health far outweigh the risks posed by the vaccines themselves. The parents' institutional distrust of pharmaceutical companies, the state, and biomedical research further supported their decisions to go against the "experts" and their recommendations to follow the routine vaccination schedule.

"This is America, and everything is tied to a big business interest"

Institutional distrust is a hallmark of late modernity of the 1980s and has contributed to increasing perceptions of risk in contemporary, modern society; trust in expert institutions is no longer a given (Beck 1992, 1999, Giddens 1990, 1994). Vaccine hesitancy research in the 2010s continues to find strong connections between institutional distrust and vaccine hesitant behavior; critical scholars are going beyond the "erosion of trust" framework and examining the intricacies of relational trust in the context of contemporary vaccine hesitancy (Atwell et al. 2017, Dube, Vivion, and MacDonald 2015, Luhmann 1988). Luhmann's relational trust theories state that dis/trust in one system impacts dis/trust in others (1988). The majority of parents in this study (13, 93%) expressed distrust and even disdain for the pharmaceutical industry, summed up by three parents who implored me to "follow the money." This sentiment highlights their perception of conflicts of interest, primarily driven by profit, between the pharmaceutical industry and other systems involved in vaccines. This perception contributed to their distrust of vaccines and pharmaceutical interventions as a whole, which was extended to doctors, schools, research, the state, and state representatives.

Distrust in pharmaceutical companies underlaid parents' perceptions about the safety and effectiveness of vaccines. When Jen, a chef in a trendy restaurant, walked me through her thought process about vaccines, she explained that she thought of them as "just like any other kind of drug," that they were somewhat experimental in nature. She believed the pharmaceutical companies were pushing drugs, including vaccines, on everyone in order to make money.

> *I feel like it's all like a pseudoscience, how they're medicating these people because they don't really know, like, 100%, if that's actually gonna help them. It's just based on like experimentation and everybody's different so it's like [...] maybe let's see if this works, you know. And then how many times have they been wrong, you know? How many times have they switched up a drug? – Jen*

Jen continued on and told me about an argument with her youngest son's teacher who was concerned that her son had Attention-deficit/hyperactivity disorder (ADHD or ADD). She explained that this interaction supported her suspicions about ties between the pharmaceutical industry and other systems.

> *And then another thing too, coming down to like ADD, right? Because they're pushing that so hard in schools now, little kids. When I was a kid, a kid was just a kid, and like now, teachers don't want to deal with kids. I have been fighting my son's teacher because he's a very energetic kid. But all my kids were. My oldest was just like him. I was an energetic kid when I was their age. I don't have ADD. I just have a lot of energy. I'm one of those people that's like, you know, has a lot of energy. But, like, they can sit down and focus and get their work done, but it's just teachers don't want to deal, especially in public schools, Mika, they don't want to deal with that. They just want the kid to sit there and listen. So, you know, she's like talking to me like, "Maybe he has ADD." I'm like, "I'm gonna stop you right there." I'm like, "My son's four years old [...] He's never been in school before. This is the first time he's ever been immersed into this kind of culture [...] I don't think for one second that he has a problem. Allow him to grow [...]" I'm like, no*

> *way. I shut her down, because, it's like, to me, you know, that's how I feel about all that stuff. That's all, along with vaccines, it's like the pharmaceutical companies, they're trying to find ways to make money. I mean, I understand that this is, you know, a capitalistic economy. Everybody wants to make money, but that's just a horrible way to try to make money. So, but if they truly are trying to help people by avoiding outbreaks, I can understand that. Because there [have] been some problems I've heard about. So, you know. – Jen*

This interaction with her son's teacher further supported Jen's suspicions that pharmaceutical companies, in concert with medical and education systems, were promoting drugs and vaccines to children purely for profit. These perceived conflicts of interest shaped her distrust in vaccines in particular, but also her general belief that doctors and teachers did not have her son's best interest at heart. Since Jen and her husband both worked full time, homeschooling was not a feasible alternative at the time. She ultimately had her son fully vaccinated but on a delayed schedule, as recommended to her by a friend, but she admitted that she wouldn't have vaccinated her son if it were not required by law.

The pharmaceutical industry's emphasis on profit was also an important factor that shaped Sofia's distrust in vaccines. Sofia, a writer/producer with two children, feared that children were being treated like guinea pigs by pharmaceutical companies. She believed that there was an intentional lack of transparency in their processes which worried her even more about vaccinating her children.

> *I think my concern is just with pharmaceutical companies and so many things being tested, too. At what point is the tipping point for a child's body, or anyone's body, to put chemicals and diseases into, and what are we trying exactly to prevent? [...] And, then also the denial of fast-tracking vaccines through the marketplace and testing in other countries that we don't even hear about all the things that are going wrong. I mean, sometimes you do hear about those things. Or, you know, with the polio vaccine, when they first came out with it and it was given orally, and people contracted polio from that. We don't talk about that, but these things happen, and when you fast-track things through. – Sofia*

Based on her evaluation, Sofia believed many vaccines, including for HPV (human papillomavirus), were simply unnecessary considering how common and treatable she perceived HPV infections are compared to potential risks posed by vaccines. As she explained:

> *There's vaccines like Gardasil that I'm very skeptical about, not only because of the different major things that happened with people being affected by it, but also because, ok, so almost every single person does get HPV or has HPV, but if you're going to the gynecologist on a yearly basis, it's not going to be a problem. If you're getting a Pap smear and getting checked up, you get it dealt with. It's going to be ok. So, like, Gardasil, part of its whole sales thing is, like, "If you don't get this checked up on, it'll keep you [protected from serious complications of HPV]…" It's like no, if you just do the basic care, you're gonna be fine. You're not gonna die from this. – Sofia*

Sofia's risk assessment and skepticism of the HPV vaccine for her daughter, which would have been more than five years in the future, were based on her knowledge of HPV, her experience with HPV screening, and her experience with relatively easy access to routine preventive healthcare supported her plan to forgo the HPV vaccine, which was counter to expert recommendations (routine HPV vaccination for 11-12 year olds) (CDC 2020). Her distrust in pharmaceutical companies further reinforced her decision and allowed her own knowledge and experience to overrule expert recommendations.

James, a psychoanalyst and a father of two, thought of profit-driven conflicts of interests between various systems as typical in US society. He believed that once one took the time to investigate any relationship further, one would find that all systems were somehow caught up in conflicts of interest that prioritized either profit or political power, as he explained:

> *We live in the "land of the free" and there are* **so** *many rules here, there are more rules here than anywhere else, and it's "for your own good," and I just don't think that… again, the argument here can be, it's not just for your own good, this isn't a helmet, this is so you don't infect your neighbor or another kid or, but, you know it's just, this is America and everything is tied to a big business interest, it seems. Every single time you peel back a layer of the onion, you find this. It's a repeated, like, archetypal phenomenon. And so, it's like, why should I believe that a mandated*

> *injection is not being somehow tied to some gigantic, you know, political economic force? – James (original emphasis)*

James took a libertarian view of public health laws, including helmet laws, seatbelt laws, and vaccination requirements, believing that the government should not be involved in dictating individuals' behaviors. At the same time, he acknowledged that vaccine requirements do not just affect the individual, referring to the dual function of vaccines and herd immunity. Nonetheless, the perceived conflicts of interest and his belief that vaccines were tied to a "big business interest" further bolstered his hesitance toward vaccinations for his children. Rachel, a midwife with one unvaccinated daughter, took a similar libertarian stance when she explained her distrust in the state and vaccine requirements. She brought up other health issues that she believed were equally important to population health, such as trans-fats and genetically modified organisms in food, but were not regulated or controlled to the same degree that vaccines are. This discrepancy supported her notion that the state does not truly have the people's best interest at heart, and profits were the end goal. In her words:

> *I don't think they do have our best interest at heart. Otherwise, why would McDonald's be allowed to use trans-fat. You know, like, there's only two fast-food restaurants that don't use trans-fats and that is a major detriment to health, and so if they gave a shit, they would outlaw that. And, they would outlaw Monsanto and all this other, like, I don't know, maybe even smoking or something. Like, if they really cared about our health. So, I just think it's interesting that they're so clamped-down on [vaccines], you know, but "Poison yourselves and get heart disease. We don't care." Like, I don't, I just think it's about money. It's about profit. – Rachel*

When parents in this study perceived conflict of interest between various systems and representatives involved in vaccinations, such as healthcare providers, politicians, public health professionals, it called into question the beneficence of their promotion of vaccinations. Sara, a nurse midwife and mother of two, believed there was a conflict of interest between State Senator

Richard Pan, the co-author of Senate Bill 277, and the pharmaceutical industry, which made her believe that vaccinations laws were put in place to promote profit for pharmaceutical companies rather than to promote public health.

> *I'm a healthcare provider, I'm a mom, I have a license as a healthcare provider, and you can't tell me what I can do with my kid. You know, like, that's beyond overstep your boundaries, sorry government. And the whole thing, how it went down with [Senator] Pan [during the Senate hearings for SB 277] the moment where the judge was like, "Ok, do you want to pass [SB 277] or do you want to hold and get more […] proof and more evidence," Pan turns around to two people, two guys that were lobbyists for the pharmaceutical companies, walked up to the podium, he whispered something into his ear and he turns around with this, like, sheepish smile, and then was like, "Pass the bill." Directly from the lobby from the pharmaceutical companies. It's outrageous. It's just beyond comprehension that this can happen in California. So, you know, it's par for the course, it's like our crazy government system. – Sara*

Sara believed it was "the corporations and the pharmaceutical industrial complex that really run the show" and that politicians were "choosing their bottom line and their stockholder satisfaction over the health and wellness of our nation." Suffice it to say, the perceived conflicts of interests between politicians and the pharmaceutical industry supported her belief that mandatory vaccinations were not in the best interest for her two children.

Lay knowledges and individual experiences shape informal logics of risk that are sometime counter to expert opinions and rationalities. In this study, parents' knowledge and memories of how the pharmaceutical industry and government regulatory bodies have dealt with past failures weighs heavily on evaluation, and ultimate distrust, in expert institutions that were previously relied on to assess and manage everyday risks. The perceived conflicts of interests between systems involved in vaccinations further supported their distrust in vaccines and their decisions to refuse or delay vaccinations for their children.

Challenging Biomedical Authority

In this environment of increasing institutional distrust, most participants (13, 93%) talked about taking an engaged and critical approach to their own healthcare, actively questioning and challenging the advice and recommendations of medical professionals and public health intuitions. They felt the need to advocate for themselves and their children, particularly if their healthcare decision were perceived as counter to the norm. Parents turned to other forms of authoritative knowledge, including their social group and alternative health providers and childbirth professionals to prop up their own beliefs. Parents also turned to doctors who were known as "vaccine-friendly," or vaccine-flexible, to reinforce their approaches to vaccines.

"Of course you have to question your doctor"

Parents expressed value in questioning the advice of doctors and advocating for yourself, often conflating the two. This was the case for Ariana, a doula whose daughter is unvaccinated. She explained that she saw parallels between the process around vaccines and childbirth. In her view, one could either listen to the doctors' recommendations and go along with them or one could do your own "research" and figure out what is best.

> *Do your research. Yeah, it'd be good if everyone just researched which [vaccines] they feel they need instead of just, which a lot of people just do trust doctors and that they're doing what's best for their kid. And they just say, "Sure, doctor. Whatever you say. I don't understand anything, but sure." I'm not like that at all. I think that's why I'm a doula now, too, because moms and birth are the same. They don't know what's happening during birth and then the doctor comes in and is like, "Hey, so we're gonna do this," and the mom's like, "Sure." And, I'm like, "Well, this is what this means, and these are your other options." You don't need [to do] just what the doctor says. So, it's kinda like that. Just get informed about what you're putting in your body. – Ariana*

Ariana believed her role, as a doula, was to help individuals navigate this process and make more informed decisions. In the same way, Sofia talked about questioning her doctor's expertise and recommendations for her treatment for colitis, and believed she was better off for doing so. She valued a more critical approach to healthcare and expected it from her doctors as well.

> *So, there's a lot of things like that that make me question Western medicine because, maybe it's the way that doctors are trained to because they're put through their paces in such a way in medical school that, this is what you're taught, this is what's right, if you question it, then you're the idiot. And then they kind of sometimes pass that onto their patients, where it's like, "Don't questions me, I went to medical school." This sort of holier than thou, I know better than you. And it feels, of course, patronizing. Of course, they did study all these studies that were given to them, but when I look sometimes at the way the studies were made that they look at, there's shortcomings everywhere. And if you're not questioning it, then that makes me nervous [...] People questioning things should not be shamed out of questioning things, and I think that was the biggest issue that I've seen, is the shame for even asking a question. "How dare you question your doctor?" If I didn't question my doctors about my colitis, I would be a very different person today. There were even doctors who were like, "We might have to remove your colon." I mean, of course you have to question your doctors [...] We have to question everything. If you don't, then you're just a sheep following along with the flock. – Sofia*

Hannah, a marriage and family therapist with two children, also talked about advocating for her son during a recent visit to her pediatrician. She resented having to challenge her doctor but felt it was necessary in order for her son to receive the kind of care she wanted.

> *[My son] must have gotten some kind of mosquito bite on his eyelid and had some allergic reaction, he had a gigantically swollen, I mean, he looked like he was in Star Trek, it was so crazy. But we took him to the doctor, we took him to the first pediatrician because that guy accepts insurance. And I was like, with this kind of thing, let's just go to him. And he was like, "Uh, woah, I'm gonna give him some antibiotics," and I said, "What if it's a bite." And he goes, "Oh, well it could be a bite." And I was like, "Ok, because there was a tiny red dot right here," and I was like (pointing motion), and he said, "Ok, you can give him Benadryl, you can give him Claritin, and see." I'm just like, I'm so glad I didn't put him on antibiotics for no reason. So that's sort of an example of how I advocate for him, for myself, or us. But I find it very annoying that I have to do that. And think about all the people that never do that. They just, whatever they tell you, they always do and, you know, the kind of patients that people like to have. Like, Ok. But we're not those people. – Hannah*

For these parents, the only way they could receive the quality of care they wanted and expected was to engage with their doctors in a critical way. In the US, 75% of mothers report being primarily responsible for managing their children's health, compared to 20% of fathers (Gomez et al. 2018). This defensive interaction with their doctors creates an unequal burden on mothers to be vigilant and hyperaware of everything affecting their children to be able to assert their authoritative knowledge as mothers and act in the best interest of their children. Each parent acknowledged that they were privileged to be able to do so, at the same time felt that it was ultimately their responsibility to advocate for their children and for their health.

Parents' Social Networks

Nine parents (64%) specifically talked about engaging with friends and family in-person and online about vaccines, infectious diseases, and strategies to avoid vaccines. Some of these parents turned to social media, such as Facebook mom-groups, while others would actively avoid the topic of vaccines on social media. For example, Allison, a former teacher and mom of two, was embarrassed to admit that she found a lot of vaccine-related information online. She explained that she relied on her in-person network of friends and family for trusted information. Her older son, who was almost three at the time, was partially vaccinated on a delayed schedule, but she decided to forgo all vaccinations for her younger daughter who was almost one at the time.

> *You can find a million things that are good and a million things that are bad. And, I try to look for credible sources. There's a lot of hype out there on both sides of this issue, and a lot of propaganda on both sides of the issue. But for me, what it comes down to is, my personal experiences, my friends, people I've worked with, doctors I've spoken to [...] – Allison*

Sofia expressed similar reservations about social media due to the cyberbullying she witnessed of vaccine hesitant parents.

> *I talked to most of my close friends about it [...] Yeah, I had my close friends. I just wouldn't post about it on social media. – Sofia*

Parents turned to their social networks seeking specific advice or reinforcement for their own vaccination plan, especially from other parents. Ariana, a doula, wished she "could just find one mom" online that would tell her how to avoid vaccinations without a medical exemption; and Zoe, a lactation consultant, turned to her friends and colleagues with children to reinforce her own decision not to vaccinate her two children. Parents in this study were at various points in their decision-making and had children with varying levels of vaccination. In their process of rejecting biomedical and public health authority, they found resources, advice, recommendations, and reinforcement within their own social networks.

Alternative Health Providers and Childbirth Professionals

All of the parents in this study talked about receiving care from alternative healthcare practitioners, such as naturopaths, homeopaths, and chiropractors, to supplement their medical care. They turned to these practitioners and midwives to provide guidance with their vaccine decisions or to reinforce the decisions they had already made. While Jessa was pregnant, she visited her naturopath to discuss vaccines.

> *Probably half-way through my pregnancy [...] my gut was screaming at me. Like, it would make me sick to think about [vaccinating]. So, we went back to the naturopath that I was seeing and she kind of was like, "You know, obviously my stamp is gonna be* ***not*** *to [vaccinate] but I don't want to sway you either direction. And, it really put us on the path, and I recommend you guys do a lot of research, talk about it, and you can always do it later, but you can't take it back" type thing... – Jessa (original emphasis)*

This advice validated her concerns and she ultimately decided not to vaccinate either of her two children. Hannah had a similar experience when she asked her midwife about vaccines.

> *I remember asking my midwife, I was like, "Hey, I know it's my decision but what's your personal stance on vaccines?" And she said, "No more than two at a time and nothing before six months." And, I was like, I don't think she said so directly but she tried not to answer, but I was like, "What did you do?" Because she has three kids. And I was like, Ok. So that influenced it, you know. – Hannah*

When making vaccine decisions for her daughter, Rachel considered her daughter's eczema, her own "weird family [medical] history," and her "gut feelings," and ultimately decided to forgo vaccines for her daughter. She later visited her naturopath for a check-up.

> *My naturopath one day said, "Oh, well it's a good thing you never vaccinated her. She'd be autistic." You know, and you could say that's her opinion, but I believe her. – Rachel*

For both Jessa and Hannah, their health providers encouraged them to do their own research and make their own decisions, yet their implications were pretty clear. For Rachel, her naturopath confirmed her own evaluation and decisions about vaccines.

"I looked for one that was much more open and liberal about vaccines"

All of the parents in this study intentionally sought out doctors that would be likely to reinforce their overall approaches to health, including their decisions to delay or forgo vaccines. Tori was eager to find a doctor that would support her decision to delay her daughters' vaccines.

> *Going to [our pediatrician], when I first started going there […] because at that point, I already knew that I wanted someone that was open to an alternative schedule, and we moved when my daughter was only 4 months old so her first pediatrician was the same thing, was back in Pasadena. Same sort of doctor, he was a DO, the first one we went to and I really liked him. And, same thing, took a lot of time with us, it felt like I was going… in fact, they even had their practice set up in an old craftsman [house] […] a, so you kind of felt like you were going to see your family doctor from back in Little House on the Prairie And so, and he was great, you know. He was very patient. Took so much time with us. Talked about so many things. You didn't feel like you were in a factory, and like, ok, what initially brought me there was the vaccine thing but I'm staying for the whole experience. And so, it's very important and I do want that. – Tori*

Similarly, Sofia specifically found a doctor, through her friends, who she knew would listen to her concerns about vaccines and support her approach.

> *I turned a lot to my friends to see which pediatricians they went to, and I looked for one that was much more open and liberal about vaccines, in particular. He's THE guy, he's Dr. [name]. I'm sure that you'll hear his name. And he's very, um, he's taken some pretty hard stances [against vaccines] and he's also softened his stance a lot over the years. So, and he's also open to vaccinating. In fact, my kids were there yesterday getting shots. Yeah, so, it's a dialogue and that's I think what's important to me about choosing him as… he was someone who wanted to discuss it and was open to discussing it. And, took into account my history and my health history and our concerns […] Luckily he's been able to give me medical exemption for them and that's how we've been able to go into the schools and deal with all of that. – Sofia (original emphasis)*

She worked with her doctor to "redefine" her children's vaccination schedule so that they could monitor their reactions to them. She is planning to have both of her children fully vaccinated eventually, but in "slow succession." When Rachel was looking for a doctor, she wanted to find one that took a more "holistic" approach that was more in line with her own healthcare philosophies. She thought it was important to seek expert medical advice but on her own terms.

> *I think I've chosen someone who, I know she'll talk, like, you know, she was talking to me about antibiotics. We talked about [my family history] a little, like, she was intrigued and was like, "We need to talk about this more." [She's] not a "Do as I say. I'm your doctor" type of person, which I don't do well with. – Rachel*

Rachel and Sofia had already decided what they wanted to do, which was refuse or delay vaccinations for their children. They found doctors that would support their vaccinations plans and also engage with them in the process. This was also the case for Sara, a nurse midwife with an older son and a younger daughter who was deaf and on the Autism spectrum. Both of her children were partially vaccinated; her daughter had only had the Prevnar 13 and Pneumovax 23, which her doctor required before and after her cochlear implant surgery, and her son had gotten the DTap after he was exposed to pertussis by a family member. When Sara was explaining her concerns around vaccines, she brought up behavioral changes that she saw in her children soon after they received vaccines. She explained that she brought up her concerns with their doctor at the time who "blew it off." This experience prompted her to find a different doctor.

> *So, what sucks about [our previous] pediatrician is like I brought up this story about [my daughter and her change in appetite] and [my son's] drooling, and both times he blew it off as, "Oh, well that was the appropriate time when kids start to do that," instead of trusting my instincts as a mom […] and as a healthcare professional, you know, that this was different. So, finally when I took her to this Osteopath, who's amazing, works with kids with Autism […], when I told him those stories, he was like, "I totally believe you. That sounds exactly like…" He validated what I said. For the first time, a professional had validated it. And I was like, Thank you! Because none of the other doctors think [vaccination] has anything to do with [their behavioral changes]. – Sara*

Finding and choosing forms of medical authority that would support parents' approaches started before the birth of their children for some parents, with their birth plans (discussed further, below). Hannah is one example. After Hannah, a marriage and family counselor, found out that her son was breach, she was told by her obstetrician at the time that she would need a cesarean. Hannah did not want that, so she sought out a doctor who would support her decision to attempt a breach-homebirth. She knew that if she stayed with her provider at the time, she would have no other option than a cesarean.

> *I was hoping [childbirth] would be as […] least intervened upon as possible, but then when we found out he was breach, which at that hospital meant an automatic C-section. I did some research and I was like, yeah, I don't want to have surgery just because somebody decided that they don't want to take him out upside down, whatever, right side up. So, then I researched doctors. There's one guy in Los Angeles who does VBAC, twin, and breach homebirth, and I was like, ok, let's meet him. – Hannah*

In the end, Hannah took the initiative and made it happen. She was able to successfully deliver a healthy baby boy at home with the help of her midwife and her new doctor, although her son broke his arm in the process. Each of these parents sought out doctors, either through their own research or through recommendations, who would support their approaches to health, in general, and vaccinations, specifically. Although they opted out of conventional biomedical approaches, they wanted the support of health professionals to reaffirm their own plans and approaches to health. They were looking for doctors to serve as consultants, rather than as the experts (Reich 2016). When it came to the parents' health and the health of their children, the parents themselves were the experts. They found ways to circumvent dominant medical opinions and recommendations (i.e. routine vaccination schedule) but were harnessing authoritative medical knowledge nonetheless to reinforce their own approaches toward health and healthcare.

"I wanted everything very natural"

> *I don't have a doctor, I don't have a dentist, I don't have a gynecologist. Because I literally don't even know where to start because I don't trust anybody [...] They just give me a bunch of pills, like, [and tell me], "You need to take these antibiotics, and you need to take these." Thank you! I'm not taking that, you know. I got mastitis when I was breastfeeding when [my daughter] was very young, and it was bad. But I didn't want to do the antibiotics because my breastmilk, I don't want that in my baby. So, I just took care of it myself, my herbs, with my, you know, and it might take a little longer but, like having to be in bed because I'm not treating symptoms, but then I was fine, you know. It's doable. You just have to know where to go. I'm not very into the whole, "Let's just fix this now, just fix it fast." I like the just natural [approach] [...] I love it. Nature gives you all that you need, that's where I want to get all my stuff. If everything else fails, then sure, there's Western medicine. That's what I feel it should be there for. Not to replace everything. – Ariana*

As Ariana explained her concerns about vaccines to me, the conversation turned to her distrust in conventional Western medicine and her integration of more "natural" approaches to health, which meant avoiding biomedical interventions whenever it was possible, including routine vaccinations for her children. Her story exemplifies a trend among parents in this study. All 14 parents in this study talked about integrating alternative medicine and alternative providers into their overall approach to health and healthcare, and eleven of those parents specifically referred to various treatments, processes, and approaches they preferred as "natural." Eight women in this study had planned for a homebirth (five of which transferred to a hospital), and two women had unmedicated hospital births.

For Tori, the last thing she wanted to do was vaccinate her children after her "natural" childbirth. She described herself as "pro-Western medicine" but preferred to take a more "natural" approach when she could, which meant avoiding conventional biomedical interventions unless they "need it."

> *So, even though I'm in some ways pro-Western medicine and everything, I'm also very, I like to be natural about things, too. Like, we had a natural [unmedicated] birth [...] You know, the last thing I wanted to do was give them, what is it? Hep B or C, Hep whatever it is [...] So yeah, that's kind of where we are, we're in this weird let's keep it as natural as possible but supplement with medicine when you need it. – Tori*

Tori waited until both of her children were at least two before they received any vaccines, a decision that was supported by their doctor. Her older daughter and husband contracted whopping cough soon after her younger son was born, even though they had received the vaccine while Tori was pregnant with their son; she had been vaccinated a few years prior. Luckily, her newborn son did not get sick thanks to what she called "the powers of breastmilk."

The "natural" approaches to health that the parents in this study took precluded routine vaccination for their children. This was also the case for Jessa, a mother of two unvaccinated children. Jessa described herself as taking a "middle of the road approach" when it came to health. She explained that she thought the healthcare system in the US is "useful in a lot of ways but that it's overused." She elaborated, "I try to reach for something natural first before I reach for something conventional or Western." She had refused vaccines for herself when she was pregnant and ended up just getting the RhoGam shot, which protects a fetus from Rh negative mothers' antibodies, because her doctor, as she put it, “put the fear in me”. She had planned to go “all natural” for the birth of both of her children.

> *I had a hospital birth. I did have a birth plan and the plan was to go all natural. I wanted none of everything. I wanted no epidural, no eye ointment for the babies after they were born, no vitamin K, no hepatitis B. I wanted delayed chord clamping, basically all the interventions I could avoid. But my labor, in both cases, ended up being so long that we went with the epidural […] I didn't get to do delayed cord clamping but I did avoid all of the other interventions. – Jessa*

Ariana, Tori, and Jessa's decisions to avoid biomedical interventions during childbirth extended to their babies through their refusal or delay of vaccinations. They reinforced the natural versus medical dichotomy in their exclusion of vaccines from their “natural” approach to health. They perceive vaccinations as medical interventions that were unnecessary at best, and potentially harmful at worst. Their preference toward “natural” childbirth processes follows the second-wave feminist view of the medicalization of childbirth as “medical authority's usurpation of authority, choice, and control over women's reproduction” that framed childbirth as a medical problem that required biomedical intervention (Brubaker and Dillaway 2009, 35). For the women in this study, their efforts to demedicalize their healthcare and assert their authoritative knowledge extended beyond childbirth and into vaccinations decisions for their children.

Summary

In this chapter, I described how for parents in this study, informal logics of risk and institutional distrust informed their decisions to delay or refuse vaccinations for their children. Distrust of pharmaceutical companies and their regulatory bodies fed into distrust of other systems involved in vaccines, which included but were not limited to biomedicine, public health, research, schools, and the state. This relational distrust contributed in part to a breakdown of trust in the system in general, and vaccines in particular. Parents accessed alternative, nonauthoritative knowledges to challenge biomedical recommendations and opted for a more “natural,” demedicalized approach to health, which excluded routine vaccinations for their children.

Mothers in this study challenged biomedical authoritative knowledge through their vaccine hesitancy and their “natural” approaches to health by tapping into their social networks, alternative health providers, and their own expertise as women and mothers as integral to their vaccine decision-making. This challenges the top-down hierarchical structure of biomedicine and the medical system. In the next chapter, I discuss how vaccine hesitant mothers reinforce traditional gender roles and ideologies of moral motherhood through their vaccine hesitancy and intensive mothering practices.

CHAPTER 7: GENDER AND VACCINE HESITANCY

Introduction

In the US, women are often the link between their family and the healthcare system; women take on the responsibility of managing their partners' and children's health needs as well as their own (Salganicoff et al. 2005). In their interactions with biomedicine, there is overwhelming evidence that women in general and in particular pregnant, queer, and immigrant women, and women of color experience high levels of discrimination, differential treatment, and barriers to access within the US healthcare system (Beatty et al. 2014, Best et al. 2017, Bridges 2011, Krieger 2014, Miller et al. 2018). Historically, second-wave feminism and the women's health movement brought to light abuses of power in the medical field, which impacted the way mothers viewed medical interventions in general, and vaccines specifically for their children (Conis 2013).

Health policies also have gendered effects across the policy process, even for policies that are considered "neutral" (Morgan et al. 2018, Paterson and Scala 2015). This is due to a variety of factors. There is a gender bias in the make-up of the US political system. Only 23.6% of congressional seats are held by women (126 of 535 total); women of color make up less than half of the women currently serving in Congress (37.2%) (Center for American Women and Politics [CAWP] 2019). This gender bias represents the long-standing norm of male dominance in US politics, leadership, and policies (Dittmar 2018, Potter and Volden 2018). Health policies are written, implemented, and analyzed in the context of society's gender norms which impacts the process and outcome of health policies in gendered ways (McPhail 2003, Paterson and Scala 2015, Quinn 1996).

In this chapter, I describe how support and opposition around Senate Bill 277 was gendered, and how consequences of vaccine hesitancy under the new law disproportionately impacted mothers in California. Secondly, I demonstrate how neoliberal trends toward intensive mothering and emphasis on maternal responsibility gendered and moralized the process and experience of decision-making around vaccines. Finally, I describe mothers' experiences of vaccine hesitancy and the disproportionate emotional and mental burden expressed by mothers in this study, and the social consequences of being a vaccine hesitant mother.

The gendered process of Senate Bill 277

In 2015, Senate Bill 277 eliminated the personal belief exemption in California for vaccinations required for school entry (CLI 2015). The bill was co-authored by State Senator and pediatrician Dr. Richard Pan of Senate District 6 (Sacramento area), and State Senator and attorney Ben Allen of Senate District 26 (Los Angeles area). I had the chance to interview Senator Dr. Pan, as his office administrators referred to him, about 6 months into my fieldwork in California. I met him at his capitol office in Sacramento and we talked for about an hour and a half about his experience with SB 277 through the legislative process and the context around the bill's advocacy, opposition, and intentions. While he did not explicitly discuss how the political process around SB 277 was gendered, the insight he provided illuminated the gendered effects it had on women and mothers. In this section, I summarize portions of my interview with Senator Pan and analyze how the support, opposition, and consequences of SB 277 were gendered.

"We organized the parents"

In 2014, Senator Pan, who was a member of the California State Assembly at the time, introduced Assembly Bill 2109 (AB 2109) which required any parent who wanted a personal belief exemption (PBE) for their child for school-required vaccinations to be counseled by a licensed healthcare professional. This bill was modeled off of a similar bill from Washington state and was proposed as an effort to stem increasing personal belief exemptions in California by creating an additional step for parents to have to take to obtain a PBE. Washington state saw a one-time drop of about 20% in the PBE rate due to their law, which is what Senator Pan was expecting to see in California as well. He said there was a lot of support for the bill from the medical and public health communities and a vocal opposition headed by the National Vaccine Information Center, which he called a "misnamed" advocacy group. The bill eventually passed that same year, and the Senator talked about an important lesson in optics that he learned in the process. As he explained:

> *We had strong support from the physicians and public health community for the bill. They came out to speak for the bill, but the opposition, actually, mainly what they did is they brought in parents who claimed that their children were vaccine-injured. So, they organized parents who were misinformed about vaccines to come testify [during the Senate hearings for the bill]. But it just isn't, it's not a good dynamic to have doctors basically saying, "Well, you know, you're wrong," right? Telling a bunch of parents, "You're wrong," even when they are wrong. So, I recognized that was probably not a successful model for passing future legislation in that regard.*

Senator Pan explained that after AB 2109 went into effect, right around the time the California Department of Public Health was releasing vaccination and exemption data for the 2014-2015 school year in January 2015, the first few cases of the Disneyland measles outbreak were being confirmed. Senator Pan explained that his office started receiving calls from concerned parents who were establishing a grassroots, pro-vaccine organization called Vaccinate California as he and Senator Allen began writing SB 277. He described the process of organizing with pro-vaccine parents to go up against anti-vaccine parents, utilizing the same language of "parental right" in support of the bill.

> *A lot of the parents were calling in touch with each other and so they organized a grassroots organization called Vaccinate California [...] We organized parents with Vaccinate California, but then we're off on the bill, so. And I think it was really important that we had parents talk about, so what happens is the opposition will claim that vaccines injured their children and therefore they should have "parental choice." They call it "parental choice." I point out that they have a choice [to either vaccinate or homeschool] [...] So, we talked about, we had our parents talk about, what about our right for our kids to be safe in school and to go about safely in public spaces. So, we had parents talk about their children and their desire as parents to keep their children safe, with doctors backing them up saying, "And this is how we keep them safe. Through vaccines." Against the parents who said, "Well we don't want vaccines because we think vaccines are bad, even though we don't have evidence for that." (chuckles) So, it wasn't now just doctors telling parents, "Well, you should do this," and parents saying, "Well, we don't want to." We have, well, you claim parental rights? Well, these parents, our parents, other parents have parental rights, too. All parents have the right to keep their children safe.*

In contrast to AB 2109 where physicians were seen as working against parents, for SB 277, pro-vaccine parents were backed by physicians, organized, and operationalized against anti-vaccine parents during the legislative process.

While pitting parents against parents made for better optics, it disproportionately involved women and mothers. On the pro-vaccine side, the leadership of the organization Vaccinate California is made up of five women, four of whom highlighted their motherhood on their profile, presumably to represent the greater group of pro-vaccine mothers (Vaccinate California [VC] 2020). On the opposition, a social network analysis of the anti-vaccination "movement" on Facebook suggests that it is "primarily lead by women," with the vast majority of participants, 71.4%, being women (Smith and Graham 2019, 1324). This gender composition reflects broader cultural norms and expectations, with dominant views framing parenting and caring for children as generally mothers' responsibility, and vaccine-related decision specifically a maternal concern (Durbach 2002, Reich 2014, Smith and Graham 2019).

Organizing parents, mostly mothers, and positioning them as both supporters and opponents of vaccines puts mothers in the crosshairs for criticism from both sides: those who criticize mothers who vaccinate for "blindly following" doctors' orders and not thinking for themselves, and those who criticize mothers who do not vaccinate for being irresponsible, noncompliant, and putting their children and others at risk (Conis 2013, Sobo 2015). This dual burden on women and mothers reinforces the ideology of moral motherhood by emphasizing mothers' primary and exclusive responsibility for their children's wellbeing, at the same time supporting neoliberal expectations of mothers to make well-informed choices in the best interest of their individual child's health.

"A well-funded opposition"

As Senator Pan talked about the opposition against SB 277, he wanted to make clear that they were well-organized and well-funded. At the time, my understanding was that the opposition was made up of concerned parents, and mostly mothers, so I asked him to clarify who exactly was funding them. He openly provided insight:

> *The opposition is not a grassroots movement of parents concerned about vaccines. Let's be very clear about that, ok. Because that's what they pretend like they are. This is a well-funded opposition. They paid for one of the top lobbying firms in Sacramento to fight the bill, ok. They actually hired two lobbying firms. They paid for full-paid ads in the paper, they paid for tv ads, they bus people in. That all takes money. We estimate, because not all of it's reportable we don't know exactly how much money they spent, but we've estimated they spent at least half a million dollars in opposition to the bill. So, this is not just, oh, bunch of parents who are just fighting to protect their kids. This is a well-funded effort by people who have, this is at the level of people who have a monetary stake in the outcome. That bill was a threat to their economic well-being, to their future profits. So, they were willing to put money in to try to stop this bill, substantial resources, because they viewed it as a threat to their economic future […] [Vaccine hesitant parents], these are often well-meaning parents who have been manipulated by people who seek,*

> *who basically want to find a way to take their money from them. In other words, […] there's basically a small group of people who seek to personally profit out of raising fear and anxiety in these families and get them to buy products and give money to them.*

Senator Pan specifically named Dr. Bob Sears, Dr. Susan Humphries, and Dr. Joseph Mercola and his namesake company as prominent donors and supporters of anti-vaccine advocacy against AB 2109 and SB 277. As Senator Pan explained, they all have "something to sell" to vaccine hesitant parents who are searching for alternative ways to improve their children's health and wellbeing in lieu of vaccines.

When I researched Dr. Joseph Mercola after our interview, I found out that he is an osteopathic physician and owner of Mercola LLC, a multi-million-dollar company that sells natural health products and vitamin supplements. Dr. Mercola was the largest single donor to the National Vaccine Information Center (NVIC), a national anti-vaccine advocacy group, contributing more than $2.9 million, which accounted for approximately 40% of the group's funding (Satija and Sun 2019). On the Mercola website, there are posts that suggest that vitamin supplements, which are available for purchase on his website, are viable replacements for vaccines, with headline's like "Vitamin D is More Effective than the Flu Vaccine, Study Says" (Mercola 2015, 2017, 2020). In a recent "top story" post on their website, called "Pediatric Drug Poisoning is on the Rise," Mercola highlighted information from reputable public health and scientific sources, including the CDC and The Journal of Pediatrics, to raise awareness about the dangers of poisoning among children by pharmaceutical drugs (Mercola 2020). As Senator Pan suggested, these kinds of posts stoke fear and distrust of biomedical interventions, pharmaceutical companies, and the medical institution as a whole, which are already prominent sentiments among vaccine hesitant parents.

In the US, complementary and alternative medicine (CAM), or health-related practices that fall outside the boundaries of conventional biomedicine such as naturopathy, homeopathy, and vitamin supplements, are more commonly utilized and practiced by women compared to men (Doel and Segrott 2003, 131, Keshet and Simchai 2014, Neiberg 2011, Sointu 2011). While CAM practices are not inherently gendered, CAM is associated with socially constructed "feminine" qualities, such as gentleness, caring, naturalness, and emotion. At the same time, women gravitate toward CAM because it offers women ways to challenge those precise gender norms and inequities that exist within the patriarchal biomedical system; for example, the emphasis of CAM toward self-care challenges the traditional identities of women as caregivers to others; the clinical environment of CAM gives greater authority to the patient as an expert and active partner in their treatments, which challenges the hierarchical structure of biomedicine (Keshet and Simchai 2014).

The growth of CAM in so-called Western cultures follows the conceptual shift from health to "health-as-wellbeing," which functions to extend health issues and practices into other aspects of everyday life through individual, responsible consumptive practices (Burns and Davies 2015, Doel and Segrott 2003). The concept of wellbeing promotes holistic views of health combined with neoliberal values of self-responsibility and choice. In the postfeminist context, "health-as-wellbeing" becomes a way for women to gain agency and control over their bodies and life through responsible, healthy choices (Burns and Davies 2015). At the top of the Mercola website, the slogan reads, "Take Control of Your Health," harnessing the neoliberal, postfeminist call for self-responsible, informed consumerism toward holistic wellbeing. The CAM products, services, and information offered by Mercola, the largest single donor to anti-vaccine advocacy, are marketing to and exploiting vaccine hesitant mothers seeking alternatives to vaccinations by offering a way to practice self-responsible holistic care through consumption.

“There’s a consequence to that”

With the elimination of the personal belief exemption, homeschooling was the only option available for parents who wanted to avoid or delay school-required vaccinations for their children (aside from obtaining a medical exemption from a licensed provider) (CLI 2015). Senator Pan explained a major misconception among parents that opposed SB 277 who argued that they didn’t want to be “forced” to be vaccinate their children. He clarified the law and emphasized the purpose of the homeschooling option as a consequence to parents’ vaccine hesitancy:

> *There’s nothing in the law that requires your child to get vaccinated. There’s a consequence to that. The purpose of that consequence is not to punish them for not vaccinating their child. The purpose of that law is to protect the other children in the school. To protect the other children in school. (original emphasis)*

Since SB 277 passed, the number of children who are considered under-vaccinated and participating in private homeschool or independent study programs in California has dramatically increased, from 1,684 children (0.5% of state total) in 2016, to 6,502 children (1.2% of state total) in 2018 (2016, 2018). Over 90% of these children are concentrated in just five counties: Kern, San Diego, San Bernardino, Sonoma, and Stanislaus (CDPH 2018). While there is currently no data to connect this phenomenon directly to SB 277, some media reports suggest that parents are enrolling their children in private or charter home-based education programs to avoid vaccination requirements (Karlamangla 2019, Mays 2019).

With increasing rates of home-based education in California, the burden of the consequence of SB 277 falls disproportionately on mothers. While there are a variety of reasons why parents decide to homeschool their children, the majority of homeschooling in the US is facilitated by mothers (Apple 2013, Lois 2010, Stewart 2020). This is particularly true within gendered family structures where homeschooling is “almost always performed by at-home mothers in two-parent, heterosexual families with the father serving as the single wage-earner in the paid labor force" (Lois 2010, 422). Studies show that homeschooling is a labor-intensive task that not only involves teaching children but also researching curriculums, organizing materials, tracking progress, creating and maintaining a "proper" learning environment, in addition to the emotional and physical labor of caring for children while also instructing them (Apple 2013). Homeschooling can also have detrimental effects on mothers' mental health, through increased emotional distress, depressive symptoms, time-stress, pressure to perform as teachers, lack of discretionary time, and social stigma from those opposed to their decision to homeschool (Baker 2019, Lois 2016).

There is strong evidence that stricter exemption laws are effective in maintaining high vaccination rates and curbing vaccine-preventable disease incidence (Adrian et al. 2020, Goldstein et al. 2018, Goldstein et al. 2020, Mello 2019, Zier et al. 2020). My analysis suggests that SB 277 has gendered impacts which disproportionately burden mothers, compared to fathers, exacerbated by existing gender-based social and moral expectations of "good" mothers and unequitable division of domestic labor. These impacts are a product of the gendered process, from advocacy to opposition, and consequences of SB 277.

Intensive mothering and vaccine hesitancy

'Intensive mothering' has become a common form of parenting in industrialized, Western cultures, characterized as "child-centered, expert guided, emotionally absorbing, labor intensive, and financially expensive" (Hays 1996, 5). Intensive mothering ideologies are supported by three basic tenets, including the beliefs that 1) mothers are inherently better parents than fathers, 2) mothering should be child-centered, and 3) children are sacred, delightful, and fulfilling to parents (Rizzo et al. 2013, 615; see Hays 1996). This form of mothering emerged in the 1980s, as more and more women were participating in higher education and the labor force. As a push against changing gender norms, the promotion of intensive mothering was a way to re-establish traditional gender roles for women through motherhood and re-center motherhood as central to femininity; to restore patriarchal norms (Green 2015, Moore and Abetz 2016). The rise of intensive mothering also corresponded with the expansion of the privatized, commodified infrastructure of parenting, which included childcare, private schools, lessons, etc., an increasing number of activities and consumables required to enrich a child's development. Neoliberal rationalities that focused on individual maternal responsibility rather than social support of mothers and families further promoted intensive mothering (Caputo 2007, Green 2015, Wall 2010). New discoveries in children's brain development in the 1990s accelerated the trend of intensive mothering, emphasizing the importance of stimulation and secure attachment in a child's pre-school years for their future intellectual development. These discoveries further expanding mothers' scope of influence into more aspects of children's cognitive development, behaviors, outcomes, and their future potential (Budds et al. 2017, Wall 2010). The neoliberal notion of the "ideal" mother is one who is financially, physically, and emotionally involved at high levels, and spending any free time, energy, and money in raising their children (Faircloth 2009, 15, Hays 1996).

In the context of health, mothers and pregnant women are framed as the protectors of the fetus, infant, and child, but also a "potentially hostile environment" for the fetus if the woman does not appropriately regulate herself and her health (Atkinson 2014, Cairns and Johnston 2018, Lupton 2011, 638; Mackendrick 2014). Consequently, mothers and pregnant women often become the target of health interventions and the site of control, for the sake of the baby; they are told not to engage in risky behaviors and consumption practices, and encouraged to self-regulate and practice forms of intensive mothering as a way to protect the health and future potential of the child, throughout all stages of motherhood (Eagle 2019, Faircloth 2013, Johnson 2014, Knack 2010 Lupton 2011, Wiley et al. 2014). In the environment of intensive mothering and maternal responsibility, motherhood itself has become "imbued with the meanings of risk, danger, responsibility, and constant reflexivity" (Lupton 2011, 638); mothers are responsible for ensuring their children's success and, in turn, are accountable for any ills, failures, and misfortunes their child has ever, and would ever, experience.

"As healthy as possible"

> *I did a lot of things before the kids were born to remove heavy metals from my body because I thought maybe that was causing inflammation. So, there was a lot of thought before they were born about what I should try to get, what kind of shape I could get my body into before having them, to be as healthy as possible. And then what should go into their bodies to keep them as healthy as possible, not knowing what causes [my] colitis. – Sofia*

Even before her children were conceived, Sofia thought about how to get herself and her body "as healthy as possible" so she could give her future children the best possible start in life. In the public health context of pregnancy and breastfeeding (discussed further, below), the focus on women's bodies as potential vectors of pathogens and toxins to a fetus or infant places added pressure and responsibility on mothers toward the health and wellbeing of their children, regardless of the socio-economic, environmental, or genetic context (Bell et al. 2009, Lupton 2012, MacKendrick 2010, 2014). This perspective reinforces intensive mothering practices by emphasizing the individual mother's responsibility toward her own health for the sake of their children's health.

Sofia, a writer and producer with two children, suffered from ulcerative colitis, an autoimmune condition. Her doctor had prescribed her medications to control her symptoms, but she decided not to take them because she was concerned that some were classified as Category D drugs and could potentially harm a fetus, even though she wasn't pregnant at the time. She later became pregnant "with no drugs," which she was very proud about. During her pregnancy, Sofia explained, "I didn't want to put anything else in my body," so she refused the TDaP and flu vaccines, which are routinely recommended for pregnant women. She was worried that vaccines could cause inflammation, which could potentially affect her pregnancy.

Sofia's engagement with intensive mothering began prior to conception and continued through her pregnancy and once her children were born. Her primary concern was her children and what she could do to ensure their health, primarily by controlling what goes into her body and later, theirs. She wanted to eliminate any possible threat to her children's health that could come from her own body. While she was concerned with her health and controlling her own symptoms, it was in service to her future children's health. Five additional mothers in this study specifically discussed the various ways they prepared their bodies for pregnancy, including metal and parasite detox regimens, acupuncture, herbal treatments, and removing "silver" (dental amalgam) fillings from their teeth. This was the beginning of their journeys into intensive motherhood.

"It's not breastfeeding that increases your risk dramatically"

The health benefits of breastfeeding for both infant and mother are well-established and underpins the dominant public health discourse promoting breastfeeding in the US (Leung et al. 2005, Lawrence 2000, Monasta et al. 2010, Mortensen et al. 2002, Murphy 1999). Breastfeeding and infant feeding, in general, are areas of mothering that are highly moralized; since infants and children are represented as innocent and vulnerable, their health and feeding becomes a particular site of risk consciousness (Faircloth 2010; see also Lee 2007, Lupton 2013). Breastfeeding discourse invokes ideas around "good" mothers who prioritize their children's needs over, and sometimes at the expense of, their own (Murphy 1999, Faircloth 2009). Critical perspectives of "breast is best" messaging point to their exploitation of normative assumptions about mothers' role as the primary protectors of their children, and its neoliberal values that reinforces the maternal responsibility of breastfeeding despite the lack, or absence, of structural, economic, and social support for mothers (Acker 2009, Knaak 2010, Wolf 2007).

Among the mothers in this study, the ideology of "breast is best" was taken to heart, particularly in the context of their vaccine hesitancy. Zoe, a lactation consultant working at a large public hospital, exemplified how intensive mothering impacts ideas and practices around breastfeeding and immunity. As an advocate of breastfeeding, Zoe talked about its benefits and its curative powers, suggesting breastfeeding as a sufficient way for her to enhance her children's immune system in lieu of vaccines. Neither of her children were vaccinated. Zoe breastfed her son, who was seven at the time, until he was four and a half; she was continuing to breastfeed her daughter, who was three at the time. This kind of child-led, extended breastfeeding practice, "to full-term," represents one permutation of intensive mothering in accordance with the philosophy of "attachment parenting" (Fairchild 2009, Knaak 2010). Zoe attributed her children's relatively low risk of contracting infectious diseases, such as pertussis, to her own parenting and breastfeeding practices. She reinforced the ideals of intensive mothering through her decision to breastfeed "to full-term," even at the expense of her "own bodily autonomy." In doing so, she inadvertently blamed mothers who didn't breastfeed their children for their children contracting and dying of pertussis.

> *An outrageous number of pertussis cases a few years ago, because it comes in waves, these diseases. They go dormant for a bit and then they come back up, and then they go dormant for a bit and they come back up. And, when we want to be honest, the infants who are dying of pertussis had underlying health concerns and were not being breastfed. They were not being breastfed. So, breastfeeding does not reduce your risk, it actually is just normal. It's not breastfeeding that increases your risk dramatically [...] I think that committing to breastfeeding for the full-term, um, I think is part of, and without restriction. Like, their body knows what they need and so I'll just let them determine. So, in that sense, I've sort of given up*

> *a little bit of my own bodily autonomy, but I haven't yet had anything happen to them that breastmilk couldn't fix. – Zoe (original emphasis)*

While Zoe's views were on the extreme side, seven other mothers in this study specifically discussed breastfeeding and their reliance on what one mother described as the "powers of breastmilk" to "boost" their children's immune systems in the context of their vaccine hesitancy. They emphasized their breastfeeding practices to balance out vaccine hesitant behaviors that they knew were deemed "risky" by dominant public health, biomedical, and social norms. Four of these mothers breastfed "to full-term," until their children were or past the age of four. These intensive mothers attributed their children's health, their "never getting sick," and their "never having to go to the doctor" to their commitment to breastfeeding.

"Just don't want to do anything to mess that up"

Intensive mothering in the US plays out in a neoliberal environment that expects mothers to spend enormous amounts of time and energy towards collecting information, analyzing risks and benefits, and making educated, informed choices for themselves and their families in their own self-interest (Reich 2016). Every parent in this study (14; all but one were women) expressed concerns around vaccine safety and potential side-effects. Even with little to no scientific evidence to justify their high levels of anxiety, they worried about a plethora of acute and chronic conditions they believed could be caused by vaccines, ranging from adverse reactions, such as fever and seizures, to allergies, asthma, SIDS (sudden infant death syndrome), autoimmune disorders, cancer, cognitive, developmental, and behavioral issues, attention-deficit/hyperactivity disorder (ADHD), and autism. This heightened anxiety about the risk of vaccines demonstrates a change in risk consciousness in the context of modernity; risks that were once understood in terms of *probability* are now understood in terms of *possibility* (Fox 1999, in Lee et al. 2014). Uncertainty, or "the outcomes about which we cannot be sure at the outset," cannot be confronted rationally and therefore are met with anxiety (Lee et al. 2014, 11). In the face of this uncertainty and all of the possible negative outcomes, all of the parents in this study decided to delay or forgo their children's vaccines, going against routine recommendations from public health and biomedicine.

Rachel, a midwife, demonstrated this shift in risk consciousness in her decision-making process around vaccines. She felt the need to protect her daughter from all of the known, and unknown, risks of vaccines. This hypervigilance, or "anticipatory work of shielding their children," is emblematic of the "motherwork" involved in intensive mothering (Gurusami 2019, 129). In her calculation, the *probability* of her daughter being exposed to a vaccine-preventable disease was relatively low due to their socioeconomic and geographic position in the world; compared to all of the known, and unknown, *possibilities* of that could go wrong with vaccinating. Rachel's belief that her own childhood vaccinations could have contributed to her health issues as an adult further propelled her desire to protect her daughter from vaccines, which she believed could have irreversible effects on her daughter's health. She explained:

> *I feel like this is a decent basis for my [vaccine] hesitance to start. It's like, because we don't know. You can't prove to me they're safe. I'm not completely convinced they're not but to me in the middle, I'm not gonna vaccinate. So, um, I just want way, way, way more research, and maybe I'd like organic vaccines that are single [disease], you know, whatever [...] You feel like your kid is perfect and amazing and in great health and just don't want to do anything to mess that up. It's not like we're traveling to India or anything. – Rachel*

In the neoliberal context of intensive mothering and a social climate in which parenting has become so moralized, the perceived uncertainty around vaccines places mothers in a particular double-bind. They inhabit a space in which they are held fully responsible and accountable for making decisions around their children's health; however, in this case, those decisions are counter to dominant public health, biomedical, and social norms. Heather, a stay-at-home mom with one son, was navigating vaccine decisions in this precarious space. Heather had recently become vegan and was going through health issues that she believed stemmed from her gut health and microbiome imbalance. She thought of bacteria as a good thing, without differentiating between "good" bacteria (e.g. *Lactobacillus sp.*) from "true pathogens," bacteria and viruses that could cause serious illness (e.g. *Bordetella pertussis*). She tried a variety of homeopathic and herbal remedies, as well as allergy and genetic testing to help diagnose her health problems. She had seen a gastroenterologist and asked him if a recent vaccine she had received (Tdap booster) could have contributed to her gut problems; he didn't think so. Heather lamented about society's obsession with sterility and sanitation (against bacteria), while holding extreme views of purity herself (against chemical contaminants).

> *We have this kind of tradition of being this heroic, hypervigilant, clean society, and then we're backing up and going, "Wait, bacteria is important." Why? Right? That's what happens throughout history is that people make decisions that seem finite and then we realize later that it wasn't right, because that's life. And so here we are, my precious child who is brilliant and wonderful, and they want to put chemicals in his body. Why? I just want to know why, you know? – Heather*

Heather believed the outcomes of vaccines were still unknown and yet to be determined, and thus could not imagine putting them into her son's body, regardless of routine public health and biomedical recommendations. The view that children are innocent and vulnerable, and that mothers are accountable for protecting them from potential harms that could undermine their development, is another key feature of intensive mothering (Nelson 2010, Nomaguchi and Milkie 2020). When discussing their decisions to delay or refuse vaccines, nine of the mothers in this study specifically evoked language related to protecting their "precious," "tiny" children from vaccines. They didn't want to set them down the wrong path by vaccinating them "on day one of birth," "right out of the womb," especially in the face of such perceived uncertainty. In the context of intensive mothering, they were responsible for anticipating any *possible* harm, and protecting them. More importantly, if they failed to do so, they would be accountable for any possible illness or condition their child could face in the future.

Mothers' Experiences with Vaccine Hesitancy

In the US, women are often the link between their family and the healthcare system, making approximately 80% of the healthcare decisions for their families (Matoff-Stepp et al. 2014, Salganicoff et al. 2005). Among mothers in the US, about 75% reported taking charge of their children's health, compared to 20% of fathers (Gomez et al. 2018). The women in this study followed this trend, with the majority of mothers (10) reporting that they took the lead when it came to researching and making decisions about their children's vaccines (the one man who participated in the study said he deferred to his wife; two women made joint decisions with their partners; one woman did not mention their partner in their decision-making process). Ten women, in total, reported also working outside of the home. In the context of vaccine hesitancy and SB 277, these healthcare responsibilities created additional mental and emotional stress for the women in this study, who carried the brunt of the political and social consequences that came with being vaccine hesitant.

Judged, Shamed, and Bullied

When talking about their decision-making process and concerns around vaccines, all (14) parents in this study discussed the emotional aspects of their process. The most prominent experience (12) related to feeling judged, shamed, and bullied for being vaccine hesitant. In the biomedical setting, seven mothers discussed experiences with their providers where doctors were "very judgmental," "dismissive," and "condemning" towards them, rather than engaging with them about their concerns around vaccines. One mother told me she was called "irresponsible" at one of the three doctor's offices that refused to see her children due to their unvaccinated status. Another mother, Heather, said she sympathized with her friends who had had negative experiences with doctors but tried to "hold space" for those who were on the "other side" of the vaccine issue.

> *[Vaccine hesitant parents] go through hell and back sometimes. They get scrutiny, kicked out of [doctor's] offices, um, so there's that going on, too. Or, just to be made to feel shamed about, or you're stupid for making that choice [to delay or refuse vaccines]. Because, you know, and I was just telling my friend, I have to hold space for this other side of people that are saying, "You're gonna kill everybody if you don't vaccinate." So, there's that very extreme thinking there, too, um, and then we're shunning people and talking down to them rather than trying to understand each other. – Heather*

Heather's sentiments represented a general theme among the parents in this study: they wanted to better understand, and to be better understood. The negative interactions in the medical setting are problematic not only on a personal level for the mothers experiencing it, but it also reinforced parents' distrust in biomedical professionals and institutions, and reflects broader trends of negative interactions between medical professionals and women. Women in the US face higher levels of discrimination and differential treatment based on their gender. Women are often not believed or mis- or under-diagnosed by doctors, given lower doses of pain medication, and receive poorer care compared to their male counterparts (Govender and Penn-Kekana 2007, Hamberg 2008, Hoffman and Tarzian 2001, Krieger et al. 1993, Ruiz and Verbrugge 1996). Provider-patient interactions plays an important role in vaccine decision-making among parents. In the US, the percent of parents who refused one or more vaccines for their children almost doubled between 2007 and 2013, from 9.1% to 16.7%; in the same time period, pediatricians who reported encountering vaccine hesitant parents rose from 75% to 87% (Edwards and Hackell 2016). To address increasing vaccine hesitancy, the American Academy of Pediatrics (AAP) published guidelines for providers to follow when interacting with vaccine hesitant parents (AAP 2020). It does not recommend that providers kick families out of their practices or refuse services due to their vaccination status (Edwards and Hackell 2016). Rather, the AAP recommends that providers engage with vaccine hesitant parents and listen to concerns; partner with them for decision-making and personalize relationships; discuss the benefits and possible adverse events; and, discuss state laws for school entry (AAP 2020, Edwards and Hackell 2016).

In this study, six parents (43%) specifically spoke about feeling judged in their social group, including friends and family, and misjudged in general; for four of these parents, this led to feeling isolated and unable to talk to their friends and family openly as they went through their vaccine decision-making process. Lena, a preschool owner with a background in medical research, talked about feeling misunderstood when I asked her about the social effects that her vaccine hesitancy had on her life. She believed that her background in medical research gave her assessment and caution around vaccines credibility, and it made her upset to think that "everyone" thought that people who are vaccine hesitant are "uneducated" or only concerned about autism.

> *I'm incredibly educated, and I come from a scientific background. I understand medical research. And it's because of that that I'm extra cautious […] I mean, I understand herd immunity and we as a group can be at greater risk if that group gets too big, but almost no one I know is in that [anti-vax] group. We're all in here [the middle] somewhere else in this spectrum. So, and I think if there was more discussion about delayed versus anti, and one-at-a-time versus anti, you know, that there might be more like, "Oh, ok. I get it. That makes sense, I don't need to attack these people, I don't need to…" and stuff like, the stuff that I read, "Oh, they don't know what they're talking about. They're all uneducated. They only think that their kids are going to get autism." That's actually not my concern at all. Of course, I don't want to get that but that is like way down, and, oh maybe that slight chance of, yeah. So, that's why. I want this [middle] section heard, and, yeah, and also show that like we're not just like, you know, hippie parents who don't know. In fact, most of the people around here in this area that are more of, like, crunchy, hippie, alternative lifestyle and stuff. We're all incredibly educated, you know. We're not, yeah, we all have college degrees. We all have, you know, there's psychologists, midwives, myself who was in research, you know, it's like, yeah. So, I just kind of*

> *want to debunk some of these myths that are out there [about anti-vax], I guess. Yeah. – Lena*

This judgement and social isolation extended to the children of vaccine hesitant parents. Lena also recalled an instance when her son was barred from going with her to her friend's house because he had not received his vaccines. Lena had heard of similar experiences happening to other friends as well.

> *I have a friend who wouldn't let me bring my son to her house because he hadn't had his, when she was pregnant, he hadn't had his MMR yet or something like that. And like, ok. He doesn't have [measles, mumps, or rubella], you know. I understand he could have picked it up on the plane ride to New York, I guess? You know, but I'm like that's your, you know, that was her decision and, you know, […] that was one of the few times where I've had to deal with it with a friend. I have other friends who they have been uninvited. They've been told that they can't come over to their friend's house anymore because her kids aren't vaxxed, so. And this is one of her best friends who was just like, "I just, I'm not comfortable with you guys coming over anymore." – Lena*

Sense of Community

In contrast to the women who experienced social isolation, four women (29%) in this study felt that they found a *stronger* sense of community among like-minded, vaccine hesitant peers. This is especially significant in the context of information-seeking behaviors among vaccine hesitant parents. Parents' people networks, i.e. friends, family, peers, were found to have a significant impact on vaccine-related decisions (Brunson 2013, Sobo 2015). If parents are feeling socially ostracized and isolated from broader society due to their vaccine hesitancy, particularly at points in their decision-making process when they are open to receiving information, they may be more inclined to turn to fellow vaccine hesitant parents for social support, and subsequently "double-down" on their vaccine hesitant beliefs and behaviors (Brunson 2015).

Stress

Over half of the mothers in this study (8; 27%)) talked about feeling "stressed" or "overwhelmed" throughout the vaccine decision-making process, researching every single vaccine, their ingredients, cross-referencing sources, and navigating the new requirements under SB 277 and what that meant for their families. While each mother had their own strategy for seeking out information and making decisions around vaccines, the overarching theme was that it was and intense and stressful process. Approximately 90% of American women make healthcare decision for members of their families (Matoff-Strepp et al. 2014). Together with escalating intensive mothering norms, these gendered phenomena places increasing pressure on mothers in the US (Nomaguchi and Milkie 2020). One of the key neoliberal characteristics of intensive parenting, parental determinism, i.e. the assumption that individual parents' actions determine children's outcomes, severely undermines mothers' well-being (Nomaguchi and Milkie 2020). Intensive mothering practices are linked with a variety of negative mental health consequences, such as increased stress and guilt, and reduced life satisfaction (Rizzo et al. 2013, Sutherland 2010, Tummala-Narra 2009).

Lena, whose son was five at the time of the research, was trying to figure out how to catch her son up on his vaccines so he could enroll in preschool. Her experience exemplifies the stressful intersection of intensive parenting practices and the responsibility of making vaccine-related decisions for her son.

> *It's been a huge stress. I'm consumed by it, and I'm just like, I seem like a crazy person. I don't talk to people about it because I would seem crazy. – Lena*

On top of all of the vaccine decisions and catch-up appointments, Lena and her family were in the middle of packing up their house for an imminent move; the owners of the house they were renting were selling the house. This required Lena to urgently consider her son's school options, with his entire future in mind.

> *Unfortunately, I'm moving from what would have been a really good school here to a not a great school there. And this whole time I'm like, I hope we move maybe after he starts kindergarten, that way he's in and then, but it's all happening right now. So now we're losing our good school. It's frustrating. I could enroll him before we leave but because of the new law [SB 277], I can't. And, then I feel like, did I totally just… There's so much pressure nowadays on getting into the right schools. Did I totally just fuck myself for the rest of his life because he didn't have his Hep B shot when he was 4 instead of right now?*

The weight on Lena's shoulders to make the right decisions for her son, for his vaccines, for moving, and for his school, and more broadly, for his future, was heavy. Other parents expressed similar levels of anxiety and stress. Sofia could not recall specifics about her process since her children were three and five at the time and it had been a couple years since she was in the thick of it, but she remembered that she clicked on "every single article [online] about everything, pro and con" related to vaccines. Ariana simply summed it up: "It's been so stressful. Research, research, research." The experience of Lena, Sofia, Ariana, and other mothers' in this study demonstrate the disproportionate amount of mental and emotional work put on vaccine hesitant mothers to navigate their children's health landscapes after the elimination of the personal belief exemption (SB 277).

Summary

This chapter revealed several ways in which vaccine hesitancy is gendered. The political process around Senate Bill 277, from the support and opposition, to the political consequences overwhelmingly involved and impacted women and mothers in California. Mothers were operationalized during the legislative process and backed by powerful lobbying groups on either side. From the mothers' accounts, their decisions around vaccines were influenced by their practice of intensive mothering, a child-centered, resource-demanding parenting ideology that overemphasizes mothers' exclusive and primary role in ensuring their children's health and overall success in life. These dynamics reinforce, and were reinforced by, existing social and ideological expectations of motherhood, putting additional emotional and mental stress on the mothers in this study.

For mothers in this study, having a critical view of vaccines, and everything that goes along with it, is in line with the practice and ideology of intensive parenting particularly in a neoliberal society that puts the "burden of responsible consumption" on individual citizens (Kaufman 2010, 23; see also Sobo 2015). As a vaccine hesitant parent, it takes an enormous amount of time and mental and emotional work to question medical and public health experts and go against their recommendations which is includes, but is not limited to, researching vaccines and all the probable, nay possible, short-term side effects and long-term health outcomes; finding a doctor that supports your approach, co-developing an alternative vaccination schedule, and going to additional follow-up appointments required to follow that schedule; paying for additional follow-up visits; finding and purchasing CAM supplements that boost the immune system or counterbalance the possible negative effects of vaccines; or, obtaining a medical exemption; staying vigilant against exposure to vaccine-preventable diseases among friends, family members, and their community; and, managing social stigma around vaccine hesitancy. These efforts by mothers to be engaged and hyperaware are in service to their children and their health, but at the expense of their own emotional and psychological wellbeing.

CHAPTER 8: ANALYSIS AND DISCUSSION

Introduction

In this chapter, I discuss the findings of this study and the theoretical and applied implications of each of the themes presented in the analysis. I summarize the immediate outcome of SB 277 in California with relation to vaccination rates, exemptions, and homeschooling, and present a snapshot of vaccine legislation in the US.

Individualized Risk

Parents in this study perceived vaccines as an individual intervention with individual risks; they assessed and managed their risks through individualized processes and individual actions. This trend toward individualization is representative of broader trends in the US towards more individualized, personalized healthcare, following neoliberal market individualism (Basu 2011, Burris 1997, Chan and Ginsburg 2011, Hamburg and Collins 2014, Szusza 1997). While more individualization can produce more effective treatments for some individuals for certain public health conditions, such as obesity and diabetes (type II) (Franz, Boucher, and Avert 2013), adopting individualized perspectives to public health issues more broadly can be problematic. When public health issues are perceived as individual health problems, the social, economic, political, cultural, and structural factors that contribute to one's vulnerability or resilience are overlooked (Parmet 2009); the impacts that individuals' health have on each other and the community are also ignored, particularly in the context of communicable diseases. Emphasizing neoliberal approaches to health can promote blame and reinforce negative assumptions around groups that are structurally vulnerable to “sociomedical” conditions, while at the same time, inflate perceptions accountability among privileged groups (Farmer 1997, 347, Nichter, Oczarzak). This dynamic is illustrated by parents in this study who adopt highly individualized approaches to risk assessment and management around vaccines and vaccine preventable diseases. Parents acted against vaccination recommendations and found ways to circumvent school requirements, demonstrating structural forces that privilege their ability to make individualized health decisions for themselves and their families. In other words, the socioeconomic, geographic, and immunological privilege of the vaccine hesitant parents in this study, due to higher socioeconomic status, location in the so-called Global North, and relatively high herd immunity within their own communities are what provided protection for their unvaccinated children from both vaccine-preventable diseases and potential complications due to them. Meanwhile, those that are already vulnerable, including infants, elderly, pregnant women, immunocompromised persons, and those who have structural barriers to access routine vaccinations become more vulnerable to VPD due to deteriorating herd immunity and subsequent increase in VPD outbreaks.

Parents specific concerns and assertions to delay or refusal the Hepatitis B (Hep B) vaccines call into attention concepts of “at-risk” groups, blame, and citizenship, in this case sexual citizenship (Reich 2016). From the public health perspective, the Hepatitis B vaccine is given shortly after birth not because newborns are at highest risk but to provide a vaccination against a serious disease which will protect individuals into adolescence and adulthood, when they are less likely to keep up with their vaccinations (Conis 2011). Parents in this study refer to the common modes of transmission for Hep B, of sexual contact and injection drug-use, to determine that their children were not in need of the vaccine at the age it is recommended. In doing so, they are not only making decisions for them at the time, but also for the ideal, healthy versions of their future adult children. Parents' vaccine decisions for their children, particularly around HPV and Hep B, are shaped by their aspirations for and expectations of their children's lives and sexual futures (Reich 2016). The individual processes of risk assessment and management that ultimately lead to individualized vaccine choices that are counter to the routine recommendations are representative of neoliberal parenting ideals, that parents are expected to make informed, responsible, self-interested decisions for their children based on the competitive pursuit of their future success. When these processes play out in neoliberal environments of institutional distrust, parents rely on other, nonauthoritative forms of knowledge to inform their health decisions. In the case of the parents in this study, this led to a trend of demedicalization supported by individualized approaches to health characterized by responsible, informed, precautionary consumption.

Institutional Distrust and Challenging Biomedical Authority

Parents' perceptions of conflicts of interest between the pharmaceutical industry and policy makers contributed to further distrust of institutions and their representatives, alike. These perceptions were not inaccurate (and are common knowledge), if misguided. Market Watch reported that pharmaceutical lobbyists spent $70 million in 2018, the second highest level ever recorded; it was the highest in 2009, at $87 million, when the Affordable Care Act was introduced to congress (Reklaitis 2019). Parents' rationales were multifaceted and supported by logics of risk that were based on individual experiences, knowledge, collective memories, and their evaluations of expert institutions; these rationales are not easily contestable with scientific, evidence-based information, particularly due to their institutional distrust. In their approaches to health and vaccines, parents existed in a liminal space including both "good" and "bad" health behaviors in relation to biomedical norms: "good" by being highly engaged, integrative, and exclusively breastfeeding, but “bad” by rejecting conventional biomedicine and delaying or refusing vaccines for their children.

Several knowledge systems exist in society; sometimes they exist in parallel but more frequently, one gains dominance and legitimacy over others (Jordan 1997). For parents in this study, alternative health systems ran parallel with biomedical health systems; they moved between them to meet their needs and the needs of their children. Rather than taking part in the hierarchical structure of medical care where biomedicine is at the top, they created a horizontal structure of authoritative knowledge in which alternative health providers, biomedical doctors, their social network, and they themselves were all integral parts. This horizontal structure follows what Jordan and colleagues found in their studies of childbirth in the Yucatan, where “no one was in charge,” and women drew from a larger body of wisdom that was assembled from various people in the community and their knowledge, experiences, stories, and remedies (Jordan 1997, 60). Parents in this study took this horizontal structure of knowledge and applied it to their overall approaches to health and their decisions around vaccines in the context of institutional distrust. While their approach to vaccines is counter to biomedical recommendations, more integrative and engaged approaches to health generally tend to yield better health outcomes, produce higher patient satisfaction, and be more cost effective (Crocker et al. 2017, Herman et al. 2012, Hibbard and Greene 2013).

Pluralistic approaches to health were the norm well into the twentieth century in the US, with people commonly integrating alternative providers, midwives, and various folk healers into their medical care. As allopathic, or conventional biomedical, knowledge gained dominance and cultural authority, other knowledge systems became devalued and delegitimized following the general process by which hierarchical knowledge structures are constructed (Jordan 1997). Public health initiatives, particularly in the areas of maternal and child health, are challenging this top-down approach and incorporating “common sense,” integrative approaches in the biomedical setting (Alves and Rosa, 2007, Bodeker and Kronenberg 2002, Hawk et al. 2012). For example, baby-friendly hospital initiatives, which provides guidelines and structural support for breastfeeding initiation, have been effective in improving breastfeeding initiation and exclusivity in hospitals in the US (Bass et al. 2020, Merewood et al. 2005, Naylor 2001, Perez-Escamilla et al. 2016, Philippe et al. 2001). Also, policies that promote and support midwifery care in the hospital setting have the potential to increase efficiency and health outcomes for women and newborn infants (Renfrew et al. 2014, ten Hoope-Bender et al. 2014).

Gender and Vaccine Hesitancy

The responsibility of managing health and health decisions, including vaccine decision, for children have historically and still primarily fall on women and mothers. While I wasn’t expecting gender, moral motherhood, and intensive mothering to play such a prominent theoretical role in my analysis, they emerged as major themes that extends across each chapter of this dissertation. Mothers were harnessed/exploited by political and corporate interests on both sides during the legislative process of Senate Bill 277, pitted against each other and vilified in the media; mothers carried the brunt of the emotional, mental, and psychological burden and political consequences of the ongoing “vaccine debate.”

The prioritization of the mother-child relationship above all else, a central tenet of intensive mothering, regardless of whether the mother works outside of the home or not, undermines women’s happiness while at the same time, keeps the focus on private problems rather than on public, structural issues that promote and exacerbate gender inequities, such as the lack of paid family leave, universal childcare, and quality public education (MacDonald 2013). The vaccine hesitant mothers in this study focused their time, energy, (mostly-white) privilege, and social capital on improving the life chances of each of their individual children through privatized channels, such as individualized vaccination decisions, private and charter schools, and cash-only private healthcare providers, rather than collectively acting to make broader structural changes that could yield social improvements for the wider population.

This analysis is not meant to place the burden of responsibility back onto women and mothers to solve gender inequities, rather to illuminate how vaccine hesitancy, in concert with intensive mothering, acts to reinforcing traditional, patriarchal gender norms and oppressive strucutres. I argue paradoxically (in earlier chapters) that vaccine hesitant mothers challenged patriarchal, hierarchical power structure of biomedicine through their access and utilization of nonauthoritative knowledge in their demedicalized approaches to health. Vaccine hesitancy is complicated; it plays out in complex, multidimensional ways to both challenge and reinforce structures of power, of biomedicine, authoritative knowledge, and gender.

Post-Senate Bill 277

When California passed Senate Bill 277 (SB277) in 2015, it was the first state in over three decades to eliminate all nonmedical exemptions for childhood vaccinations required for school entry (Colgrove and Lowin 2016, Mohanty et al. 2019). In 2019, the US experienced the highest number of measles cases since 1992; there were 1,249 cases across 31 states, including 22 outbreaks (CDC). That same year, Washington, Maine, and New York followed California's lead in eliminating nonmedical exemptions. In this chapter, I review the immediate outcome of Senate Bill 277 and the elimination of the personal belief exemption in California and its effect on vaccination rates and medical exemptions. I provide a snapshot of vaccine-related legislation in the US and challenges around vaccination policies. Finally, I review public health tools and interventions that have been developed to assess and address vaccine hesitancy.

Immediate Outcome of Senate Bill 277

After California passed Senate Bill 277 (SB277) in 2015, there was a steady increase in the vaccination rate among kindergarteners in the state. In 2015-2016 school year, the year prior to SB277 going into effect, the vaccination rate among kindergarteners in California was 90.5%; by the 2018-2019 school year, the vaccination rate was up to 94.8% (CDPH 2016, 2019). Conditional entrants, defined as children who had not received all vaccine doses but were not considered overdue due to age or temporary medical exemptions, sharply declined from 6.7% to 1.7% between 2016 and 2018 (CDPH 2016, 2019, Pingali et al. 2019). In general, SB277 was effective in bringing vaccination rates back up to maintain community immunity (Olive et al. 2018).

There remain vulnerable pockets of low vaccination throughout the state (Mohanty et al. 2019, Olive et al. 2018). This is due, in part, to increased numbers of medical exemption, particularly in areas that previously had high rates of personal belief exemptions (PBE) (Delamater et al. 2017). For example, for the 2015-2016 school year, the average PBE rate in California was 2.4%. In Sonoma county, the PBE rate that year was 4.8%, twice the state average; by 2018-2019, the medical exemption rate increased 17-fold, from 0.2% to 3.4%. In Marin county, PBE rate for the 2015-2016 school year was 5.9%; the medical exemption rate increased by 12.5 times, from 0.2% to 2.5% by 2018-2019 (CDPH 2016, 2019). After SB277, the average medical exemption rate rose from 0.5% to 0.9%, with the rate at private schools (2.4%) more than triple the rate at public schools (0.7%) (CDPH 2016, 2019). In 2019, 105 schools in California had medical exemption rates over 10%, with 31 of those schools with rates over 20% (Ostrov 2019). Overall, the reduction of nonmedical exemptions due to SB277 offset new medical exemptions and improved overall vaccination rates in California, particularly in “high-risk” counties that had the lowest vaccination coverage prior to SB277 (Nyathi et al. 2019)

Senate Bill 276 (2019)

The increased number of medical exemptions after the passage of SB277 caused frustration and concern for health officers and local public health departments in California around processing, managing, and providing technical support to schools (Monhanty et al. 2018). Local public health departments reported variations in the interpretation and implementation of SB277 due to the bill’s vague language, and in the absence of a centralized review of medical exemptions, there were no standards for which specialties of physicians could provide exemptions, which conditions qualified as valid contraindications for vaccinations, tracking medical exemptions, and how to report questionable medical exemptions (Mohanty et al. 2019). To address these problems, in February 2019, the midst of the country’s worst measles outbreak in decades, California legislators introduced Senate Bill 276 which created a system of oversight that required California Department of Public Health to annually review vaccination reports to identify schools with vaccination rates lower than 95%, physicians that submit more than five medical exemptions in a calendar year, and schools that do not report their vaccination rates to the state (California Legislative Information [CLI] 2019). The bill was approved by Governor Gavin Newsom on September 9, 2019, just over three years after SB277.

Snapshot of Vaccine Policies in the US

Support and opposition around vaccination laws continue in California and around the country. In general, there has been an upward trend in vaccine legislation in the US in the last ten years spurred on by falling vaccination rates and increasing vaccine-preventable disease outbreaks

(Goldstein et al 2018, Yang et al 2015). State legislators proposed 175 bills around childhood vaccinations between 2011 and 2017. While the majority (53%) of bills sought to expand access to exemptions for vaccinations required for school entry, the bills that proposed further restrictions on exemptions were more likely to pass into law (Goldstein et al. 2018). Between 2006 and 2018, 42 states and territories proposed legislation to require the HPV vaccine, fund the vaccine, or provide education and outreach around the HPV vaccine (National Conference of State Legislature [NCSL] 2018). While at least 25 states enacted HPV vaccine-related legislation, only Rhode Island, Virginia, and the District of Columbia were able to successfully pass bills that required it for school entry (NCSL 2018).

State legislators face many challenges in eliminating nonmedical exemptions. Increasingly, vaccine-related bills are framed, supported, or opposed using ideological and popular beliefs rather than scientific evidence. In 2015, New Jersey's 2015 Assembly Bill A497 erroneously linked the Hepatitis B vaccine with autism (Goldstein et al. 2018). In 2020, parents in Maine proposed a referendum to the repeal a new law eliminating nonmedical exemptions on the basis of personal freedoms (NPR 2020). There are also ethical arguments supporting and opposing vaccine legislation, primarily centered collective action, justice, and moral obligation toward one's community, versus free will and parental autonomy, i.e. parental choice (Dawson 2018, Giubilini et al. 2018, Hendrix et al. 2016 Patryn and Zagaja 2016). Proponents of vaccination requirements argue that one has a moral obligation to the principle of group beneficence, to contribute to herd immunity if you are healthy and able. Opponents argue that mandatory vaccinations violate parental autonomy to make decisions pertaining to their children's health (Dawson 2018, Giubilini et al. 2018).

Several national medical organizations support stricter vaccination laws as a way to improve the effectiveness of vaccines, protect individual health, and promote community health (Goldstein et al. 2018). In 2019, eliminating nonmedical exemptions topped the priorities of the American Academy of Pediatrics (AAP) Annual Leadership Forum (AAP 2019). As of 2020, all 50 states have specific legislation requiring vaccinations for school entry. Religious exemptions are available in forty-five states and Washington, D.C., and personal and philosophical belief exemptions are allowed in 15 states (NCSL 2020).

CHAPTER 9: RECOMMENDATIONS AND CONCLUSION

Introduction

In this chapter, I summarize my findings, situate them within the literature and our global public health landscape, and consider directions of future research. I provide an overview of select tools and interventions that have been developed to assess and address vaccine hesitancy and discuss future directions in vaccine hesitancy research. Finally, I make practical recommendations at each level of the Social Ecological Model, aimed at public health practitioners and health policy makers.

Summary of findings

In this dissertation, I presented three major themes that emerged from ethnographic analysis of in-depth interview with vaccine hesitant parents in Southern California. Using an overarching political economic framework, I applied theories of risk and relational trust through a gendered lens to 1) identify the underlying factors that shaped vaccine hesitancy, 2) examine vaccine-related strategies, decisions, and behaviors in the context of Senate Bill 277 and the elimination of the personal belief exemption, and 3) understand the social and cultural impacts that Senate Bill 277 had on vaccine hesitant parents in Southern California.

This study showed that vaccine hesitant parents applied highly individualized processes of risk assessment and management around vaccines and vaccine-preventable diseases, while disregarding the collective function of vaccine, of maintaining herd or community immunity, and their responsibility to contribute to it. Their individualized processes included internalization of risk as vulnerabilities, attributing their children's potential risk of adverse reactions to vulnerabilities that were passed down from parents or inherent to the individual child. In this context, parent's delay or refusal of vaccines can be viewed as their expressions of agency to reduce their sense of vulnerability and enhance their perception of control, through individual vaccine decisions and actions. This analysis is framed by Nichter's model of harm reduction (2003) which, to my knowledge, has not yet been applied to analyzing vaccine hesitant behavior. In lieu of vaccines, parents individually took on the responsibility to protect their children from communicable diseases by enhancing their health through individual actions, through deliberate consumption of "high quality," organic, low-sugar foods and use of non-toxic household products, demonstrating and reinforcing neoliberal capitalist ideologies of self-responsibility through informed consumption. These findings are consistent with existing social science literature of vaccine hesitancy that found neoliberal values and practices permeating health and vaccine decision and behaviors (Burns and Davies 2015, Reich 2014). The delay or refusal of vaccines as a way to avoid toxins was theorized as a form of precautionary consumption, a concept coined by Norah Mackendrick in her analysis of mothers' efforts to mitigate their and their children's exposure to environmental toxins through vigilant consumption practices, particularly in deregulated, privatized neoliberal political economic environments (2010, 2014). While Mackendrick does not apply the concept of precautionary consumption to analyze vaccine hesitancy, I argue that parents' refusal or delay of vaccines is a form of precautionary consumption, particularly in the neoliberal health system in the US where individual patients are encouraged and expected to make individualized, informed decisions about their health and healthcare. In their individual actions and consumption practices to promote their and their children's health, vaccines were one of many health commodities parents in this study chose to include or exclude in their overall approaches to health care.

Secondly, this study found that an environment of institutional distrust was a driving force behind parents challenging biomedical authoritative knowledge, prioritizing other forms on knowledge, and ultimately demedicalizing their approaches to health and healthcare. Perceived conflicts of interest between the pharmaceutical industry, biomedical and public health institutions, and the US political system further eroded trust in vaccines and the systems and their representatives involved in vaccines, including doctors, hospitals, vaccine research, and schools. In the absence of institutional experts parents trusted, they sought information from their family and friends, fellow moms, alternative medicine providers, and trusted their instincts as mothers and experts of their children and constructed their own systems of knowledge with regards to vaccines. In doing so, they challenged the patriarchal hierarchy of biomedical knowledge and asserted their primary roles as health decision-makers for their children and their families. In the context of their logics of risk which were informed by individual experiences and knowledges, it was rational for parents to delay or refuse vaccines for their children. These findings support existing literature that find trust in systems and their representatives play an important role in parents' vaccine decisions, to delay or refuse in this case; perceptions of conflicts of interest, particularly driven by profit, erodes the trust in individual systems as well as the system as a whole (Attwell et al. 2017, Benin et al. 2018, Casiday et al. 2006, Glanz et al. 2013, Sobo 2015). In promoting their demedicalized, "natural" approaches to health, which excluded vaccines, the mothers in this study were continuing a long tradition of challenging biomedical patriarchy.

The third and final theme discussed in this dissertation was gender, and the ways in which the legislative process of Senate Bill 277 (SB 277), from support to opposition to political consequences, overwhelmingly involved and impacted women and mothers. This study showed how vaccine hesitancy traced the principles of intensive mothering, of high levels of engagement and investment of resources, which reinforced traditional gender norms and expectations of primary and exclusive maternal responsibility that are driven by patriarchal, neoliberal, capitalist ideologies. This study revealed that the process and the experiences of vaccine hesitancy, in concert with intensive mothering practices, created disproportionate emotional and mental burden on mothers in this study. These findings follow other works of social science research that examine the impact of neoliberal values and intensive parenting practices on vaccine hesitant mothers (Reich 2014, Sanders and Burnett 2019). The gendered processes of vaccine hesitancy highlight the contradictory pressures on women and mothers and persistent gender inequities in broader society. On one hand, mothers are expected to take primary and exclusive responsibility for their children and make responsible, "informed" decisions in their best interest, as ideal neoliberal citizens; yet when they do so around vaccines and act against institutional recommendations disseminated by patriarchal systems of power (i.e. biomedicine, the state), they experience harsh social and political consequences. In the neoliberal context of withering social support for parents, families, and children, mothers in this study, again, take on the responsibility to make health decisions in the best interest of their individual children, often through privatized channels. In doing so, vaccine hesitant mothers are represented by popular media as privileged, selfish, and ignorant. Mothers were mobilized as the public face *of both sides* of the "vaccine debate" during the legislative process for SB 277, while corporate interests operated behind closed doors. To my knowledge, there is a gap in critical feminist analysis of childhood vaccination policies in the US that analyze how gender impacts the process and outcomes of vaccine-related legislation. The mother-vs-mother optics that were manufactured during the process of SB 277 exemplifies the double-bind that women and mothers are often placed in not only in the context of vaccine hesitancy but in practically every other aspect of neoliberal American society.

The "anti-vax movement," as it is popularly referred to at times, is driven by a large majority of women and mothers, in in-person and online platforms. Historically and presently, women and mothers have been instrumental in advancing social movements against social, economic, racial, environmental, and gender-based injustices and have led to broader structural and institutional changes (Brown and Fergusson 1995, Carson [1962] 2002, DuBois 1975, Garza, Tometi, and Cullors 2014, Meyer and Whittier 1994, Lorde 1993, Minkoff 1997, Rosen 2013, Thunberg 2019, Watters 2017, Zurrbriggen and Anzorena 2013). While past and current anti-vax movements were and still are primarily led by women and mothers, the current iteration of the movement in the 2000s is distinct from previous anti-vax and other social movements in that the aim is to enable more individualized decisions and "choices" in the private arena to the benefit of individual children and individual family units, rather than toward broader social change. This anti-vax movement is firmly rooted in neoliberal capitalist ideologies, promoting individualism at the expense of social benefit and cohesiveness.

Addressing Vaccine Hesitancy: Tools and Interventions

Several tools have been developed to assess vaccine acceptance and hesitancy, primarily in survey form to measure key facets and psychometrics that impact vaccine hesitancy and acceptance in various contexts. The domains touch on institutional trust, perceptions of risk, safety and effectiveness of vaccines, and values and affect associated with vaccines (Larson et al. 2015, Massimi et al. 2017, Opel et al. 2011, Sarathchandra et al. 2018, Shapiro et al. 2018). These surveys are primarily designed to be used in the clinical setting by providers to identify vaccine hesitant parents and follow-up interventions that may be effective in increasing their intent to vaccinate their children and improving vaccine uptake. Evaluations of one popular screening survey tool, the Parental Attitudes about Childhood Vaccines (PACV) survey (Opel et al. 2011a), reveal mixed results indicating that while the survey is easy to administer and effective in categorizing parents on a linear hesitancy scale, there are additional domains, such as communication, media environment, health approach, and provider-patient relationship, that have important impacts on parents' vaccine decisions and behaviors that are not included in the survey (Bianco et al. 2019, Domek et al. 2018, Napolitano et al. 2018, Oladejo et al. 2016). In this regard, developing a screening survey tool that is easy to use and administer, such as the PACV survey, that can also be customized for use in specific socio-cultural, regional, or practice settings would address some of the limitations with survey instruments. This can be done by expanding the survey tool to include other domains but allowing the provider to select what domains are most relevant in their practice.

There have also been a number of interventions that have been designed to address vaccine hesitancy and improve vaccine uptake, with mixed results. A value-based campaign called "I Immunize" in Australia appealed to values, ideologies, and identities around social justice, parenting, alternative lifestyles (e.g. homebirth, baby-wearing, cloth diapering), and vaccinating (Attwell and Freeman 2015). There was an overall positive response around the campaign's messages which were disseminated through a website featuring local residents and their testimonials. However, it further alienated some parents that were already vaccine hesitant. These results suggest that this type of intervention could be effective as one part of an overall campaign with additional efforts to reach other hard-to-reach groups (Attwell and Freeman 2015). In another web-based intervention, parents were presented with messages that were designed to reduce misperceptions about vaccines, such as the MMR vaccine-autism link (Nyhan et al. 2014). Parents were randomly assigned to take part in four interventions that presented 1) information explaining the lack of evidence supporting the MMR vaccine-autism link, 2) information about the dangers of measles, mumps, and rubella, 3) images of children with measles, mumps, and rubella, and 3) a dramatic narrative about an infant who almost died due to complications measles. Although the intervention that refuted the MMR vaccine-autism link was effective in reducing that particular misperception, none of the interventions were found to increase intent to vaccinate. Moreover, for vaccine hesitant parents, refuting the MMR vaccine-autism link further decreased intent to vaccinate (Nyhan et al. 2014). These studies highlight the complex, context- and vaccine-specific nature of vaccine hesitancy and acceptance. The decision to delay or refuse vaccines made by parents in this study were not necessarily based on ignorance or lack of awareness of the benefits and risks of vaccines. Rather, they were ideologically driven and informed by neoliberal values, institutional distrust, and dynamic impacts of gender within the healthcare setting. My findings highlight the value of in-depth, qualitative analysis in revealing the experience of vaccine hesitant parents and the root of vaccine-related ideas and beliefs that inform their decisions and behaviors. Further qualitative research is necessary to evaluate existing interventions within specific political economic contexts, and to develop effective interventions that can be tailored toward parents with varying levels of vaccine hesitancy and acceptance driven by a variety of ideologies and values (Jarrett et al. 2015, Sadaf et al. 2013).

Parents continue to cite their physicians and providers as their most trusted source of vaccine-related information (Barrows et al. 2015, Glanz et al. 2013, Opel et al. 2014, Paterson et al. 2016, Smith et al. 2006). As such, providers play a critical role in vaccine uptake. Studies suggest that providers can have a positive impact on parents' decisions to vaccinate their children by communicating honestly and openly about the benefits and risks of vaccines, fostering respectful relationships with parents, and periodically revisiting the topic of vaccines with vaccine hesitant parents (Barrows et al. 2015, Smith et al. 2006). On the flip side, providers can have an enabling effect on vaccine hesitant parents to delay or refuse routine vaccinations for their children (Barrows et al. 2015, Jones et al. 2018, Smith et al. 2006). Providers, just like anyone else, have varying beliefs, concerns, and practices around vaccines (Dube 2016, Paterson et al. 2016). As a group that wields significant influence on parents' vaccine-related decisions, it is critical to examine vaccine hesitancy among providers, investigate the roots of their concerns and practices, and provide resources to support providers to navigate vaccine hesitancy among their patients (Dube 2016). Further qualitative research with providers around their beliefs, practices, experiences, and challenges with vaccine hesitant parents are potential research directions that could provide opportunities to address vaccine hesitancy.

Although it is too soon to evaluate the long-term impacts of SB277 and SB276 in California, the new laws have been effective in improving vaccination rates in the state. It is still to be determined what the outcome of the 2019 elimination of nonmedical exemptions will be for Washington, Maine, and New York. Mississippi and West Virginia, the first states to eliminate nonmedical exemptions three decades ago, consistently have vaccination rates for MMR that are higher than the national average, at ≥99.2% for Mississippi and 98.8% for West Virginia, compared to 94.2% national average (Seither et al. 2019) (see Figure 6).

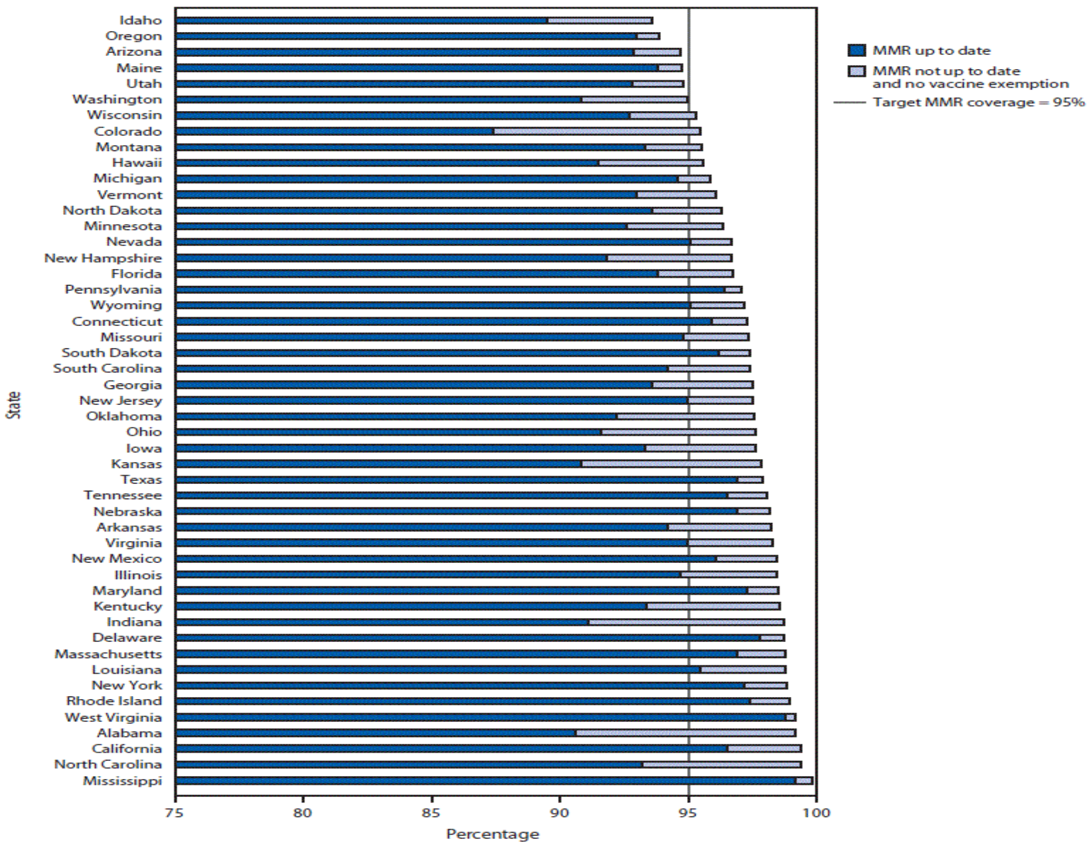

Figure 6. Vaccination rates for MMR, by state (2019).

With the recent spate of vaccine preventable disease outbreaks around the world, many countries and states in the US have implemented stricter vaccination policies or removed some or all nonmedical exemptions. Vaccine policies and mandate instruments (i.e. requirements, fines, consequences, administrative actions, etc.) come in a variety of forms, but what is critically influential in their development, implementation, and effectiveness is the politico-cultural context in which the policies are constructed and disseminated (Attwell et al. 2018). For example, in France where there is a long history of vaccination mandates starting with the smallpox vaccine in 1902, noncompliers could face imprisonment and fines, though enforcement was rare. As vaccines became available for a growing number of diseases, there was a movement to abolish vaccine recommendations and make all vaccinations mandatory. After a citizen consultation process was facilitated by the health ministry including juries of citizens, health professionals, online public contributions, and qualitative and quantitative studies, they concluded that participants preferred to consolidate recommended with mandatory vaccinations into overall mandates, preferring to defer to the state rather than making individual decisions for themselves. In the process, criminal sanctions were removed, however parents who decided not to vaccinate could still be prosecuted for putting their children and others at risk. There were no further requirements to isolate children who were unvaccinated from school, since that was viewed as socially unacceptable. The main focus of the vaccination mandates was on a new birth cohort rather than catch-up groups of undervaccinated children (Attwell et al. 2018).

In comparison, Australian vaccination policies and compliance has been linked to financial incentives since 1998. Vaccination status designated payments at age-based milestones and eligibility for childcare subsidies, although parents who decided not to vaccinate could still obtain benefits after counseling from a vaccination provider. Vaccination rates across the country sat at around 91%, although there were pockets where rates were as low as 50%. In 2012, a nationally representative study found that about 20% of Australians had concerns about vaccine safety, including long-term health outcomes and autism connected to vaccines (Chow et al. 2012, in Attwell et al. 2018). Following the study, the regional newspaper of New South Wales mobilized the discourse of collective responsibility, utilizing high profile deaths of infants due to pertussis, to promote vaccination garner support for the “No jab, no pay” campaign that rescinded benefits and financial incentives for vaccine refusers. The campaign garnered popular and political support and the “No Jab, No Pay” law came into effect in 2016, removing all nonmedical exemptions. The law was written to govern vaccine refusal through administrative procedures and financial incentives; vaccine refusers stood to lose $8,350 per year in incentives and childcare subsidies and face limited access to childcare programs. That year, vaccination rate increased across the country to 92-93% (Porter 2016, in Attwell et al. 2018).

Tools, interventions, and policies designed to assess and address vaccine hesitancy would benefit from qualitative research that investigates the multiple facets of vaccine hesitancy. These facets are shaped by the social, political, and economic context, as well as the particular vaccine, community, and region in which these dynamics play out. The structure and function of the overall healthcare system is another important factor to consider.

Recommendations for Public Health

From a practical, public health standpoint, findings from this study support the notion that interventions aimed at increasing vaccination rates should target multiple levels of the social ecological model (SEM). In addition to emphasizing the collective function of vaccines, i.e. herd/community immunity, interventions at the *individual* level aimed at vaccine hesitant parents should also emphasize individual benefits vaccines can provide to individual children. Findings from this study confirm existing literature that found that vaccines, particularly in highly individualistic, neoliberal environments, are conceptualized as individual health interventions with individual benefits and risks, without consideration to collective function; vaccination campaigns with a communal focus, therefore, are not effective in neoliberal societies such as the US (Casiday 2007, Burns and Davies 2015, Hobson-West 2003). While I personally and practically believe in the benefits of both the individual and collective functions of vaccines, vaccine hesitant parents in this study already conceptualized vaccines as an individual intervention, and their refusal or delay were considered one aspect of their broader approach to health. Following this trend, promoting the individual benefits of vaccines, and the benefits of *preventing* vaccine-preventable diseases, particularly framed as part of an overall approach to health, could be the most effective when targeting parents who already conceptualized vaccines as an individual intervention. For example, vaccine promoting messages could bring to light the detrimental consequences of a measles infection on an individual's immune system, i.e. prolonged immunosuppression (Petrova et al. 2019); emphasize the potential health outcomes of a mumps infection for boys reproductive health, i.e. infertility (Masarani, Wazait, and Dinneen 2006); raise awareness of HPV-related oropharyngeal cancers, for which there are no standard screening protocols (Daley et al. 2016). From this perspective, vaccines will not only protect children from particular infections but also protect their bodies and systems as a whole.

Parents in this study did not prioritize recommendations from their medical health provider or public health institutions, rather they relied on information from a variety of sources including their in-person and online social network, alternative health providers, and childbirth practitioners in addition to health providers who supported their overall approaches to health and vaccines. On an *interpersonal* level, additional research that examines these relationships and avenues of information could be fruitful in gaining a deeper understanding of parents' decision-making processes and the impacts of various authoritative and nonauthoritative knowledge sources. While parents in this study sought information from a variety of sources, they also included their medical providers in their processes, albeit in a critical way. Public health research consistently find that physicians and providers remain the most trusted source of vaccine-related information for parents (Barrows et al. 2015, Glanz et al. 2013, Opel et al. 2014, Paterson et al. 2016, Smith et al. 2006). In environments of institutional distrust and perceived conflicts of interest, the trust within the provider-patient relationship is vulnerable. Interventions that are aimed at supporting providers and their efforts to establish stronger provider-patient relationships and follow-up with vaccine hesitant parents could be one avenue to achieve positive change. Partnerships with provider groups, such as the Academy of Pediatrics or the American Board of Family Medicine, would enhance research efforts and dissemination and evaluation of potential interventions. Understanding alternative medicine providers' and birth practitioners' (including midwives, nurse midwives, lactation consultants) perspectives on vaccines is also critical, since they were trusted providers for vaccine hesitant parents in this study.

In the US, since the first vaccination mandate for smallpox in Massachusetts in 1809, vaccination laws and requirements have been linked to schools since they are active sites for disease transmission and common epicenters of community-wide outbreaks (Diekema 2014, Hinman et al. 2002). Due to this structural relationship, on an *organizational* level, school-based interventions are an appropriate avenue for promoting vaccination uptake. The proportion of kindergarteners who were considered conditional entrants (those who catch up with vaccination requirements after school enrollment) sharply declined between 2014 and 2018, from 6.9% to 1.7% of all kindergarteners in California (CDPH 2015, 2019). There is still opportunity to improve vaccination rates by ensuring that all catch-up students complete their required vaccinations. Other organizational avenues to consider are community-based early childhood development programs, such as First 5 LA in Los Angeles, California and Healthy Start programs in Tampa, Florida. These community-based programs are a critical point of contact particularly in catching *under*vaccinated children who face barrier to accessing routine vaccinations who are more vulnerable due to waning herd/community immunity due, in part, to *un*vaccinated children whose parents decide to delay or refuse vaccines. Interventions could focus on raising awareness among parents early and emphasizing the benefits of vaccines through collaborative efforts with trusted community-based partners.

The current iteration of vaccine hesitancy, in the 2000s, has been enhanced in unprecedented ways by social media and online culture. As this study found, vaccine hesitant mothers spearheaded efforts to "research" vaccines through a variety of channels, the majority of which are accessed online through the internet or social media. Therefore, *community* level interventions should include a focus on addressing vaccine hesitancy among online communities and promoting vaccines through online social networks. School, again, could be another avenue for shifting norms and values associated with vaccine hesitancy. Alternative school environments have been found to foster values that favor vaccine hesitant beliefs and behaviors (Sobo 2014). Partnerships with alternative schools, including private schools and charter school which generally have higher rates of personal belief exemption and conditional entrants than public schools, to develop appropriate interventions are encouraged.

Finally, on a *policy* level, while there are agencies that manage vaccine-related issues on a federal level, such as the congressional Vaccine Injury Compensation Program, and organizations that make vaccination recommendations, such as the Advisory Committee on Immunization Practices (ACIP), there are no vaccine-specific mandates at the federal level. States are responsible for establishing vaccine-related requirements, laws, and administrative processes (CDC 2018). There is strong evidence that stricter vaccine laws at the state level in the US result in higher vaccination rates (Adrian et al. 2020, Goldstein et al. 2018, Goldstein et al. 2020, Mello 2019, Zier et al. 2020). However, due to variations between states shaped by political affiliation, values, religiosity, and other socio-cultural and political differences, implementing stricter vaccination laws or eliminating all nonmedical exemptions may not be a viable path forward for some states. Alternatively, proposing policies that support financial incentives or penalties for delaying or refusing vaccinations required for school entry may be effective in boosting vaccination rates.

Punitive fines had a significant effect in increasing measles and pertussis vaccination coverage in European countries that imposed fines to noncompliant parents (Vaz et al. 2020). There would be justification for fines, particularly with decreasing funding available to public health programs and institutions. Fines collected from parents who delay or refuse vaccinations required for school entry could off-set some of the costs associated with vaccine preventable disease outbreaks, particularly in pockets of low vaccination (Sundaram et al. 2019). A review of 16 measles outbreaks in the US in 2011 revealed substantial costs associated with the public health response, with the estimated financial burden on local and state public health departments ranging from $2.7 million to $5.3 million (Ortega-Sanchez et al. 2014). While this strategy does not address the non-financial costs of disease outbreaks, such as morbidity and mortality among vulnerable populations and the strain on the public health and healthcare system, it strikes a balance between maintaining parental rights and holding parents accountable for endangering their children and others.

Future directions in research

With regard to vaccine hesitancy, there are a number of opportunities for further research. As vaccine preventable disease incidences continue to rise globally, countries and US states will inevitably introduce policies related to vaccines and vaccine requirements. Continued critical research is needed to understand the everyday impacts of such policies, particularly through critical feminist policy scholarship and analysis. In the same vein, evaluation of the short-term and long-term effects and outcomes of vaccine-related legislation, as well as cross-cultural analysis and comparisons between US states and between the US and other similar countries, would contribute to a more comprehensive view of vaccine policies.

As parents continue to seek health and vaccine-related information online, it would be beneficial to understand how parents navigate and categorize the information they consume through science and health literacy frameworks. It would also be advantageous to understand how parents prioritize their sources, whether they are online (websites, articles, social media) or in-person (alternative health providers, friends and family). As this study found, mothers are disproportionately burdened by vaccine-related processes. Understanding the links between intensive mothering ideologies and vaccine hesitant behaviors through further in-depth, qualitative research would provide further insight on mothers' processes and experiences with vaccine hesitancy, at micro- and macro-levels.

With birthing centers and homebirths rising in popularity again in the US, parents who are making decisions about vaccines are interacting with a variety of healthcare providers and birthing practitioners, such as midwives, doulas, and lactation consultants. Recent social science research has examined the parallels in the pedagogical processes of birth advocacy and vaccine hesitancy (Reich 2019). This study found broad associations between "natural" birth processes, extended breastfeeding practices ("to full term"), and vaccine hesitant behaviors. As trusted healthcare providers, research exploring prominent vaccine-related ideas, beliefs, and practices among birthing practitioners and their clients would also be a fruitful avenue of research.

Theoretically, an area of interest for further research is the shifting ideas and concepts around immunity and the immune system in relation to vaccines and vaccine preventable diseases. These investigations could incorporate theories and concepts related to environmental health, precautionary consumption, governmentality, and science and technology studies.

Concluding Thoughts

As I reflect back on this process and the themes that emerged throughout this dissertation, in the US, we are three months into 2020 and the global coronavirus (COVID-19) pandemic. The three broad themes presented here, of 1) highly individualized health processes, 2) institutional distrust, and 3) gendered impacts of health phenomena are frighteningly relevant as medical and public health professionals, experts, and institutions are urging, begging, and depending on individuals to take collective action to slow the spread of the virus and protect those who are most vulnerable. This global pandemic has brought to light failures of extreme neoliberal capitalist systems, such as those in the US, in which the so-called social safety net has eroded into practical nonexistence and public health programs and institutions have been systematically defunded and dismantled over the past four decades. The President of the US is actively contradicting health officials at the highest levels and disseminating inaccurate, and sometimes blatantly false, information, stoking already existing fear, distrust, and doubt among people in the US. At the same time, unprecedented numbers of people are finding themselves out of a job and suddenly without health insurance coverage, many of whom are already economically disadvantaged, as shelter-in-place orders are issued across the US. As with many health crises, women, who make up the vast majority of health support service providers, not to mention childcare and school staff, carry the burden of responsibility of keeping society and health systems functioning while placing themselves directly in harms' way.

This dissertation is in the tradition of critically applied medical anthropology, as envisioned by Medical Anthropologist Nancy Scheper-Hughes who set forth the "simple imperative to position ourselves squarely on the side of human suffering. Ours must be an anthropology of affliction and not simply an anthropology of medicine" (Scheper-Hughes 1990, 196). With this dissertation, I provide a framework through which providers, public health practitioners, and policy makers can think about vaccine hesitancy and apply these perspectives in their fields and practices. Through the voices of vaccine hesitant parents, I conveyed the complex, heterogenous, multifaceted, at times contradictory, fluctuating, stressful, and gendered nature of vaccine hesitancy through my ethnographic analysis, and demonstrated how in-depth, qualitative methods contribute to a more comprehensive, deeper understanding of vaccine hesitancy toward more equitable health and social outcomes.

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