

Negotiating Uncertainty: Risk, Responsibility, and the Unsettled Facts of  
HPV Vaccination in the United States

By

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*To my family*

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## **ABSTRACT**

This dissertation explores the ethical reflections of parents as they negotiate the uncertain cultural, moral, and corporeal risks and benefits of the human papillomavirus (HPV) vaccine with desires to protect their children from potential harm. The “facts” of the HPV vaccine remain unsettled and highly contested. Within the scientific and medical community, as well as the public sphere, consensus over the benefits, risks, and safety of the vaccine has not been reached. Despite these uncertainties, significant promotional efforts have been made by pharmaceutical companies and governmental agencies to encourage (or mandate) parents to vaccinate their children, constituting parents as moral subjects responsible for protecting their children against HPV and, by extension, ensuring the health of the nation. Drawing from ethnographic field research among parents living in the San Francisco Bay Area, this dissertation examines how parents are negotiating these uncertainties, and considers how categories of risk and responsibility are being configured through—and configuring—these deliberations. My results suggest that communication between healthcare providers and patients play a significant role in HPV vaccination decisions. Additionally, I found that the majority of parents who had not yet vaccinated their child expressed desires to delay rather than refuse vaccination based on uncertainties regarding the safety of the vaccine, temporal assessments of their child’s sexuality (in)activity and perceived risk, and provider support to delay vaccination. In conclusion, I

identify novel ways in which social workers can assist in assessing structural and interpersonal factors contributing to health outcomes inside the clinical encounter as well as in complementary arenas of policy and research external to direct clinical care.

## CHAPTER ONE: INTRODUCTION

*HPV vaccine is a safe and effective way to prevent cancer. How can anyone be against that?*  
–William Schaffner<sup>1</sup>, MD

*Gardasil is associated with serious adverse events, including death. If Gardasil is given to 11 year olds, and the vaccine does not last at least fifteen years, then there is no benefit—and only risk—for the young girl*  
–Dr. Diane Harper<sup>2</sup>, MD

*How can we facilitate a more informed debate about the uncertainties of the science, effectiveness, and true costs of therapeutic advancements?*  
–Joao Biehl<sup>3</sup>

The 'facts' of the HPV vaccine remain unsettled and highly contested. Within the scientific and medical community, as well as the public sphere, consensus over the benefits, risks, and safety of the vaccine has not been reached. Despite these uncertainties, significant promotional efforts have been made by pharmaceutical companies and governmental agencies to encourage (or mandate) parents to vaccinate their children, constituting parents as moral subjects responsible for protecting their children against HPV and, by extension, ensuring the health of the nation. Drawing from ethnographic field research among parents living in the San Francisco Bay Area, this dissertation presents qualitative and quantitative

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<sup>1</sup> Schaffner (2011)

<sup>2</sup> Harper *quoted in* Yerman (2009)

<sup>3</sup> Biehl (2011)

data on how parents are negotiating these uncertainties, and considers how categories of risk and responsibility are being configured through—and configuring—these deliberations.

Furthermore, drawing on Lakoff and Collier's (2004) notion of *regimes of living*, this dissertation examines the specific values, norms, and practices parents invoke as they reflect upon the best way to care for their children amid the uncertainties of technological transformation. Beyond theoretical considerations, this project has several implications for social workers and other care professionals engaged in the practice of health promotion, health education, and health care in the United States. Drawing from long-standing theoretical approaches to understanding health inequalities and behaviors (Link & Phelan 1995), as well as more recent critical engagements with public health promotion as a moral practice (Metzl & Kirkland 2010), I will identify ways in which social workers can assist in reducing structural and interpersonal factors contributing to health inequalities inside the clinical encounter as well as in the external arenas of policy and research. Furthermore, I will consider how and why highly educated parents with access to material and social resources, including information and quality healthcare, are “choosing” against vaccination (or at least delaying vaccination), and consider the practical and ethical implications of designing interventions for those in positions of power.

## **I. BACKGROUND: DESIGN, MARKETING, AND CONTROVERSIES OF THE HPV VACCINE**

The human papillomavirus (HPV) is argued to be the most common sexually transmitted infection (STI) in the United States with an estimated 6.2 million individuals newly infected annually (Food & Drug Administration 2006a). In the early 1990s, epidemiological studies showing the consistent association of HPV with precancerous

cervical lesions led to a concentrated effort by two pharmaceutical companies, Merck and Co. and GlaxoSmithKline, to develop a vaccine that could prevent the spread of the virus (Kahn 2005; Koutsky et al. 2002). Gardasil, developed by Merck, was the first HPV vaccine to be licensed for use in the United States in June 2006. Following a series of randomized controlled trials documenting the immunogenicity and safety of the vaccine (Villa et al 2006), the Food and Drug Administration (FDA) originally licensed the vaccine for use in girls and young women ages 9-26 for the prevention of cervical cancer (Centers for Disease Control & Prevention 2007; Food & Drug Administration 2006b). A few weeks later, the Advisory Committee on Immunization Practices (ACIP) formally recommended that all females ages 11-12 receive the HPV vaccine. In October 2009, the FDA extended the approved use of Gardasil for the prevention of genital warts in boys and young men aged 9-26 (Food & Drug Administration 2009). More recently in October 2011, based on a growing number of studies linking HPV with anal, penile, neck and other cancers that directly affect males (Haddad & Shin 2008; Palefsky et. al 2011), the ACIP recommended routine vaccination for boys ages 11-12 (Centers for Disease Control & Prevention 2011).

Shortly after the June 2006 FDA licensure of Gardasil, the “One Less” marketing campaign developed by Merck began appearing on televisions and computer screens around the United States. Framed by the phrase “I choose to be one less,” the advertisements urged girls and young women to choose to be vaccinated and be one less victim of cervical cancer, encouraging the “safeguarding” of female bodies through vaccination (Prescott 2010). Markedly absent from these advertisements were discussions of the links between the vaccine, genital warts, and the sexual transmission of HPV (Aronowitz 2010; Rothman & Rothman 2009). In addition, connections between HPV and anal cancer, particularly among



men who have sex with men (MSM), were silenced (Epstein 2010; Palefsky et. al 2011). Even though the primary function of Gardasil is to prevent the spread of a sexually transmitted virus, the initial marketing campaign desexualized the vaccine by discursively framing it as a (female) cancer vaccine (Epstein & Huff 2010), and produced girls and their bodies as ideal subjects of vaccination (Mamo, Nelson & Clark 2010). This project proposes that the initial marketing campaigns and the more recent campaigns promoting vaccination for both boys and girls are producing parents as moral subjects of HPV vaccination responsible for protecting the bodies of girls and boys—and the collective public—by “choosing” to vaccinate.

Despite Merck’s attempt to avoid controversies, Gardasil and its implementation quickly became a contentious and unsettled topic, situated within cultural anxieties over the sexuality of young women, the role of the state in parenting decisions, the efficacy of the vaccine, and the financial incentives of pharmaceutical companies (Casper & Carpenter 2008; Wailoo et al. 2010). For some, the HPV vaccine represented a pathway to promiscuity and risky sexual behavior (Forster, Wardle & Waller 2010). For others, the vaccine signaled the overextended arm of the government interfering in the private decisions of parents (Livingston, Wailoo & Cooper 2010). For many, the lack of the sufficient evidence showing the long-term efficacy (and cost-effectiveness) of the vaccine caused hesitation and fear that the vaccine may lead to more risk than benefit (Berlinger & Jost 2010; Yerman 2009).

Nearly six years after the initial FDA licensure, controversies around the HPV vaccine remain, exemplified by the recent comments of the “very dangerous side effects” of the vaccine made by Tea-Party/Republican Presidential Candidate, Michele Bachmann (New York Times 2011). Although Bachmann’s statements prompted immediate dismissal by

medical groups (Burton 2011; Martin 2011), there continues to be debate over the risks and benefits of HPV vaccination. Most of these debates have occurred in the expert realm of scientific conferences and journals (Huang 2009; Tomljenovic & Shaw 2011); however, Dr. Diane M. Harper, who conducted early clinical trials for the HPV vaccine, has been outspoken in her opinion that the promotion of HPV vaccination has glossed over many of its potential risks. “Gardasil is associated with serious adverse events, including death. If Gardasil is given to 11 year olds, and the vaccine does not last at least fifteen years, then there is no benefit—and only risk—for the young girl” (Harper *quoted in* Yerman 2009) More than mere words, these claims of risk and danger are thought to be having a direct effect on the uptake the HPV vaccine as public health officials argue “misinformation” and “myth” are the central reasons behind lagging numbers of vaccination rates in the United States (Tucker 2011). Drawing on ethnographic research in the San Francisco Bay Area, this dissertation examines how parents are negotiating these uncertainties, and consider how categories of risk and responsibility are being configured through—and configuring—these deliberations. Furthermore, I will examine the specific values, norms, and practices parents invoke as they reflect upon the best way to care for their children amid the uncertainties of technological transformations.

## **II. THEORETICAL FRAMEWORK AND LITERATURE REVIEW**

### *Technologies, Subjects, and Ethics*

A rich body of literature in science and technology studies (Franklin 1995; Haraway 1997; Hacking 1999; Jain 2004; Latour 1987, 2005; Pickering 1992) and medical

anthropology (Kleinman 1995; Lindenbaum & Lock 1993; Lock 2001; Ong 2003) exists around the ways in which new medical technologies or biotechnologies produce and transform local and global categories of being and understanding the world (Bray 2007; Gibbon & Novas 2008; Oudshoorn & Pinch 2003; Rose 2001). Within these technological transformations, “living” has become problematic—meaning these technologies have implications for the social and biological life of individuals and collectives (Lakoff & Collier 2004: 420). A significant portion of this work has focused on the beginnings and ends of life, particularly around reproductive technologies (Cohen 2002; Inhorn 2003; Kaufman 2005; Roberts 2011); however, increasingly a variety of biotechnological practices including brain imaging (Dumit 2003), organ transplantation (Lock 2002; Sharp 2006), and genetic testing (Novas & Rose 2000; Taussig, Rapp & Heath 2001) are being examined. The concepts of bio-power—and related notions of bio-politics and anatomo-politics—are central to these undertakings (Foucault 1990).

In his historical examination of 17th-century Europe, Michel Foucault (1990) claims a shift in the ways by which individuals are subjected to power occurred from a repressive structure to a productive system that operates through subtle yet ubiquitous power over life—namely bio-power (140). Bio-power is exercised through visible and covert techniques at the level of the individual (anatomo-politics) and the population (bio-politics), which simultaneously work together to promote certain ways of being (Foucault 1990:140). These concepts have been useful for thinking through the implications of biotechnologies as they signal the variety of subtle and overt ways individuals are subjected to—and subjected themselves to—certain practices, as well as indicate that these historically-specific, power-laden techniques are productive rather than repressive, resulting in the novel categories of

being in and experiencing society (Collier & Ong 2005; Faubion 2011; Lakoff & Collier 2004; Petryna, Lakoff & Kleinman 2006; Rabinow 2003).

For this dissertation, Lakoff and Collier's (2004) notion of regimes of living is particularly insightful. Drawing from Foucault (1997), the authors define regimes of living as the "configurations of normative, technical, and political elements that are brought into alignment in problematic or uncertain situations" (Lakoff & Collier 2004: 427). In uncertain situations, a given regime offers one (among many) possible means by which to organize, reason, and live ethically—with "respect to a specific understanding of the good" (Lakoff & Collier 2004: 427). Different actors (individual or collective) may invoke different regimes of living to give these situations a certain moral or ethical structure. In the case the HPV vaccine, this analytic concept is particularly insightful due to the scientific and cultural uncertainty of the situation, as well as the conflicting moral structures offered by different actors surrounding HPV vaccination. This project will build upon these theoretical and methodological approaches by examining what practices, norms, and modes of reasoning come into play as parents reflect on the best way to protect their children and society from harm.

### *Risk Societies*

Social theorists have proposed that modern society is a "risk society" (Beck 1992, 1999; Giddens 1990), whereby risk is "fundamental to the way both lay actors and technical specialists organize the social world" (Giddens 1990:3). Risk is seemingly everywhere—from the air we breathe to the food we eat, leaving individuals to engage in risk management (Lupton 1993, 1999). However, risk is not merely an object to be observed, but is made

known through power-laden networks of institutions, knowledges, and practices, particularly in the realm of science (Hess 1997; Nader 1996). Scientific understandings of the world have shifted from singular, mechanistic models to complex, interrelated models of environment, social, and genetics, leaving individuals to “evaluate the heterogeneous supply of scientific interpretations” (Beck 1992: 157). Science and technology itself is a potential source of risk (Douglas & Wildavsky 1982), and scientific fact as absolute truth is to be questioned and studied (Hess 1997; Kuhn 1962; Star 1983). Feminist technoscientific studies have continued and inspired aligned approaches highlighting the ways many categories of being, particularly sex and gender, are co-produced through scientific practices and bodies of knowledge (Keller 1985; Haraway 1999; Harding 1996; Jain 2007; Mamo & Fishman 2001). Although this project will not specifically investigate the production of sex and gender in the context of the HPV vaccine (*See* Casper & Carper 2008; Mamo, Nelson & Clark 2010), this project will speak to the ways parents draw on normative notions of sexuality, gender, and sexual behavior to structure their decision of whether or not to vaccinate their children, and to construct notions of risk.

The production of risk is an interactive and fluid process, making the communication of risk more complex than simple disclosure of technical information and the response to risk more complicated than mere comprehension (Nelkin 1989). As such, risk discourses, and correspondingly risk management as a practice, are riddled with moral, political, and cultural implications in addition to potential corporeal consequences (Becker & Nachtigall 1994; Harthorn & Oaks 2003) and have been of central interest to anthropologists studying health and affliction for several decades (Douglas 1970, 1992; Hayes 1992; Lupton 1993). Lupton (1995) stresses that current health promotion and disease prevention discourses tend to define

disease as a danger that places certain groups as “at-risk,” urging these groups to engage in harm-reducing practices, such as vaccinations, to protect their future selves from a probable rather than actual affliction (Cohn 2000; Gibbon & Novas 2007; Nichter 2003; Scott, Prior, Wood & Gray 2005). Individuals are urged to take responsibility over their own health, to become empowered, by engaging in “healthy” habits that will reduce the risk of harm and illness (Mol 2008; Nettleton 2006). Risk discourses are communicated to individuals through a variety of public pathways as well in the intimate spaces and relationships of everyday life. These discourses cannot be disconnected from larger shifts in the structure and practice of health in the United States.

### *The New Public Health*

Following World War II, several factors including increased federal funding for new hospitals and medical schools, and the success of penicillin and other pill-based treatments, led to shifts in healthcare in the United States and other industrialized countries. For those who had access, medical care became routinized, expanding from the emergency care of illness or trauma to include more preventive visits to the “family doctor” (Clarke 2010:122). During this time, medicine became part of daily life, intensified by the simultaneous infiltration of visual culture via television into the homes of American families (Clarke 2010). In the early 1980s due in large part to the development and use of computer and information sciences in biomedical practice, a new era emerged deemed the “era of biomedicalization” (Clarke 2010) or the “new paradigm of health” that calls for public health services to be primarily directed toward “the prevention of illness and the promotion of health” rather than curing illness (Moore 2010: 101). The “new public health” replaces

previous public health approaches that focused on contagion or sanitary control with the practice of health promotion (Awofeso 2004). The new public health is concerned with the health of the population (Peterson & Lupton 1997) and although it has brought heightened awareness of the external risks (e.g. pollution, climate change), it is primarily focused on the individual and his or her lifestyle, decisions, and behaviors. Health “problems” are often constructed as being caused by behavior and thus health promotion targets behavioral change (and environmental change to allow healthy behaviors to be “chosen”) rather than the disease itself (Mair 2011). These practices are also reflective of larger shifts and processes under which social concerns have been medicalized.

The growth of medicalization—defined by Zola (1972) as the ongoing process by which social problems become characterized as medical problems—has long been of interest to medical anthropologists and science and technology scholars (Kleinman 1995; Lindenbaum & Lock 1993; Lock 2001). Drawing from insights gained from studies of biopower (Foucault 1990; Mamo & Fishman 2001; Ong 2003) and science and technology (Franklin 1995; Haraway 1999; Hacking 1999; Latour 1987, 2005; Pickering 1992), the concept of medicalization has been redefined as biomedicalization (Clarke et al. 2010). Biomedicalization encompasses the “increasingly complex, multisited, multidirectional processes of medicalization” as they are intensified by technoscientific innovations in genetics, molecular biology, and new medical technologies (Clarke et al. 2010: 47). According to Clarke and her colleagues (2010), biomedicalization is organized around five interactive processes including 1) the creation of a new biopolitical economy; 2) an elaboration of risk and surveillance practices in conjunction with an intensified focus on health itself; 3) the increasingly technoscientific nature of biomedical innovations and

practices; 4) transformations of biomedical knowledge production and consumption; and 5) productions of new social identities. This project will attend to these processes by investigating how practices and claims of parents are reconfiguring the production, consumption, and boundaries of biomedical knowledge. In addition, this research will consider HPV vaccination—as self-regulated practices of biopower—are embedded in the new era of health promotion (Foucault 1990).

This new paradigm urges individuals to take responsibility over their own health, to become empowered, by engaging in “healthy” habits that will reduce the risk of harm and illness (Mol 2008; Nettleton 2006) and achieve the goals of the state (Foucault 1979, 1990). The body is the site where citizens are supposed to “work” on themselves to become productive members of society—the self has become somatic (Novas & Rose 2000). This paradigm is inextricably linked to the increase in public access, largely through the Internet and health information websites, to biomedical knowledge once reserved for health professionals (Clarke et al. 2011, and to the proliferation of health promotion and disease prevention discourses (Lupton 1995).

### *Health Promotion as Practice*

Early conceptualizations of health promotion, defined initially as “the art and science of helping people change their lifestyle to move toward a state of optimal health” (O’Donnell cited in Minkler 1989), rested on two central assumptions: 1) the individual has significant influence and power over the decisions he or she makes regarding diet, physical activity, and other lifestyle behaviors and 2) these decisions have significant effects on health outcomes (Minkler 1989). Although early government doctrines in the United States (e.g. Healthy



People Objectives) regarding this new focus in public health did include environmental influences, early programs and interventions tended to focus solely on changing individual behavior, rather than addressing the context or determinants of health broadly defined (Minkler 1989). The 1986 Ottawa Charter formalized current health promotion definitions as “the process of enabling people to increase control over and to improve their health” (WHO 1986; Kickbusch 2003). The World Health Organization (WHO) stresses that health promotion embraces actions directed at both “strengthening the skills and capabilities of individuals” but also actions directed at changing the social environment to allow for healthy behaviors (WHO 1998). The concept of empowerment, at both the individual and community level, is central to these formulations. Empowerment emphasizes the individual or community’s “ability to make decisions and have control over their personal life” and over the determinants of health in their community (WHO 1998). The corresponding notion of social capital has also become central to the practice of health promotion (Hawe & Shiell 2000).

Programs or interventions in health promotion range in scale from local efforts to increase fresh produce consumption to mass media campaigns to encourage condom use (Cattrell, Girvan & McKenzie 2009). The target of health promotion has expanded from just the individual to include the community, the population, and the organization (Minkler 2006). Although health promotion practitioners and researchers have become increasingly aware of how the environment—including social, political, and economic factors—affects the (perceived or structural) ability for individuals to make healthy decisions, the individual and his or her “lifestyle” or behavioral decisions remains central (Glanz, Rimer & Viswanath 2008). Health behavior theory guides most health promotion practice and research, supported

by the assumption that the “most prominent contributors to death and disease in the United States and globally are behavioral factors” (Glanz & Bishop 2010). This assumption is linked to Westernized notions of the individual and decision-making, which will be discussed (Mol 2008); however, it is first important to outline the major theoretical foundations guiding contemporary health promotion practice and research.

### *Theoretical Foundations of Health Promotion Research and Practice*

Based on published articles in the past two decades, Glanz and Bishop (2010) identify four central behavioral theories guiding health promotion research and practice: Health Belief Model, Transtheoretical Model, Social Cognitive Theory, and Social Ecological Model. The Health Belief Model (HBM), developed originally to understand why people decided (or not) to use public health services in the 1950s, theorizes that people’s beliefs about their risk for a certain disease, and their perception of the benefits of acting to reduce risk, influence whether or not they take action (Hochbaum 1958; Rosenstock 1974). The key constructs of HBM are perceived susceptibility/risk, perceived benefits and perceived barriers, cues to action, and the recently added self-efficacy (Rosenstock, Strecher & Becker 1988).). This model is often applied to health concerns that are prevention-related (e.g. early cancer detection or vaccination) and health promotion practices that seek to reduce risk factors (e.g. diet and sexual behavior) linked to disease (Glanz & Bishop 2010).

Transtheoretical Model (TTM) adds the dimension of stages of change to health behavior change, whereby individuals are understood as having different levels of readiness to adopt healthful behaviors (Prochaska, Redding, & Evers 2008). Stage progression is not necessarily linear.

Social cognitive theory (SCT), often used in counseling sessions for disease management, explains human behavior as dynamic, continuous interaction between personal factors, environmental influences, and behavior (McAlister, Perry & Parcel 2008). A basic premise of SCT is that people learn through their experiences, and from observing the actions (and results) of others' experiences (Bandura 1986). Social Ecological Model argue that multiple levels (including individual, interpersonal, organizational, community, and public policy) of the social environment affect health and also indicate that behaviors both shape and are shaped by the environment (McLeroy, Bibeau, Steckler, & Glanz 1988). Health promotion that uses a social ecological perspective target both individual and social environmental factors for change and have been used to understand health disparities at the population level as well (Krieger 2001).

Health promotion interventions designed with an explicit theoretical foundation(s) may be more effective than those without a theoretical base (Noar, Benac & Harris 2007; Glanz & Bishop 2010). However, health promotion and health behavior theories are predicated upon a series of assumptions that scholars in the fields critical public health, medical anthropology and sociology, and science and technology studies have called into question as potentially contributing to health inequalities or at least perpetuating a view of health that may be disconnected from the practices of everyday living (Mykhalovskiy 2008; Lindsay 2010).

### *Investigating Assumptions: Critiques and Reconfigurations*

Critical public health researchers have considered the assumptions at play in health promotion and the ways certain conditions such as alcohol, tobacco use, and obesity have

become categorized as “problems” since the emergence of the new public health (Bell, Salmon & McNaughton 2011; LeBesco 2011). The language of these “epidemics” are scientific not moral; however, many argue that they have become the “new morality” urging individuals’ to choose health and sanctioning those who choose “risky” behaviors (Metzl & Kirkland 2010; Brandt & Rosin 1997). “Health is term replete with value judgments, hierarchies, and blind assumptions that speak as much about power and privilege as they do about well-being. Health is a desired state, but it is also a prescribed state and an ideological position” (Metzl 2010:1). The goal of these critiques is not to reject health or deny the ways health promotion has improved the lives of many, but to unpack the assumptions and proscriptions that accompany it.

Health promotion as a practice is based upon a series of assumptions—including the assumption that “all that is needed to change people’s behavior is better education regarding the risks of certain lifestyle choices” (Thompson & Kumar 2011:106). Increasing people’s health literacy—defined as “the degree to which an individual has the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” is believed to be a way to increase the likelihood of healthy lifestyle choices (Liechty 2011:99). In addition to constructing biomedical knowledge as neutral, these assumptions are embedded in a Westernized view of the rational, decision-making individual and his or her relationship to the state (LeBesco 2011). However, the daily lives of people, particularly marginalized groups, are often disconnected from these guidelines (Lindsay 2010).

Thompson & Kumar (2011) argue that in marginalized groups health promotion may be viewed as proscriptive, resulting in resistance (framed often as “non-compliance”), and

result in the continuation of health inequalities. For impoverished individuals whose lives are already inundated with relationships with state agencies (including interactions with social workers), biomedical expertise and information may be seen as a form of regulation rather than neutral information from which to make autonomous decisions (Mykhalovskiy 2008). “From the sites of their healthwork, biomedical reason does not operate to “empower” them to make decisions, but is continuous with more coercive institutional relations of ruling” (Mykhalovskiy 2008). In the choice model, the everyday work of individuals to care for themselves is lost. Challenging the underlying logic of choice, perhaps by purposing a new logic of care, may help eliminate these disparities (Henwood, Harris & Spoel 2011; Mol 2008).

In the context of HPV vaccination, the promotion of the vaccine has been constructed as a moral mandate, by which “choosing” to vaccinate is articulated as a way to ensure the future health of your child and potentially his or her future partners. As such, the act is reflective of not only notions of responsible citizenship, but responsible parenthood. For those parents who “choose” not to vaccinate, much of the literature has approached this choice from a deficit or barrier perspective—meaning the choice is positioned as the result of a not having access to either a structural, social, or individual need (that would result in making the healthful—“right”—choice to vaccinate) (Holman et al. 2014). Lack of knowledge or desire to have more information regarding HPV and HPV vaccination among parents and providers are cited as one of the top barriers to vaccination among all groups in the United States, including educated parents, ethnic minorities, low-income parents, and geographically diverse populations (Dorrell, Yankey & Strasser 2009; Laz, Rahman & Berenson 2012; Luque, Raychowdhury & Weaver 2012; Perkins & Clark 2012; Wilson,

Brown, Booth & Harris 2013; Hamlish, Clarke & Alexander 2012).

Additionally, parental attitudes, concerns or beliefs—often but not always framed as cultural beliefs among ethnic minorities but attitudes or concerns among Non-Hispanic White or educated populations—have also been identified as a barrier to HPV vaccination (Holman et al. 2014). These include parental concerns regarding the safety or efficacy of the HPV vaccine, belief that child is too young to receive the vaccine, perceived risk of HPV and HPV-related diseases, and influence of social norms (Allen et al. 2010; Holman et al. 2014; Luque, Raychowdhury & Weaver 2012; Reimer et al. 2012; Wilson, Brown, Boothe & Harris 2013). Beyond individual- or group-level factors, structural barriers such as lack of health insurance, lack of receipt of healthcare provider recommendation to vaccinate, and lack of long term relationship with provider (or “medical home”) have also been identified as barriers to HPV vaccination, particularly among underserved or disadvantaged populations (Dorell et al. 2012; Holman et al. 2014; Kester et al. 2013; Schluterman et al. 2011; Tsui et al. 2013; Ylitalo, Lee & Mehta 2012). The assumption underlying much of the literature is that if these barriers were removed—whether they are structural or individual—parents would choose to vaccinate their child, and in many cases, parents would. However, these assumptions are based on certain notions of what it means to both care and choose in the United States, which may not always prioritize the needs of patients in all contexts.

In response to a growing trend toward patient choice and autonomy in health care, Annemarie Mol (2008) claims that ‘care’ and ‘choice’ operate under two distinct sets of logic, and thus advocating for choice may not always result in good care for patients. Rather health care needs to be improved on its own terms—terms that operate under the logic of care. Drawing from ethnographic data on people living with diabetes in a Dutch hospital,

Mol considers what constitutes the logic of care and the logic of choice by examining the practice of care, which includes all material and non-material actors. Mol contends that the logic of choice is tied to the western assumption of the rational, autonomous individual operating under the illusion of free choice. In practice, this does not correspond to the needs of the patients, whose care is dependent upon the actions of others and of themselves. Mol claims that patients of care are not passive beings who are subjected to the will of the paternalistic doctor, but active members of the care team. Mol encourages readers and practitioners not to be taken in by the “magic” of choice, but instead look at the specific, unpredictable practices of *care* to improve the lives of individuals living with chronic disease. In this dissertation, by examining the decision to vaccinate and not to vaccinate as an act of care, I will attempt to critically engage with the notions and practices of care, not only as a didactic practice between parents and children, but also interwoven set of practices between individuals, material resources, values, and conceptualizations of citizenship in specific contexts.

Furthermore, Metzl and Hansen (2014) argue that beyond individual health practices and choices—as a focus of health interventions and medical care practice—structural conditions must be addressed that result in individual health outcomes. “Clinical presentations of persons at both ends of the economic spectrum are shaped by “cultural” variables, and also by the economic and political conditions that produce and racialize inequalities in health” (Metzl & Hansen 2014:127). In medical care and health promotion, “cultural variables” often include race, class, gender and ethnicity—variables that have been (attempted to be) attended to in the U.S. healthcare system through “cultural competency” (Metzl & Hansen 2014). Cultural competency education and practice are constructed as a

way to mitigate tensions between patients and physicians of different cultural backgrounds, and thus reduce marginalization of patients based on race, ethnicity, language or other points of difference. However, while cultural competency as a practice and basis for individual-level interventions has helped to reduce stigma and disparities based on difference in some ways (Metzl 2013), Metzl and Hansen (2014) argue the moment has come to rethink cultural competency as a way to help patients clinically, and shift focus onto the structural institutions and practices above individual interactions that influence health outcomes. This new paradigm, deemed “structural competency”, is grounded in both a practical—at the level of medical education—and a conceptual shift—at the level of theory, intervention design, and the way we think about health promotion (Metzl 2010).

*Central to [structural competency] is the belief that, just as stigma in clinical encounters must be addressed structurally, so too must inequalities in health be conceptualized in relation to the institutions and social conditions that determine health related resources. We contend that medical education needs to more systematically train health-care professionals to think about how such variables as race, class, gender, and ethnicity are shaped both by the interactions of two persons in a room, and by the larger structural contexts in which their interactions take place. And, that as such, clinicians require skills that help them treat persons that come to clinics as patients, and at the same time recognize how social and economic determinants, biases, inequities, and blind spots shape health and illness long before doctors or patients enter examination rooms (Metzl & Hansen 2014:127).*

In the context of HPV vaccination, disparities regarding vaccination completion (three-dose series) based on race, ethnicity, class, and education have been documented; however, as noted, in close review, the majority of these disparities are based on structural factors, such as access to care, access to education, or access to quality healthcare. Historically, disparities have been based on what are formulated as “cultural variables” at the individual level, but as Metzl and Hansen (2014) argue these individual-level variables are often the result of “economic and political conditions that produce and racialize inequalities in health in the first



place” (127). By placing these differences in the context of individual “choice”—or as barriers to be overcome to ensure individuals can engage in such choice—structural factors are not directly targeted or understood. These conditions do not only influence the health of those marked with difference or lacking access to structural equality, but also those in power with access to economic, social, and material resources. In this dissertation, I will attempt to critically examine how parental notions—often constructed as beliefs or attitudes—of risk, sexuality, and safety shape vaccination decisions, and consider how these reflect both conditions of power and potential need for intervention.

### *Promoting Health in the Information and Digital Age*

There is significant debate over the connections between health status, frequency of using the Internet to seek for health information, and health behavior changes (Ayers & Kronenfeld 2007). However, on any given day more Americans use the Internet to search for health information than visit a health professional (Fox & Jones 2009) and youth may be using this technology to learn about sexual health (Bleakley, Merzel, VanDevanter, & Messerti 2004). Health promotion researchers and practitioners are hopeful for the potential of new communication technologies to engage and entertain the audience and consequently have greater impact (Crilly, Keefe, & Volpe 2011; Glanz & Bishop 2010); however, there is concern that these technologies may deepen the “digital divide” between those who have access to computer technologies and those who do not furthering health inequities (Berland, Elliott, Morales et al. 2001; Sorensen 2001). Although, with the development and proliferation of mobile communication, some argue that minority populations in the United States and other countries not only have access to using mobile devices but also are using

them more than Whites, and thus health promotion using these technologies has great potential to address health disparities (Smith 2010).

A key strategy of health promotion is mass media marketing (Lupton 1995) and is deployed as a means to convey and communicate selective information about a disease to the public. Mass media has the ability to influence health behavior and choices, particularly in areas where preventive care from medical professionals is not readily available or used by community members. The media, particularly the Internet and television, has been shown to have significant effects on the personal attitudes and uptake of the HPV vaccine (Habel, Liddon, & Stryker 2009). Text message reminders are increasingly used in sexual health prevention efforts and have shown to be effective in increasing on-time receipt of the second and third doses of the HPV vaccine (Kharbanda et al. 2011). Experts in the field of technology-based health promotion are cautiously optimistic about the use of digital media and electronic technologies to both research and promote sexual health among youth (Gilliam et al. 2011; Levine 2011), particularly in its potential to improve health outcomes among youth and individuals unconnected to the formal health care system (Crilly, Keefe, & Volpe 2011).

Pharmaceutical advertising also highlights the connections between capitalism and biomedicine in the United States, often creating discomfort and debate among individuals who believe medicine is or should be neutral and apolitical. The domaining of the medical from the social has significant political and cultural implications (Gordon 1988), and is a constructed boundary that serves to perpetuate health inequalities (Comaroff 1985). A significant amount of anthropological research examines the production and use of pharmaceuticals (Petryna, Lakoff, & Kleinman 2006; van der Geest, Whyte, & Hardon

1996), medical technologies (Inhorn 2003; Oudshoorn & Pinch 2003), and mass media (Ginsburg, Abu-Lughod, & Larkin 2002; Spitulnik 1993). This project seeks to contribute to these discussions by considering how the marketing of the HPV vaccine shaped parents' vaccination decisions and constructions of risk.

Scholars in STS have theorized that although electronic technologies and the associated proliferation of information may not change health inequities, they will have a cultural impact and possibly create a new world view that Nettleton & Burrows (2003) have deemed “E-scaped medicine” (*See also* Nettleton 2004). The information age has impacted biomedical knowledge in significant ways, most notably: “medical knowledge has *escaped* and is thus no longer something that can be accessed and, more importantly perhaps, produced and regulated by medical experts” (Nettleton & Burrows 2003: 78). The demarcation between producers and users of knowledge is being dismantled, and medical professionals may view online support groups and other electronic sites potentially as threats to their expertise (Broom 2005) leading to attempts to define “proper use” by citizens (Oravec 2001). Biotechnologies are not neutral objects to be applied but greatly impact understandings of the self (Novas & Rose 2000; Rose 2001), the foundations of knowledge (Haraway 1999), and potentially worldviews (Nettleton & Burrows 2003) in unpredictable ways. This dissertation project seeks to contribute to these studies by investigating how health promotion in the information age may be reconfiguring health, risk, and biomedical knowledge in the United States.

*Changes in Healthcare Technology, Changes in Health Social Work*

Increasingly, social work health interventions rely on the evidence-based, medical model to guide practice and research (Lohr, Eleazer, & Mauskopf 1998; Vourlekis, Ell, & Padgett 2005). There are important and legitimate debates about the benefits and scope of evidence-based approaches in social work (Gambrill 1999; Howard & Jenson 1999; Richey & Roffman 1999). One potential benefit of evidence-based practice is that it may provide health services and clinical decisions based on the “best available research evidence” standardized through “empirically supported practice and program guidelines” (Vourlekis et al. 2005); however, a significant drawback is that these standardized programs and practices do not allow for the diversity of clients to be recognized. Application of external models often ignores the complexities of the local situation and practices that worked in a different setting may be ineffective in another. Evidence-based practice also supports the separation of the medical from the social and positions science as external to cultural and social ideologies (Wendland 2007).

The systems under which social workers are engaging in health care settings are constantly in flux and effective social work practice requires flexibility and ability to work in multidisciplinary teams (Abramson & Mizrahi 2003; Dhooper 1997). The disease management model that has come to dominate many hospital and health care settings has forced social workers to become “disease managers” of sorts (Claiborne & Vandenburg 2001). The disease management model is a “coordinated, proactive approach that maximizes the effectiveness of patient care for specific chronic diseases over time” (Claiborne & Vandenburg 2001: 217). The model relied on a case manager to provide care coordination between the patient, primary care physician and interdisciplinary team. The care is guided by

standards, or evidence-based practice, which are established through population health research and primarily quantitative data collection. Patient feedback and continuous quality improvement is essential to this model (Clairborne & Vandeburg 2001). Evidence-based approaches rely greatly on the evaluation of physical, psychological and social risks.

Social work within health care service is often described as secondary to medical or nursing care, and thus may not have the same degree of control over care. It is often subject to the medical model and organizational context (Browne 2005). Understanding how the organizational context affects social work practice is important to many realms of social work, but is especially important in social work in health settings. Browne (2005) highlights four areas within the context of the medical model that may raise issues for social work practice: 1) technology and associated patient care issues; 2) dynamic face of affliction, demographic changes, and the increased medicalization of social phenomena; 3) funding for costly technological services; and 4) ethical dilemmas spurred by this factors. Technological advances have brought significant benefits to the lives of patients and those social workers have aimed to help; however, they have also brought potentially negative effects as well. The length of time that patients stay in hospitals have shorten greatly making social workers have to intervene quickly to ensure patients will be released into a safe environment and address any practical or emotional needs of the client (Browne 2005). “Social work intervention becomes one of crisis management, and hospital social workers know that they must refer their patients elsewhere for more long-term support and counseling” (Browne 2005: 111). In terms of social justice, this creates significant issues as community support may be minimal or non-existent and thus clients in need are disproportionately affected. In addition, the increasingly specialized model in health care adds difficulty to a social worker’s

job as he or she must try to help navigate clients through a dispersed and segmented system.

The holistic approach of social work is challenged by the medical model, which may only see the person as a “heart case” rather than a whole human being—with physical, emotional, and social needs.

Kerson (1997) clearly outlined a framework to health care social work in practice that places context in a place of central importance; thus it is labeled “practice in context” (15). Context is “a set of circumstances or facts that surround and constrain a particular event or situation” (Kerson 1997:1). The author proceeds to breakdown context into three central elements in the field of health care that help or hinder the “helping relationship” between a social worker and his or her client: Policy, Technology, and Organization. “Policy refers particularly to laws; technology, to means for diagnosis, treatment, and monitoring; and organization, to systems involved in the delivery of health services” (1). Organization for Kerson are defined as “a body of persons brought together to accomplish some end or work, or the personnel or apparatus of an agency, business, or institution” (1997: 5), often guided by a particular ethos, of which social workers should be aware. The relationship between social worker and client is the primary subject of the framework. Borrowing from Goffman’s notion of the encounter and Bateson’s notion of the interaction, Kerson purports a view of the ‘relationship’ as situational and imbedded in the context of the relationship. This structural view of the relationship is supported with psychological dimensions of “purposive, feeling, catalytic, and enabling dimensions” (17). Two basic elements of this relationship are the context and the practice decisions. Kerson selects policy, technology, and organization as the three central affecting elements of context, but acknowledges others have called other

elements to be central in the field of health social work (See Germain & Gitterman 1996; Strauss et al. 1985).

*These three elements are considered most important because of the ways in which each contributes to the structure of the social worker/client relationship. Policies increasingly provide rules specifying the services clients may receive, and under what conditions. Organizations are also rule makers, defining the nature of service often at the behest of policymakers. Finally, in the cases of many illness and traumatic situations, dependence on technological intervention has contributed to the conditions of relations* (Kerson 1997: 18).

Technological advances have changed the face of medical social work drastically in recent years particularly surrounding women's sexual and reproductive health. Kerson (1997) defines technology "is the sum of the ways in which social groups provide themselves with the material objects of their civilization. It is the branch of knowledge that deals with applied science" (4). Reproductive technologies such as the ultrasound have caused increased concern over the rights of the women-fetus, which is directly tied to notions of personhood and autonomy (Figueira-McDonough 1990). Genetic testing, particularly prenatal genetic testing and chromosomal abnormalities have increased the need for counseling (Fertel & Reiss 1997), but have also raised concerns over selective abortion and the rights of disabled individuals (Ginsburg & Rapp 2013). Health Social Work is not limited to the clinical encounter, but the clinical encounter often guides the larger health social movements and advocacy social workers engage in.

Health social work is also a bit paradoxical as the majority of medical social work occurs in circumstances where no cure is available (such as in oncology care). After technological advances occur which assist in curing or preventing the affliction, such as vaccines, the role of social workers is reduced or eliminated entirely. "The absence of a technological solution is also important for social work because our services are often valued

more in those situations where there is no effective medical treatment” (Kerson 1997:4). The example of tuberculosis highlights this as before the discovery of penicillin, social workers played a central role “to ensure that patients returned for prolonged outpatient treatment and to educate patients and others in their social circles that might have been infected” (Kerson 1997:23). Now the role is purely epidemiological or educational. However, in this dissertation, I will explore how technological and legislative shifts are creating new opportunities for health social workers to not only engage in health promotion, but directly in preventive healthcare delivery (Pecukonis, Cornelius & Parrish 2003).

As Metzl and Hansen (2014) note, achieving structural competency within the clinical encounter and beyond relies upon incorporation of insight from various disciplines in medical education, including anthropology, economy, and public health, that have been critically engaging with contextual factors—beyond the individual—for quite some time. In many ways, social workers have been arguing for structural competency outside the clinical encounter since their inception as a field, engaging in such activities as community-based and policy-based interventions to establish healthful food and play options in impoverished areas that will complement structural competency efforts in the clinical encounter. In this dissertation, I will argue in addition to continuing to work on reducing structural inequalities outside the clinic, social workers also have a direct role to play within the clinical setting, particularly in eliciting and communicating with patients regarding the structural factors, such as transportation or workplace limitation, that shape (or limit) their healthcare decisions and practices. This in turn can assist physicians to practice structural competency in the clinical encounter by considering how to tailor recommendations to align with the lived environment of patients (Rendle et al. 2013).



### III. RESEARCH DESIGN

#### *Primary Research Questions*

This project was guided by two central research questions: 1) How are different actors constructing risk in the context of the HPV vaccine, and in what ways are parents made to be responsible for protecting their children against this risk? and 2) What norms, values, and practices do parents invoke in order to structure and support their decision to vaccinate or not to vaccinate their children? In order to answer the first research question, I aimed to conduct the following activities: 1) document the multiple ways different actors are constructing the risks and benefits of HPV vaccination by systematically collecting information related to HPV vaccination in scientific journals, newspapers, and popular magazines; and, 2) trace the pathways by which parents learn about the HPV vaccine by asking parents directly about information sources through qualitative interviews. In order to answer my second research question, I aimed to conduct the following activities: 1) collect narrative evidence of the specific norms, values, and practices parents use to guide and support their decision to vaccinate or not to vaccinate their children by conducting qualitative interviews with parents; 2) collect quantitative data to identify patterns across parents; and, 3) collect ethnographic data on the interactions between parents and health professionals by conducting participant-observation at immunization classes designed to discuss HPV vaccination<sup>4</sup>. Supported by funding by the Wenner-Gren Foundation and Rackham Graduate

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<sup>4</sup> Unfortunately, during my time in the field, the proposed immunizations classes only occurred twice due to funding changes, and both times the classes were canceled due to low enrollment.

School at the University of Michigan, I conducted these activities over 12 months, September 2012-August 2013. All activities involving human subjects were approved by the University of Michigan Institutional Review Board prior to commencement.

### *Research Sites*

Increasingly, the feasibility of ethnography as traditionally conceived has been challenged, urging anthropologists to rethink the construction of the “field” and the methodological approaches used to capture the amorphous flow and influence of phenomena like mass media and biomedicine (Gupta & Ferguson 1997). In this vein, the boundaries of my field site are flexible—loosely defined by the geographic limits of the San Francisco Bay Area—and include multiple sites of production and consumption of health media (*See Ong 2003 and Dávila 2001 for examples of similar approaches*). Primarily, I conducted research in three different cities in the region that are ethnically, economically, and culturally quite distinct: San Francisco, Oakland, and Palo Alto. San Francisco is considered the center of the Bay Area due in part to its dense and large population. According to the 2008-2012 American Community Survey (US Census Bureau 2013) estimates, the median household income is high (\$73,802) and the city has a poverty rate among individuals (13.2 percent) that is lower than the national average of 14.9 percent. The topographically variegated layout of the city has created a multitude of enclaves that are climatically and ethnically quite distinct. The majority of the population identifies as Non-Hispanic White (52.3 percent); however, there is a large Asian community (35.8 percent) as well (US Census Bureau 2010). 15.1 percent identify as Hispanic or Latino. San Francisco is also home to the highest percentage of gay and lesbian individuals in the United States (15.4 percent).

Palo Alto and Oakland sit on opposite ends of San Francisco in many ways. Palo Alto located about 35 miles south of San Francisco, has an extremely high median income (\$122,482) and almost negligible poverty rate (4.9 percent) among individuals (US Census Bureau 2013). The inhabitants are primarily Non-Hispanic White (68 percent), followed by a smaller population of Asian individuals (30.3 percent) and only 2.4 percent of individuals identify as African American (US Census Bureau 2013). Oakland, in contrast, has a median income that is much lower than both cities (\$51,683), and has a significantly higher poverty rate among individuals (20.3 percent) than Palo Alto, San Francisco, and the United States. While the largest percentage of the population living in Oakland still identifies as Non-Hispanic White (38.7 percent), the city has a significantly larger portion of African Americans living there (30.5 percent) than in other regions and 25.4 percent identify as Hispanic or Latino (U.S. Census Bureau 2010). The diversity of these three cities allow for a broad understanding of parental negotiations regarding HPV vaccination.

The San Francisco Bay Area is also a well-suited research site due to recent developments regarding vaccination rates and practices across the region. Following an outbreak of nearly 9,000 pertussis (“whooping cough”) cases in 2010 in California—with the second highest incidence rate occurring in Marin county (137.66 per 100,000 in comparison to state incidence rate of 21.42<sup>5</sup>), California passed Assembly Bill 354, which required students in 7<sup>th</sup> through 12<sup>th</sup> grade to receive a pertussis booster. In conjunction with this bill, the state public health department created a promotional campaign (“Preteen Vaccine Week”) to encourage awareness of the need to receive the pertussis booster (“Tdap”) and encourage uptake of other adolescent vaccines, including the HPV and Meningococcal-4

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<sup>5</sup> <http://www.cdph.ca.gov/programs/immunize/Documents/PertussisReport2011-01-07.pdf>

vaccine. After implementation of AB 354, vaccination rates for Tdap increased to 97.2 percent across the state and nearly 97 percent in Marin County, which had one of the lowest vaccination rates before the legislation. However, HPV rates have not seen similar increases<sup>6</sup>. NIS-Teen 2012 survey estimates that 35.8 percent of adolescents aged 13-17 have completed the three-dose HPV vaccine series in California, which is slightly higher than the national average of 33.4, but significantly lower than other adolescent vaccines.

Furthermore, although childhood vaccination rates across the United States (for vaccines other than HPV) are relatively high (for example, 2012-2013 vaccination coverage medians for measles, mumps, rubella vaccination are estimated to be 94.5 percent), certain counties in California have lower (although still relatively high) percentages of kindergarteners who are fully immunization upon school entry. Alameda County (which includes Berkeley and Oakland) reported that 87.23 percent of kindergartens were fully immunized in 2012-2013. Marin Country (which includes San Raphael, Sausalito, Mill Valley) reported 82.02 percent of kindergartens as fully immunized, and both counties are among the lowest in the state. Furthermore, certain communities—notably families who attend certain schools—have higher rates of immunization exemptions and resistance, and also reported higher rates of pertussis outbreaks in 2010<sup>7</sup>.

### *Recruitment Methods*

In order to recruit potential interview participants, I primarily used local parenting networks throughout the San Francisco Bay to distribute recruitment flyers either physically

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<sup>6</sup> The California Department of Public Health does not currently collect HPV vaccination rates by county, and thus I could not assess the SF Bay Area in contrast to other areas in the state.

<sup>7</sup> <http://www.berkeleyside.com/2011/04/20/with-whooping-cough-epidemic-is-berkeley-immunizing/>

at community locations where parents frequently visited (e.g. community centers, parks) or electronically through parenting list-servs provided by the local parenting groups. I also used respondent-driven sampling (Bernard 2006), encouraging enrolled study participants to share my contact information with friends or family they thought might be interested in the study. To gather a broad range of perspectives, I purposively targeted parenting groups in different regions through the bay area including: East Bay (Oakland, Berkeley, San Leandro, Castro Valley); North Bay (Mill Valley, Sausalito, San Rafael); City of San Francisco; and Peninsula (Redwood City, San Mateo, Palo Alto). In each region, I identified local networks and when appropriate, gained permission from network leaders to recruit using extant communication channels. In addition to parenting networks, I also placed flyers on public community boards throughout the regions, and also on the local craigslist. All participants were self-referred.

The approved study flyer included study information and contact information. The electronic flyer also included a link to an online screening questionnaire (managed by secure online survey software, Qualtrics, provided by the University of Michigan). Individuals aged 18 or older were eligible to participate in the study if a) they had at least one child between the ages of 7-17; b) had at least heard of HPV and the HPV vaccine; and c) were able to speak and read English. At the completion of the screening questionnaire, study participants were offered the option to provide their contact information or to contact me directly via email or phone.

Between October 2012 and February 2013, a total of 88 screening questionnaires were started online, and 69 questionnaires were completed<sup>8</sup>. Of those who completed the screening questionnaire, 59 provided their contact information (56 provided email and phone number, while three provided their email only). For those who provided their contact information, I contacted each potential participant via email or phone within one week to further describe the study, assess interest, and schedule an in-person interview if interested. In addition to those who provided contact information in the online screening questionnaire, an additional six individuals contacted me either by phone or email directly to indicate interest in the study. Of these 65 parents who expressed interest, 50 participants enrolled in the study.

#### **IV. DATA COLLECTION AND ANALYSIS**

##### *Semi-structured Interviews*

Drawing from ethnographies that use in-depth interviews as a guiding framework (See Rapp 1999), I conducted 50 semi-structured interviews with parents considering HPV vaccination for their sons or daughters to answer my research questions. I designed the interview guide to investigate the following five intersecting themes: 1) the communicative and technological pathways by which parents learned about the HPV vaccine; 2) personal constructions of risks and benefits of HPV vaccination; 3) salient factors, including specific sources of information and actors, influencing the decision of whether or not to vaccinate their children; 4) specific norms (e.g. gender ideology) and values (e.g. moral codes) parents

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<sup>8</sup> The online screening questionnaire did not require individuals to provide identifying information (e.g. email address or name) in order to safeguard privacy. Therefore, I do not know if a unique individual completed each questionnaire entry.

call upon when discussing the HPV vaccine and their decision to vaccinate or not to vaccinate their children; and 5) interpretations of the responsibility and role of parents in protecting their children and their children's future sexual partners against HPV. (See Appendix B for full interview guide).

I conducted interviews at a variety of locations, including libraries, offices, coffee shops, and parks. Interviews lasted between 45 and 120 minutes. Unless requested otherwise by the participants<sup>9</sup>, each interview was digitally recorded. In addition, following the interview, I took field notes of my impressions and memorable themes to begin the analytic process while collecting data. Each audio recording was transcribed and all identifying information was redacted during transcription.

I analyzed transcribed interview data using a multiple stage approach, drawing from open coding techniques (Emerson, Fretz, & Shaw 1995) and tenants of grounded theory and the constant comparative method (Clarke 2005; Strauss & Corbin 1998). First, I read through ten interviews to identify common themes and experiences across participants (open coding). Using the themes I identified, I created a list of codes and drafted definitions for each, resulting in a draft coding dictionary. I then applied the coding dictionary to an additional five interview transcripts to clarify the coding dictionary further. The revision process resulted in a finalized coding dictionary consisting of 152 unique codes (See Appendix C for full coding dictionary).

Using qualitative data analysis software (Atlas.ti 7.0), I reviewed each interview transcript, and applied specific codes to text that exemplified the definition of the code. Following application of codes, I extracted and reviewed summary reports of each code to

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<sup>9</sup> Two participants expressed desire against audio-recording the interview. For these, I took extensive notes to capture their thoughts and experiences.

identify major themes by frequency and intensity across participants. In addition to identification of patterns, I reviewed themes across each participant to understand the complexities of individual experience and understanding.

### *Questionnaire*

In addition to completing the in-person interview, 44 participants also completed an in-person, written questionnaire<sup>10</sup>. The written questionnaire included several items previously used in large-scale surveys on HPV vaccination (McRee et al. 2010), social attitudes (Pew Research Center 2012), information-seeking behaviors (Kelly et al. 2010), and risk perception (Lerman et al. 1991). I included the questionnaire to supplement, rather than center, my research, and thus only simple statistical analysis was conducted (See Appendix D for full questionnaire). Descriptive statistics (e.g. frequencies, means, and standard deviations) were analyzed across all participants using IBM SPSS Statistics 21. Additionally, for those domains of particular interest to the project design—specifically, political and public controversies—I conducted independent sample t tests and chi square analysis to compare parents who had vaccinated at least one child and parents who had not vaccinated. For this analysis, I only included parents who at least one child 11 years or older. Due to the small sample size, any conclusions based on statistical analysis should be tempered, and further research is needed to test these preliminary findings in a larger sample. However, coupled with the rich qualitative data, these findings give insight into the multitude of factors shaping HPV vaccination decisions.

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<sup>10</sup> I decided to add the written questionnaire after receiving initial IRB approval, and had to resubmit for additional approval after I begin scheduling initial interviews. Thus, six interviews occurred before having approval; however, I did ask some questionnaire questions verbally, and this data is included in statistical analysis when available.



### *Systematic Collection of Information*

Throughout my time in the field (and several years before), I collected and filed public sources of information, including scientific and popular journal articles, public health awareness campaigns, and pharmaceutical marketing, that described and centered on the risks, benefits and controversies of HPV vaccination. From sifting through magazines in waiting rooms to spending hours reading and reviewing online forums, blogs, and articles, I sought to find how—and through what means—parents, scientists, and others were talking about the HPV vaccine. Only a slight sliver of the data I collected is presented in this dissertation, but it serves to give an overview of the complex information landscape. The tracking of public information also allows me to situate the local deliberations of parents and decisions of parents within the hierarchical and heterogeneous assemblages of actors, objects, and practices involved in the production and circulation of risk (Latour 2005; Lupton 1995)<sup>11</sup>.

### *Study Limitations*

This study is limited in several ways. First, study participants overall are highly educated and affluent, and live in a geographic region that while ethnically and racially diverse is predominately liberal in its political views. Thus, results are not generalizable across all populations. Additionally, further research is needed to example the experiences of parents living in other geographic regions (rural and urban), parents of lower-income and

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<sup>11</sup> In addition to these efforts, I also conducted a systematic collection of local and national newspaper coverage of HPV vaccination, resulting in over 900 unique articles. In my future research, using content analysis framework, I will compare the content and presentation of risk in these sources; however, these efforts are beyond the original scope of the dissertation.

lower education status, and parents without access to healthcare to contrast and compare the experiences of these parents. Second, the study did not collect any observational data of communication between parents and providers, and parents and children. The perspective of providers and adolescents is needed to more fully gather the perspectives of all actors involved in HPV vaccination decisions. Lastly, from a qualitative perspective, the sample is sufficient; however, statistical results presented in this dissertation should not be viewed as conclusive due to the smaller sample size of 50.

## **V. OUTLINE OF CHAPTERS**

In the following chapter (Chapter Two), I present an overview of my findings—a survey chapter of sorts—to set up themes and discussions that I will elaborate upon in subsequent chapters. It also is my attempt to speak to the growing literature in the fields of health services, public health, and biomedicine on parental decision-making and HPV vaccination in the United States by identifying patterns. Although by nature reductionist, identification of patterns is helpful to begin to understand shared themes across participants, and to begin to identify ways in which interventions—whether at the level of health promotion efforts or healthcare provider education—may be needed to reduce structural barriers to care. However, patterns often miss the complexities and ambiguities that exist in the details and lived experiences of individual people. As such, drawing from the work of Biehl and Locke (2010) on subjectivity, desire, and becoming, I conclude the chapter by detailing the stories and decisions of three parents to identify how desires to care—and systems of power—came to bear on HPV vaccination decisions.

In Chapter Three, I explore the media, pharmaceutical marketing, and controversies regarding HPV vaccination in the United States. I first provide detailed analysis and documentation of the initial “One Less” marketing campaign employed by the pharmaceutical company, arguing that the initial campaign utilized a feminist empowerment model in an attempt to avert cultural backlash. Following, I trace larger political and cultural debates regarding HPV vaccination in the United States, including those regarding Congresswoman Michele Bachmann, and Governor Rick Perry. I then situate these broader discussions in the thoughts and decisions of parents with whom I spoke, drawing from Emily Martin’s work on ambivalence and meaning making in pharmaceutical practices. I also consider the “pharmaceuticalization of public health” to highlight how vaccination decisions are scripted with and come to reflect political and economic values and practices in the United States. Lastly, amid recent shifts in the healthcare system in the United States toward patient engagement, I explore new opportunities for social workers to engage in primary care settings and assist in eliciting details from patients’ lives—beyond cultural variables—that may shape their healthcare outcomes.

In Chapter Four, merging theoretical and practical considerations, I explore the ways in which my findings may help to explain current resistance to HPV vaccination in the United States. Using fundamental cause theory (FCT) as a guiding framework, I consider how the theoretical concept of countervailing mechanisms may help to explain HPV vaccination patterns that document both disparities by race and socioeconomic status, *and* low uptake among high-resource populations (Link & Phelan 1995). Additionally, drawing from anthropological work on temporality, risk and potentiality, I consider how cultural mechanisms—specifically sexual norms regarding teenage sexuality (particularly among

young girls) and lay challenges to scientific and expert knowledge—may be contributing to low and stagnating vaccination rates among resource-laden populations acting as countervailing mechanisms against (arguably) beneficial health behaviors. Specifically, I will contend that parents are challenging expert knowledge and the universalizing assertions of public health through desires to delay vaccinate to an age that they feel is more appropriate. To defend their desire to delay vaccination, parents often invoked claims to experiential evidence validated by a sense of knowing their child and his or her sexual and emotional development—attempting to redraw the lines of power based on their claim to parental knowledge that no "expert" can possess (Gieryn 1983; Nader 1996). Entangled within these claims (or acts of boundary work) are temporal assessments of risk—whereby parents weighed their child's (perceived) present risk of HPV exposure against the unknown risks of the vaccine itself.

In Chapter Five, I will examine how tensions between individual rights, collective good and moral obligation—often scripted through political and social values—emerged in my discussions with parents. I will contextualize these tensions within the broader political shifts occurring in the United States. Within these discussions, I consider how notions of responsibility, obligation, and care as both a parent and member of society guided HPV vaccination decisions, and how these notions reflected not only relationships between parents and children, but between the individual and the collective. In these ways, the act of vaccinating (or not vaccinating) gained meaning as an ethical act, or an act that at the core is concerned with questions of how we choose to live (Lakoff & Collier 2004). In conclusion, I consider the ways in which parents constructed the HPV vaccine as distinct from other childhood vaccinations based the manner in which it is transmitted. Beyond epidemiological

understandings, these discussions reveal how normative discourses that stigmatize certain behaviors—and bodies—are remade amid medical and technological change.

## **VI. RESEARCH IMPLICATIONS**

### *Contribution to Anthropological Theory*

By studying the ethical reflections of parents considering HPV vaccination for their children, my dissertation contributes to central theories in four key fields of anthropological inquiry that have not been often connected: medical anthropology, science and technology studies, media anthropology, and anthropology of ethics. Research in medical anthropology has demonstrated how political and economic factors at the structural level directly affect localized experiences of health and affliction (Farmer 1992, 2005; Horn 1994; Inhorn 2003; Nguyen & Peschard 2003; Ong 2003; Petryna 2002), yet this research often places the media as a secondary or non-existent actor (*See* Martin 1994 and Jain 2007 for notable exceptions). Science and technology studies have shown how the ostensibly objective act of scientific innovation is based on situated views and practices (Clarke & Olesen 1999; Fausto-Sterling 2005, Haraway 1999, 1997; Harding 1996; Keller 1996; Martin 1991; Worthman 1995), but has not often extended this approach to understanding how the uncertainty of medical information is understood and negotiated by parents considering health decisions for their children. Scholars of media anthropology have dissected the underlying assumptions of images projected and produced in the media (Askew & Wilk 2002; Dávila 2001; Ginsburg, Abu-Lughold & Larkin 2002; Ortner 1998, Shryock 2004; Spitulnik 1993), yet have not often used health media campaigns and pharmaceutical marketing as direct objects for

investigation. Anthropology of ethics have examined the ways individuals and collectives construct notions of good (Collier & Ong 2005; Faubion 2011; Foucault 1997; Rabinow 2003; ), but have not often focused on personal constructions of risk as a ethical practice in the context of medical uncertainty.

My research connects and expands upon the central approaches of these fields by detailing the personal reflections of parents as they negotiate various conflicting sources of information with notions of how best to protect their children. Additionally, by taking seriously the uncertainty that exists within the public and scientific realm (Braun & Phoun 2010), this project constitutes HPV vaccination as an anthropological and ethical problem, rather than simply a medical decision, whereby the decision of whether or not to vaccinate is entangled with questions of how one should live—and parents—amid technological transformations (Collier & Ong 2005; Lakoff & Collier 2004; Rabinow 2003). In these ways, this project contributes to not only the subfield of medical anthropology, but the wider anthropological discipline.

#### *Contribution to Social Work Research and Practice*

By examining how economic, political and social factors as well as parental notions of risk and responsibility guide vaccination behaviors and practices, this dissertation contributes to a large body of social work research focused on promoting and improving health of the population through equitable access to not only healthcare. As will be discussed in Chapter Four, national patterns of HPV vaccination by race and socioeconomic status are surprising, as initiation rates are actually higher among adolescents living under the poverty line and among certain minority groups. However, completion rates of the three-dose series

are lower among underserved groups—although more recent data is showing shifts in these rates. Moreover, other studies *have* shown disparities by race and socioeconomic status—often stemming from gaps in HPV-related knowledge, access to healthcare, or receipt of healthcare provider recommendation.

My findings suggest that in addition to structural factors, collective beliefs and practices, including sexual norms, may help explain these patterns. Additionally, beyond receipt of healthcare provider recommendation, the specific content (and quality) of provider communication may also impact communication of information in an equitable way. Although further research is needed, my results suggest that public health interventions must address not only structural inequities, but also parental concerns regarding the safety and potential risk of the HPV vaccine in relation to other vaccines and the timing of the vaccine in relation to sexual behavior and immunogenic evidence. Also, my findings support the importance of not only having access to preventive health care, but the subtle ways structural, political, and economic factors shape health outcomes. Furthermore, as I will contend, social workers are uniquely qualified to help clinical efforts to achieve structural competency—and support recent legislative and structural efforts to elicit and incorporate patient values and circumstances into preventive and acute care.

## **VII. FUTURE DIRECTIONS AND OPPORTUNITIES IN U.S. HEALTHCARE**

In the late 1990s, a buzz began to grow in the edges of the medical community about a novel way to approach patient care. First defined by Charles, Gafni & Whelan (1997), the term "shared decision-making" (SDM) represented a pendulum swing back from the earlier patient autonomy movement. This movement also reflects a resistance to the historically

paternalistic model of healthcare that dominated the patient-provider relationship. In contrast to patient autonomy, which stressed the individual autonomy of the patient, shared decision making envisioned a collaborative state by which patients and providers were placed on the same level, each bringing their own expertise to the table. The infamous saying, "it takes two to tango" emerged as the way to address inequities in the doctor-patient relationship and improve patient care (Charles, Gafni & Whelan 1997).

In some circles, this term became infectious, constructed as a panacea to rid the world of the ills of healthcare practice. Over years of research and clinical trials, SDM proved to be efficacious at improving patient knowledge, improving decision quality, and even improve health outcomes in certain cases (Légare et al 2012; Stacey et al. 2011). Patients even elected less invasive (read: less expensive) treatment believed to reduce potential harms caused by undergoing more aggressive procedures, while also only decreasing extraneous costs on an already taxed health care system.

Decision aids—in the form of brochures, videos, or interactive websites—have been proffered as the tool to facilitate these shared discussions between doctors and patients, allowing for the patient to have access to the risks and benefits of different treatment options. An underlying concept is the notion of equipoise—or acknowledging that in many cases in medical treatment, there is no *one* best way to treat the patient (Elwyn et al. 2000; Elywn, Frosch & Rollnick 2009). Rather there are multiple options, with varying (often uncertain) risks and benefits, which should be selected based on patient's preferences. These "preference-sensitive" decisions have been the primary focus of shared decision-making efforts; however, some have argued SDM should apply to other medical decisions, including those where clinical evidence is low (Politi, Lewis & Frosch 2013).



Returning to the question posed by Biehl at the opening of this chapter, in some ways, this movement (more recently expanded to notions of patient engagement) aims to create a more informed debate (or at least open conversation) about the uncertainties and subjectivities of medical knowledge, acknowledging simultaneously that patient's preferences—beyond morbidity and mortality—matter and there are limits to medical knowledge. In the case of HPV vaccination, decision aids have been presented to help inform parents, and dispel misinformation floating in the public (Fiks et al 2013; Mayne et al. 2012); however, like other decision aids, beyond the realm of clinical trials, their impact has been limited, in part to the difficulties incorporating into clinical care (Lin et al. 2013) and potentially more due to mediating, structural factors guiding healthcare practices across different populations. Even when they do manage to find the hands of patients, the larger cultural ethos underlying health care in the United States—from medical schools to evaluation measures—has not shifted greatly to respond to cultural shifts. With the implementation of the Affordable Care Act, some structural aspects have been put into place to help encourage this cultural change, mostly in the form of reimbursement rates from insurance companies being linked to patient-centered metrics and preventive care, but it remains to be seen what impact they will have on patient experiences and outcomes.

Additionally, as will be discussed in this dissertation, underlying cultural beliefs, constructions, and experiences come to bear on medical decisions in unanticipated ways. When I turned the recorder off, most if not all of the parents with whom I spoke asked me what I thought about HPV vaccination, and while careful not to offer any medical advice, I told them that at the core, the uncertainty they felt made the topic not only of anthropological interest, but interest to the practice and promotion of health. In the digital information age,

facts are made and unmade and made again in a matter of seconds, and it seems that uncertainties are on the rise. In these moments of uncertainty, parents fall back upon the values, norms, and experiences they trust—to make sense and decide how best to care for their children.

## **CHAPTER TWO: MAKING AND UNMAKING PATTERNS**

Vaccines represent one of the most successful public health interventions in modern medicine. Despite successes, cultural anxieties over vaccine safety and necessity have existed in the United States since the development of the polio vaccine and continue today in the context of the human papillomavirus (HPV) vaccine. Politically charged discussions of the influence of pharmaceutical companies on HPV vaccination policies, and fears that HPV vaccination may lead to riskier sexual behavior have exacerbated existing cultural anxieties. Additionally, there has been some medical uncertainty over the vaccine, including debates over the cost and benefit of widespread vaccination, and limited evidence of the long-term effectiveness regarding cervical cancer prevention. While these uncertainties continue today, little is known about the impact these uncertainties have on parents' decisions regarding HPV vaccination for their sons and daughters.

In this chapter, I will first provide a brief summary of health sciences literature examining parental decision-making and HPV vaccination in the United States. Then, I will present an overview of the major factors and patterns underlying HPV vaccination decisions among parents with whom I spoke, using both qualitative interview data and quantitative questionnaire data. In subsequent chapters, I explore these themes further, drawing from theories in health disparities, social work, and medical anthropology, to position these

decisions in relation to the network of scientific, political, and individual actors that give meaning and resistance to these acts.

Although by nature reductionist, identification of patterns is helpful to begin to understand shared themes across participants, and to situate my findings within the larger research literature. However, patterns often miss the complexities and ambiguities that exist in the details and lived experiences of individual people. As such, drawing from the work of Biehl and Locke (2010) on subjectivity, desire, and becoming, I will end the chapter by detailing the stories and decisions of three parents, all mothers, to identify how desires to care came to bear on HPV vaccination decisions, and locate people amid the patterns.

## **I. PARENTAL DECISION-MAKING AND HPV VACCINATION IN THE UNITED STATES**

The majority of research that has examined why and how parents decide whether or not to vaccinate their children against HPV has been conducted by health scientists, including biomedical, public health, and health services researchers, and is often funded in part by pharmaceutical companies themselves. These studies also frequently rely upon the results of national survey data examining immunization and other health practices in the United States, including the Health Information Trends Survey (HINTS) and National Immunization Survey (NIS). Self-reported responses regarding health behaviors, attitudes, and outcomes (which may or may not be confirmed by medical record data) are analyzed to identify factors that are associated with or possibly predicative of HPV vaccination uptake. While not exhaustive, I will review the main findings of these studies, and how they have shifted over the last decade.

Prior to and following initial 2006 licensure of the quadrivalent HPV vaccine (Gardasil) in the United States, a number of studies examined level of HPV awareness and HPV-related beliefs in different populations to assess their acceptance or intention to vaccinate if a HPV vaccine became available (Allen et al. 2010a). Generally, these studies found that parents and young adult females knew very little about the virus (HPV) itself and its relationship to cancer (Brewer & Fazekas 2007; Gerend & Magloire 2008). Lower levels of knowledge have also been found among disadvantaged groups, including ethnic minority parents, parents with lower income or lower education levels (Cates et al. 2009). More recent studies, however, have not demonstrated a link between HPV knowledge and uptake (Lai, Tinker & Cheung 2013).

Beyond awareness, early studies also looked at how HPV-related beliefs, including perceived risk of developing cervical cancer, perceived benefit from vaccination, and perceived barriers to vaccination, impacted parental intention to vaccinate (Allen et al. 2010b; Caskey et al. 2009). Some studies examined parental attitudes regarding sexual disinhibition—or beliefs that vaccination would lead to riskier or earlier sexual activity, and in general, found very few parents held these beliefs, and thus did not greatly impact vaccination practices (Schuler et al. 2011).

More recent studies have examined factors associated with actual HPV vaccination initiation (receipt of at least one dose) and vaccination completion (receipt of all three doses), and found supporting evidence for disparities based on socioeconomic status, race, parental knowledge, and geographic location (Downs et al. 2010; Moss et al. 2012; Niccolai et al. 2011); however, not all studies or data have shown these gaps<sup>12</sup>. Other factors including

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<sup>12</sup> I will discuss the mixed findings on racial and socioeconomic disparities regarding HPV vaccination initiation and completion in a subsequent chapter.

health insurance status, perceived safety of the vaccine, parental medical history, media use and exposure, and recommendation of the healthcare provider have also been related to HPV vaccination practices (Hughes et al. 2009; Kessels et al. 2012; Reiter et al. 2001).

### *Anthropological Perspectives*

When I first started examining the marketing of the HPV vaccine in 2007, very little work had been published in the field of anthropology and sociology on the HPV vaccine (*See* Casper & Carpenter (2008) for notable exception). Since this time, a collection of essays with work from Steven Epstein, Robert Aronowitz, Laura Mamo and numerous other social scientists has been published, providing key insight into how the manufacturing and marketing of the HPV vaccine reflects larger societal, biomedical, and political practices in the United States (Wailoo et al. 2010). More recently, ethnographic investigations of HPV vaccination in the United States (Gottlieb 2013) and worldwide (Towghi 2013) have started to emerge. These insights complement large-scale health sciences research by providing a critical perspective on the biopolitics of the HPV vaccine. However, more research is needed to understand both the marketing and reception of HPV vaccination from the users themselves. By examining parental ethical and medical considerations regarding HPV vaccination in relation to broader articulations of health promotion and practice in the United States, my dissertation research contributes to theoretical discussions in the fields of medical anthropology, public health, and social work, and provides practical insight into how structural factors—either limiting or enabling—may result in not only perpetuation of health disparities, but influence health outcomes across all groups.

## II. REVIEW OF DISSERTATION FINDINGS

### *Demographics*

Between August 2012 and March 2013, I interviewed 50 parents living throughout the greater San Francisco Bay Area. Of these 50 parents, 44 also completed a written questionnaire at the time of the interview. The majority of the parents I spoke with identified as White or Asian/Asian-American and female. Eight parents were first generation immigrants, coming from a range of countries including United Kingdom, India, and China, and 16 parents were second-generation immigrants. Most of the parents reported high income based on national standards, but considered themselves middle-class, partly due to the high of cost of living in the bay area. Of particular note is the high level of education of most of the parents with whom I spoke, with 52 percent earning a doctorate level degree, and 42 percent earning a bachelor's degree. While occupational fields varied from business to computer sciences to art, nine (18 percent) parents worked in the field of law, which may be representative of the area in which I recruited or potentially the topic of study. Table 1 below includes the complete demographics for those parents interviewed.

<b>Table 1: Interview Participant Characteristics (n=50)</b>	
<b>HPV Vaccination Decision</b>	
<i>Already vaccinated at least one child</i>	23 (46%)
<i>Planning to vaccinate</i>	9 (18%)
<i>Not planning to vaccinate</i>	5 (10%)
<i>Unsure</i>	13 (26%)
<b>Gender</b>	
<i>Female</i>	46 (92%)
<i>Male</i>	4 (8%)
<b>Age: Range 38-58</b>	Mean: 48.8; SD = 9.96
<b>Number of Children: Range 1-5</b>	Mean: 2.16; SD = 1.02
<b>Ethnicity/Race</b>	
<i>American Indian/Alaskan Native</i>	2 (4%)
<i>Asian/Asian American</i>	10 (20%)
<i>Black/African-American</i>	2 (4%)

<b>Table 1 Continued</b>	
<i>Latino/Hispanic</i>	2 (4%)
<i>White</i>	34 (68%)
<b>Relationship Status</b>	
<i>Married or Living as Married</i>	42 (84%)
<i>No steady partner</i>	8 (16%)
<b>Social Class</b> (Missing = 3)	
<i>Lower or Working Class</i>	4 (8%)
<i>Middle Class</i>	37 (74%)
<i>Upper Class</i>	6 (12%)
<b>Income</b> (Missing or Decline to Answer = 10)	
<i>20,000-49,999</i>	4 (8%)
<i>50,000-79,999</i>	6 (12%)
<i>80,000-119,999</i>	8 (16%)
<i>120,000 or more</i>	22 (44%)
<b>Employment Status</b>	
<i>Working full or part time</i>	36 (72%)
<i>Homemaker</i>	9 (18%)
<i>Self-employed</i>	3 (6%)
<i>Unemployed or disabled</i>	2 (4%)
<b>Highest Education Completed</b>	
<i>HS Diploma/GED</i>	1 (2%)
<i>Technical Cert or Associate's Degree</i>	2 (4%)
<i>Bachelor's Degree</i>	21 (42%)
<i>Master's Degree</i>	15 (30%)
<i>Doctorate/Jurisdoctorate</i>	11 (22%)
<b>Children's Insurance Status</b> (Missing = 4)	
<i>Private or Employer-based Plan</i>	44 (88%)
<i>SCHIP</i>	2 (4%)
<b>Political Party Affiliation</b> (Missing = 4)	
<i>Democratic</i>	35 (70%)
<i>Republican</i>	6 (12%)
<i>Other (Independent, Libertarian, Green)</i>	5 (10%)
<b>Religious Affiliation</b> (Missing = 3)	
<i>Catholic</i>	8 (16%)
<i>Jewish</i>	9 (18%)
<i>Mormon</i>	1 (2%)
<i>Muslim</i>	1 (2%)
<i>Christian (Protestant, Episcopalian, Quaker, &amp; Unitarian Universalist)</i>	11 (22%)
<i>None or Agnostic</i>	17 (34%)



### *HPV Vaccination Decisions*

Of these 50, 23 parents (46%) had already vaccinated at least one of their children at the time of the interview. Of the remaining parents, nine (18%) reported that they planned to vaccinate their children in the future, five (10%) reported that they did not plan to vaccinate, and 13 (26%) reported they were uncertain if they would vaccinate their child or children. In interviews, I learned that most parents expressed the desire to delay vaccination, rather than refuse, but desired to wait until either their child is older than the recommended age of 11 and/or until more evidence regarding the safety and benefit of the vaccine has been documented. I will discuss these factors in more detail throughout my dissertation.

### *Children of Enrolled Parents*

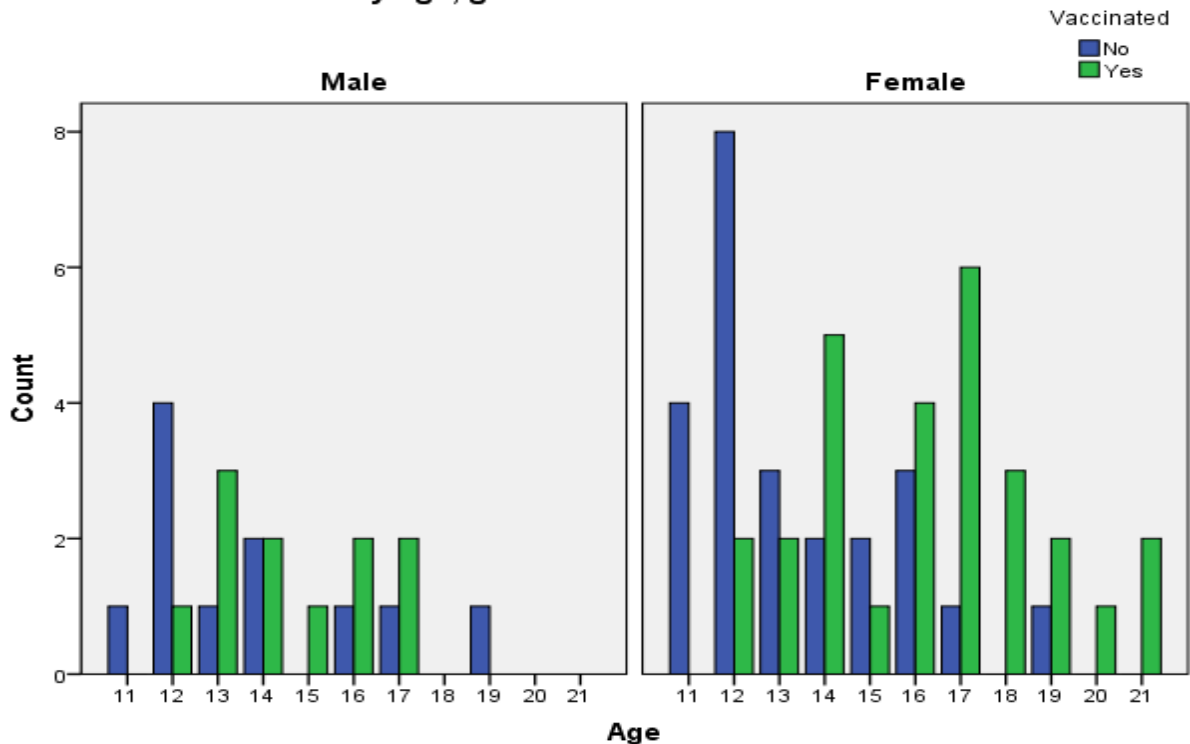
On average, parents who I interviewed had two children; however, some had as many of five. Children ranged in age from toddler to grown adult with children of their own. In our discussions, parents elaborated on the diverse ways they came to be parents beyond normative biological pathways, including tales of sifting through numerous sperm donor profiles with their partners, overcoming challenges of international adoptions, and unique parental relationships born from second and third marriages. They also gave detailed descriptions of differences and similarities between children, often through the lens of how each child responded to the practices and values held by the parent.

*Unvaccinated and Vaccinated Children*

The majority (70.3 percent) of the 74 children eligible for vaccination<sup>13</sup> were female; however, there was no significant relationship between gender and vaccination status,  $X^2(1, N=74) = 0.092, p=0.762$ . However, when looking at age, there was a significant difference between unvaccinated ( $M=13.51, SD=2.267$ ) and vaccinated ( $M=15.77, SD=2.433$ );  $t(72)=-4.111, p=0.000, CI[-3.348, -1.161]$ . Based on these results, older children were more likely to be vaccinated, with only 27.6 percent of children 13 and under vaccinated, and 47.7 percent of children 17 and under vaccinated (See Figure 1).

Recommended timing of the vaccine emerged as a pressing concern for parents during interviews, entangled with parental uncertainties regarding the safety of the vaccine and temporal assessments of when their child might become sexually active. In the next

**Figure 1: Children aged 11 or older of enrolled participants, by age, gender and vaccination status**



section, I will give an overview of how these factors and others influenced parents' decision over when and if to vaccinate, and elaborate further in subsequent chapters.

### **III. IMPACT OF PUBLIC CONTROVERSIES AND CULTURAL ANXIETIES**

One of the primary research questions of my project was to examine how evolving public controversies and cultural anxieties over the HPV vaccine impacted what parents think and decide about HPV vaccination for their own children. While the controversies have been numerous, for purposes of my research project, I categorized them in the following ways: 1) fears that HPV vaccination will lead to risky or earlier sexual behavior; 2) concerns that HPV vaccination is being pushed for pharmaceutical profit; and 3) uncertainties regarding the corporeal risks of HPV vaccination. I also asked parents generally about what they had heard regarding the HPV vaccine from media sources as well as friends, family members, and doctors to examine which sources parents drew upon—and trusted—in making vaccination decisions.

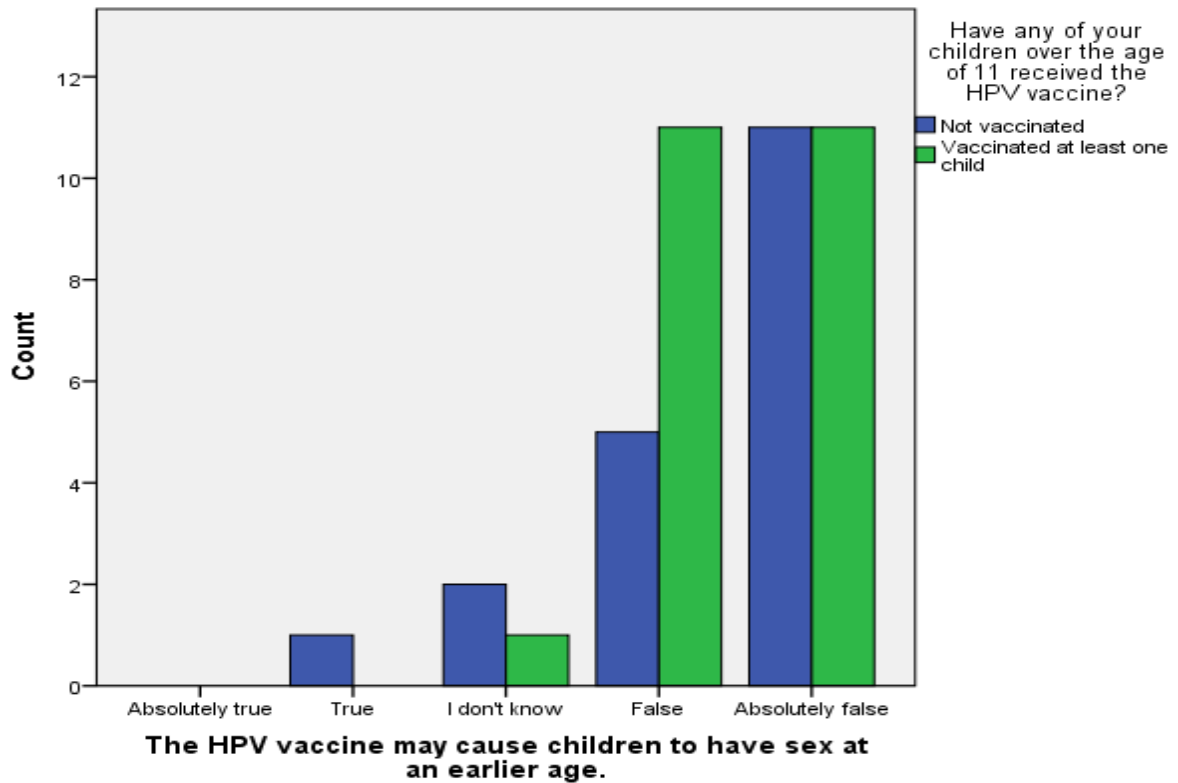


Figure 2: Parental responses to “The HPV vaccine may cause children to have sex at an earlier age” by vaccination status

Overwhelming, parents did not report that they believed HPV vaccination would lead to increased sexual behavior or earlier sexual debut, and as such, this belief did not influence their decision whether or not to vaccinate their child (See Figure 2). An independent samples t-test was conducted to compare parental belief that the HPV vaccine may cause children to have sex at an earlier age in parents who had vaccinated and not vaccinated at least one child aged 11 or above. There was not a significant difference between the scores in unvaccinated parents ( $M=4.37$ ,  $SD=0.895$ ) and vaccinated ( $M=4.43$ ,  $SD=0.590$ );  $t(40)=-0.288$ ,  $p = 0.775$ . This is not surprising as only one parent reported believing these claims to be true.

When I asked parents during interviews if they had heard anything regarding the controversies, many had heard of the parental concerns regarding the potential to increase sexual activity, but most expressed that they did not believe it. Stating it bluntly, Alice, a mother of an unvaccinated 12-year old daughter, described these rumors as "a crock of crap." The following quotes highlight other parents' general disbelief as well:

*Antonia: I haven't paid attention to any controversies. I understand there are controversies...I kind of have heard that it might encourage your kids to be more sexually active, but I don't believe that* (Mother of two unvaccinated daughters, aged 11 and 19).

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*Betsy: People think that [the HPV vaccine] was giving kids carte blanche to start having sex, and that it was interfering with the parent and child relationship – and dictating morals to kids.*

*Kate: What did you think of that?*

*Betsy: Ridiculous. The logic that you vaccinate them before they become sexually active, that makes sense. And for some kids that may be 11-12, others it might be 14, 15, 16—hopefully later than that* (Mother of vaccinated twin 13-year old daughter and son, and 17-year old son).

Although parents did not report that sexual anxieties regarding potential promiscuity or earlier sexual debut influenced their decisions, some parents did describe hearing it from other parents. Cristina, an early education teacher and married mother of a 13-year old daughter, described one surprising interaction she had with of a parent that she had known for nearly 10 years:

*Cristina: I was very surprised one day when a friend had come over after school with my daughter, and the mother came to pick her up, and we were just chatting on my front porch. And she said something about how she was just shocked that her doctor had suggested [the HPV vaccine], and what was I going to do? I was sort of a deer in the headlights in that moment because I really hadn't ever been looking at it as a bad, negative kind of choice. I only really was looking at it as a medically bad choice—like that there could be a harmful effect from a vaccine or something. I never, ever was looking at it as any kind of moral factor—like that my daughter having this shot would make her feel free to go and be promiscuous or something. That just didn't even, sorry, that just didn't even cross my mind. So then when this Mom was saying*

*that she was shocked, it became clear to me that that was what she felt. That the doctor was making some kind of statement about what his expectations were of her child or something. It was clear that that's how it made her feel. So I was uncomfortable because I pretty much already made up my mind at that point that I was going to pursue this. So it felt a little bit awkward for me and I don't think I said a whole lot, but I did say that yes, I knew about it and I hadn't thought...that it was gonna make my kid run around and have sex at age twelve. She just really was not happy about it.*

Although Cristina had not yet vaccinated her daughter, drawing in large part from conversations she had with her sister, a mother of slightly older teenage daughters, and to whom she often deferred to for parenting advice, she did not feel comfortable telling this mother that she planned to vaccinate. I asked if she had any follow up conversations with this mother after she made her own vaccination decision, and she noted:

*Cristina: I avoided it like the plague, just because—I know it sounds silly, like I can't stand up for my own decision, but I didn't want to make her feel uncomfortable. I didn't want to make me feel uncomfortable. That's a choice she has to make for her family, so I didn't go there.*

This resistance to discuss or approach parents who chose not to vaccinate, even among parents who strongly endorsed childhood immunizations, emerged again and again in my conversations, reflecting in part the tensions between values regarding individual parental rights, and collective societal obligation to promote health and protect against known harms. In a later chapter, I will explore these tensions further.

### *Pharmaceutical Distrust*

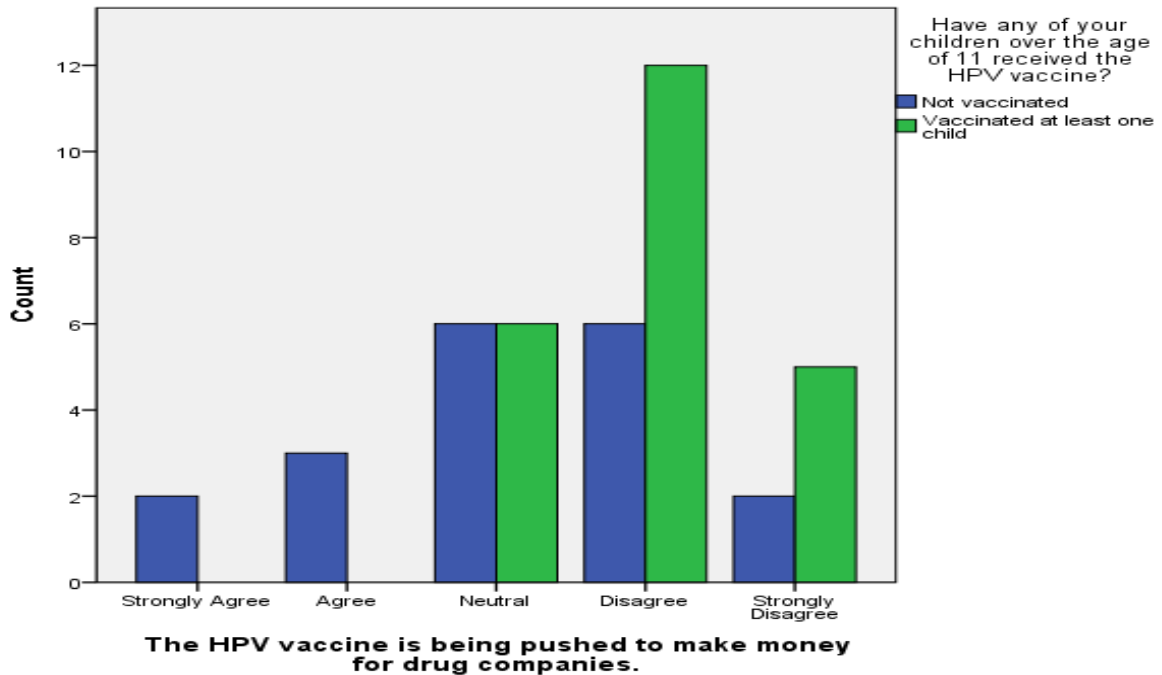
In my dissertation, I also aimed to understand how beliefs regarding the pharmaceutical industry in general and more specifically opinions regarding their perceived

role in public health policies<sup>14</sup> impacted parents' vaccination decisions. In the written questionnaire, parents were asked how much they agreed or disagree with the following statement: *The HPV vaccine is being pushed to make money for drug companies.* An independent samples t-test was conducted to compare item responses between parents who had vaccinated and not vaccinated at least one child aged 11 or above. There was a significant difference between the scores in unvaccinated (M=3.16, SD=1.167) and vaccinated parents (M=3.96, SD=0.706);  $t(40) = -2.735$ ,  $p = 0.009$ , CI (95%) -1.424, -0.173. These results suggest that parents who had a stronger belief that HPV vaccination is being pushed to make profits for pharmaceutical companies were less likely to have vaccinated their child (See Figure 3).

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<sup>14</sup> This interest arose out of early and continued controversies regarding Governor Rick Perry of Texas and the influence of lobbying by Merck on state initiatives to require HPV vaccination, which I will explore and describe in detail in Chapter Three.

**Figure 3: Parental responses to “The HPV vaccine is being pushed to make money for drug companies” by vaccination status**



Although quantitatively there is evidence of an association between perceived belief regarding pharmaceutical motives and vaccination status, in the conversations I had with parents, the connection seems much more complicated and nuanced, whereby some parents who expressed strong distrust had vaccinated their children, while others who expressed generally positive views had not. For instance, Sadie, who had vaccinated her 17-year old daughter and intended to vaccinate her 19-year old son, stated her distrust bluntly: “I think [pharmaceutical companies] are out for the money, never for the good of society.”

Latrice, a mother of a nine-year old son, also held a very strong and negative opinion of the pharmaceutical industry, but planned to vaccinate her son as soon as he turned 11. As she explained:

*Latrice: I have a very negative opinion of [pharmaceutical companies] cause I’ve taken classes on health education and I’m very skeptical. I think of them as fortune 500 companies—the big corporations. I think it’s all about money with them, and I*



*think they're affiliated with the doctors, and the doctors, instead of treating you or trying to take tests to see what's wrong—oh, let me give you a pill. Your toe hurts, let me give you a pill. It's just like they're trying to make the pharmaceutical companies rich. They're all in connection with the low income community clinics, and I think they're full of crap, I really do. I think they're dishonest and they're always trying to push the medicine on you when it might not even be medicine.*

In contrast, Lorraine, mother of two adopted daughters, who also expressed distrust, did not plan to vaccinate her daughters.

*Lorraine: I do think [pharmaceutical companies] influence the picture a lot, that doctors do get samples and make them available to people and that doctors. They're human too, and they're gonna get lots of perks and stuff from the pharmaceutical companies. I don't trust them completely to have our interests. I think we've learned over the years that lots of times people say something is safe and it is not. We've got evidence of that. And I think whenever there's that much money involved—it's a ton of money—that decisions are going to be made that aren't necessarily in our best interest.*

Most parents, including those who had vaccinated and not vaccinated their children, expressed ambivalence with regard to pharmaceutical companies, expressing concerns over the conflicting interests of providing collective good to society while simultaneously profiting from these endeavors. As Delia, a mother of an unvaccinated nine-year old son and 12-year old daughter described:

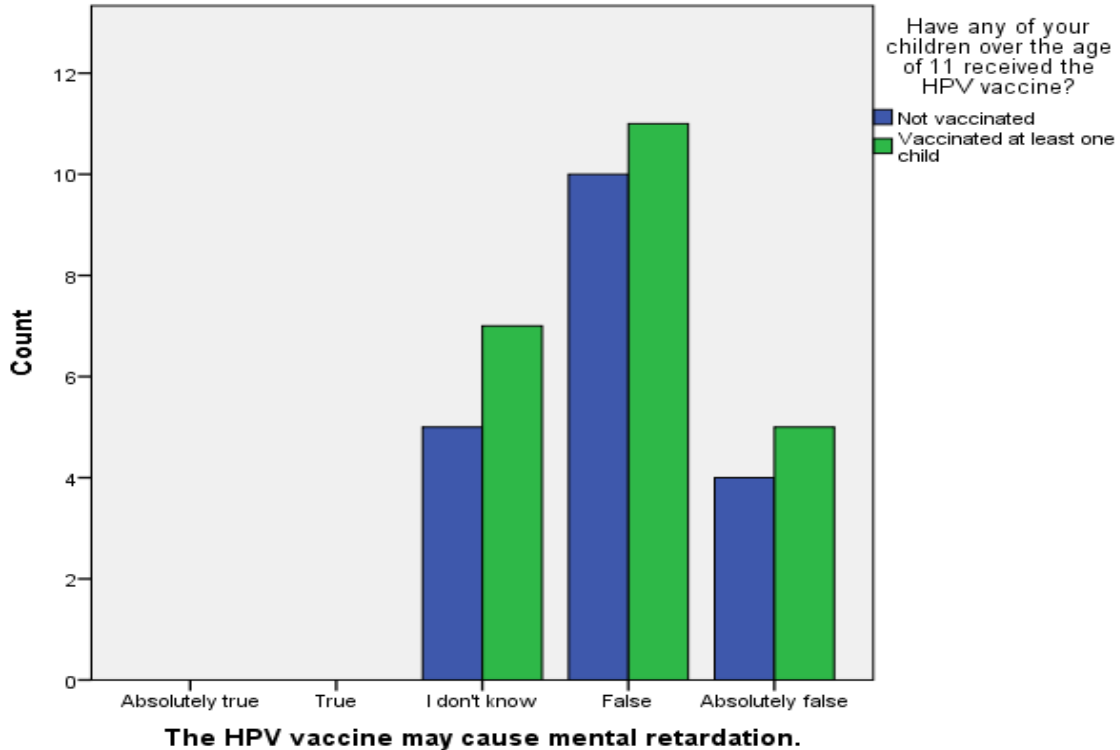
*Delia: I know a lot of people think they're a big boogieman. I'm pretty neutral about it. Maybe I'm naïve, I mean I know that some of them, or certain drugs, are bad, but you're always looking for a cure for cancer or a vaccine for this or that. And pharmaceutical companies are the ones who are developing those things. They are working with scientists and doctors. I know scientists and doctors. I think they are working for the public good, so I think pharmaceutical companies—like I said I'm just pretty neutral. So there are some horrible profit driven people, and I know some good scientific medical people who are trying to solve healthcare problems.*

In the next chapter, I will explore this ambivalence further, drawing from the work of Emily Martin and others on the meaning and use pharmaceuticals in public health.

*Corporeal Risk: Bachmann and Intellectual Disability*

A few months before I began my fieldwork, Congresswoman and staunch Tea Party supporter Michele Bachmann made her now infamous statements inferring that HPV vaccination has "very dangerous consequences" including "mental retardation", based on a conversation she had with a mother outside a Republican Presidential Debate. As such, in my project, I hypothesized that this statement would not only be well known by parents with whom I spoke, but also potentially highly influential.

In order to assess this, using Bachmann's exact framing, I asked parents directly in the written questionnaire, how much they believed the following statement to be true: *The HPV vaccine may cause mental retardation*. An independent samples t-test was conducted to compare item responses between parents who had vaccinated and not vaccinated at least one child aged 11 or above. There was not a significant difference between the scores in unvaccinated (M=3.95, SD=0.705) and vaccinated parents (M=3.91, SD=.733);  $t(40)= 0.154$ ,  $p = 0.879$ , CI (95%) -.416, .484. This is not surprising as no one reported believing that HPV vaccination may lead to intellectual disability, although several parents (12) reported that they were unsure (See Figure 4).



**Figure 4: Parental responses to “The HPV vaccine may cause mental retardation.” by vaccination status**

In conversations with parents, I learned that the general disregard of Bachmann's statements representing more a disregard of the politician who spoke these words than general disbelief in the potential for corporeal harm from the vaccine. As these two parents explained:

*Ruth: I don't remember if she said that [the vaccine] was linked to autism or mental retardation, but something weird. And Michele Bachmann chimed in and honestly at that point I turned the radio off because, that's showing my bias, but I can't listen to such inflammatory information. Now if the surgeon general came out and said, 'You know, there's some concern,' I'd probably listen. But from that kind of quarter, I'm less likely to listen (Mother of 16- and 12-year old unvaccinated daughters).*

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*Kate: Did you hear about the debate between Rick Perry and Michele Bachmann?*

*Kelsey: Both of whom are incredibly stupid.*

*Kate: Do you remember any of specifics?*

*Kelsey: Yeah, I follow presidential politics. I think she was saying that [HPV*

*vaccination] was a bad idea because it will send a message that will encourage sex before marriage and young girls to be sexually active. I expect there was some paranoia about the government in there too. I think Rick Perry favored it...I think he came down on the side I could agree with there. It's nice when you can find some areas with people you don't respect that you can agree on. She's a wing nut though – sorry. Great cheek bones! There's probably the main thing going for her! Sorry! (Mother of 12-year old unvaccinated son).*

While these comments may not be surprising (or entirely reflective of the actual debate) due to the political climate of the area in which I conducted research, even among those who considered themselves Republican, these statements were generally disregarded. As Krista, mother of two vaccinated 14- and 16-year old daughters, explained:

*Krista: Poor Rick Perry. I'm a Republican and I really thought he would be a great candidate, and that issue was one of the reasons he didn't get the nomination. There were other reasons, and that made me sad. I mean, I'm very much on the fence about whether the government should force certain things on people...so I don't know how I feel, but I certainly would have not voted for him because of what he did.*

*Kate: So are you're talking about that he passed the mandatory law?*

*Krista: He passed something. I don't even think it was mandatory. I'm trying to remember the details. Because it was about sex people flipped out the way I remember it.*

*Kate: Do you remember Michele Bachmann's involvement in it?*

*Krista: Oh no! She's the one that says that it causes retardation; I do remember this, oh my God! She was saying a bunch of crazy things, so everybody knew that was just one of them...It's really bad for someone in that position to scare people*

Contrary to what I had hypothesized, not only did parents not believe these statements, many did not recall hearing about them. As Maggie, a mother of a 17-year old vaccinated daughter, noted:

*Maggie: No I haven't heard anything about it. I don't usually tie politics and health at all. I don't value what their opinion is about my healthcare—about any politician. I already know how they lobby to gain and how unions buy their votes, so I've already been part of that process personally. I don't think they have any business in my healthcare. I think about the only laws they should be involved in is the insurance industry where it's regulated so people are not getting screwed.*

Throughout the interviews, parents described a variety of sources—human or otherwise—from which they actively sought information or advice regarding HPV vaccination. They also described sources from which they heard information without actively seeking it. Depending on the source, they may have disregarded it or taken it with great value. Although most disregarded the claims of Bachmann and other politicians, parents did express great uncertainty regarding the safety of the vaccine, and in some cases, this uncertainty was increased by hearing—even if secondhand—the story of Jenny Tetlock.

#### **IV. THE STORY OF JENNY TETLOCK**

*Lorraine: I just remembered the family's name is Tetlock. Phil Tetlock was the father and Jenny Tetlock, I think she was fifteen when she died and she had her first—I guess you get a series of these—she was getting a series of three. So I think she may have been thirteen or so when she first got sick and had a very rapid decline. She went to a school that was near us so we heard a lot about it. Other kids that I knew went to the same school with her, and although I'm not close to the family, I had met them and I had met her. So just hearing a story like that makes you wonder.*

I first heard of Jenny Tetlock from Lorraine, an East Bay mother who had met her parents—both professors at a local university—through her spouse—also a professor. Jenny developed a rapidly degenerative motor neuron disease<sup>15</sup> at age 13, shortly after receiving her third shot Gardasil in 2007. After battling the disease for nearly two years, Jenny passed away on March 15, 2009. I heard the story numerous times throughout my fieldwork, some parents giving specific details of the girl's name or disease, while others only mentioning that they had heard of a local girl's death.

In searching for more information, I came across a blog page launched about a year

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<sup>15</sup> From the website, it seems that the parents were not given a specific diagnosis, but they believe it may have been a juvenile form of amyotrophic lateral sclerosis (ALS)—commonly known as Lou Gehrig's disease.

after Jenny's diagnosis by Jenny's family<sup>16</sup> designed to primarily aid the parents in their "search for comparables," or young adults who have been diagnosed with similar neurological diseases, particularly those adolescents who experienced a positive impact from any treatments. Although across the blog postings, her parents and family members hypothesize that Gardasil may have contributed to their daughter's disease, they are careful to communicate that this is not proven, but only one of many options. For instance, in response to a CBS *Early Show* segment on Gardasil that used their story (aired July 2008), the family published the following comment:

*This morning, the CBS Early Show ran a story about Gardasil, using Jenny as the example of a girl who may have experienced an "adverse reaction" to the vaccine. CBS contacted the family; we did not contact them. Family representatives emphasized to CBS's producers Boxer and Bicknell that we do not want Jenny to become the poster child for the anti-Gardasil campaign and that it is by no means certain that Gardasil caused Jenny's illness. Rather, our goal in making Jenny's sad story public is to locate any possible "comparables" to Jenny, which could include girls (and even boys) who have not taken Gardasil, but who have experienced a rapid decline and paralysis that is resistant to the many kinds of treatment Jenny already has received.*

–Posted July 7, 2008 on [jenjensfamily.blogspot.com](http://jenjensfamily.blogspot.com)

Despite hesitation from the Tetlock family for Jenny to become the "poster child for the anti-Gardasil campaign," the story had an impact locally and nationally. For other parents who had heard of Jenny Tetlock, the story of a local girl who they could have known with a name and a face, made a striking impact on how they constructed the potential for harm from HPV vaccination. Even among those parents who had not heard this case, concerns of vaccine safety—even if just uncertainty—emerged as a highly significant and influential factor underlying parental considerations and decisions regarding HPV vaccination.

The story of Jenny Tetlock and her parents' desire to resist becoming a poster child

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<sup>16</sup> [jenjensfamily.blogspot.com](http://jenjensfamily.blogspot.com)

for the anti-vaccination movement reflects what scholars have deemed as growing “vaccine anxieties” (Leach & Fairhead 2007) or “vaccine critical movement” (Kirkland 2012) across the United States and globally. Stemming in part from claims made by Andrew Wakefield, a British doctor who published falsified data that showed a link between the Measles, Mumps, Rubella (MMR) vaccine and autism, and efforts by celebrities such as Jenny McCarthy supporting his claims, there is a growing number of parents who are “opting out” of childhood vaccinations (See Appendix A). While scientific evidence has not supported this link, Kirkland (2012) argues vaccine critics are now targeting “the culture of mainstream professional medical care, dominant cultural notions of disease, and the scientific authority structures that undergird the honored place of vaccination in public health governance” (71) to state claims of legitimacy. None of the parents I spoke with in my study considered themselves to be anti-vaccinators, although some had adopted alternative schedules of vaccines, so I cannot speak directly to how anti-vaccinators construct and engage with HPV vaccination. However, parents did invoke tropes used by vaccine critics in their discussions of HPV vaccination, most notably in challenges to the safety and perceived need of HPV vaccination.

## **V. VACCINE SAFETY**

Beyond specific statements made by Bachmann and others, there has been much public discussion regarding evidence for the safety (and benefit) of HPV vaccination. As such, I hypothesized that this would be a significant factor shaping parents vaccination decisions. In the written questionnaire, parents were asked how much they agreed with the following statements: 1) *The HPV vaccine is safe*; and 2) *There is not enough scientific*

evidence that the HPV vaccine is safe. An independent samples t-test was conducted to compare item responses between parents who had vaccinated and not vaccinated at least one child aged 11 or above. There was a significant difference between the scores in unvaccinated (M=2.95, SD=.705) and vaccinated parents (M=2.13, SD=.458);  $t(40)= 4.527$ ,  $p = 0.000$ , CI (95%) [.452, 1.182] based on reported belief regarding HPV vaccine safety (See Figure 5).

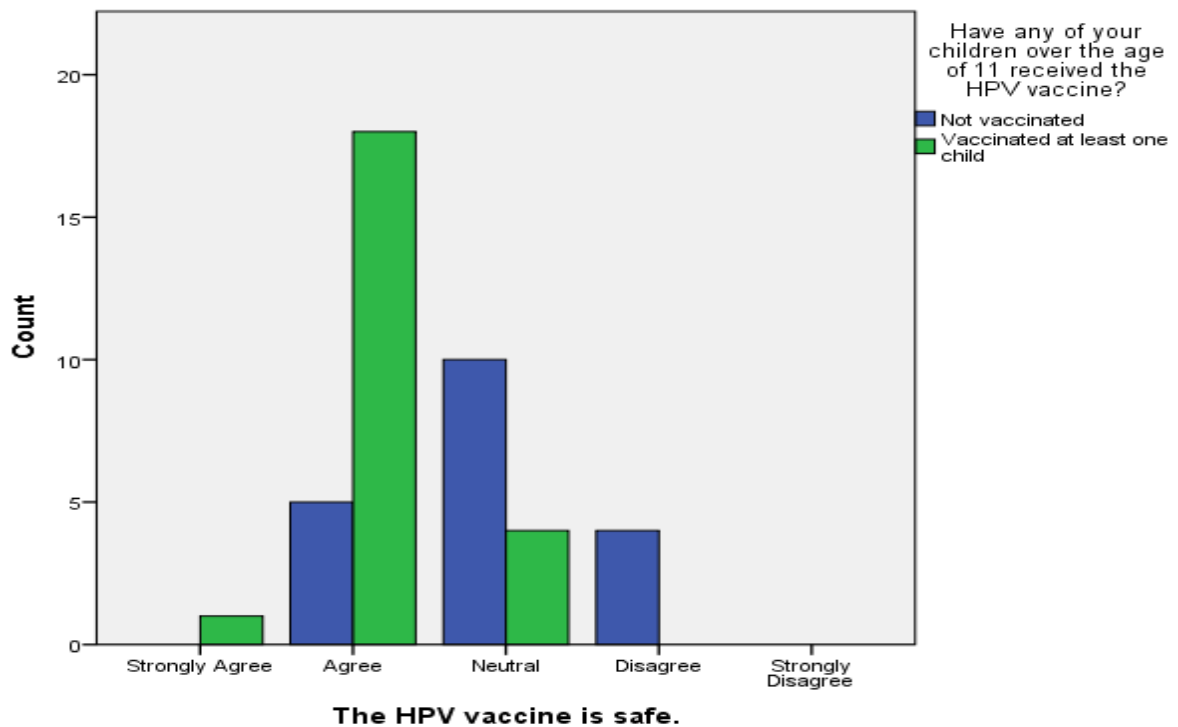
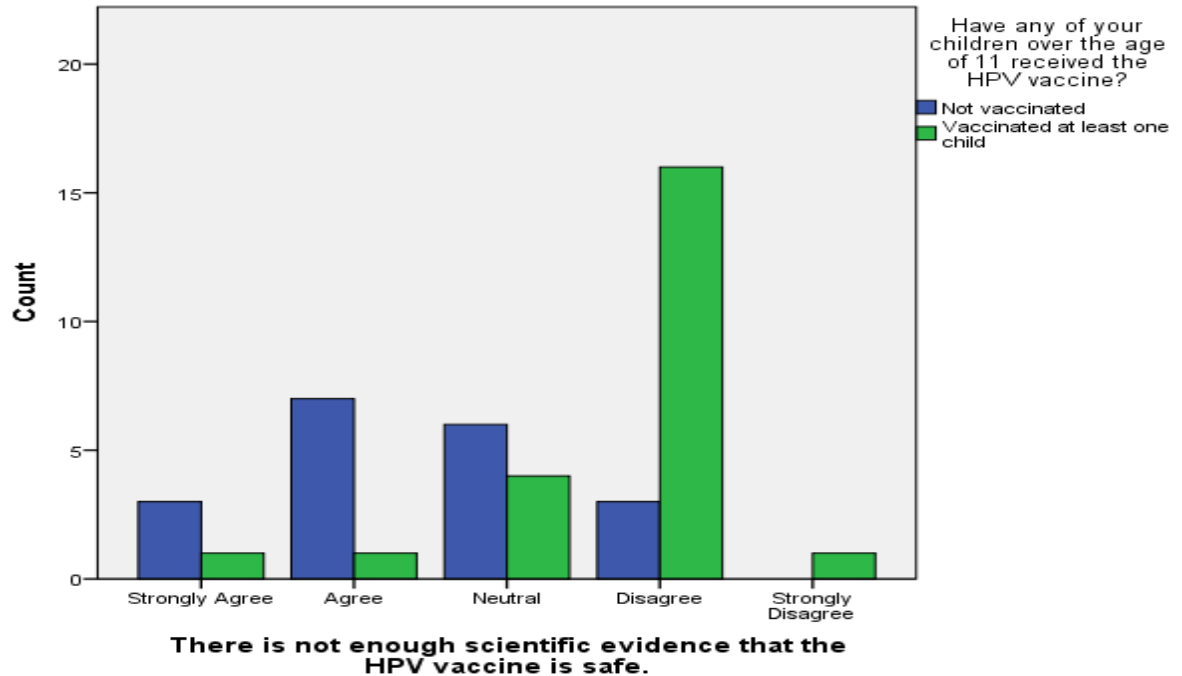


Figure 5: Parental responses to “The HPV vaccine is safe” by vaccination status

There was also a significant difference between the scores in unvaccinated (M=2.47, SD=.964) and vaccinated parents (M=3.65, SD=.832) conditions;  $t(40)= -4.253$ ,  $p = 0.000$ , CI (95%) [-1.749, -.608] based on reported belief regarding evidence of vaccine safety (See





**Figure 6: Parental responses to “There is not enough scientific evidence that the HPV vaccine is safe” by vaccination status**

Figure 6). Based on these results, parents who expressed a higher belief in the safety and evidence of safety of the HPV vaccine were significantly more likely to have vaccinated at least one child. In my conversations with parents, uncertainty regarding the safety (and thus potential risk) of vaccination surfaced as an influential factor in parents’ decision to delay or refuse vaccination. As Kendra, mother of an unvaccinated 13-year old daughter, explained:

*Kendra: So what’s my plan for [vaccination]? If don’t know. I guess I’m not against her getting it later. If it turns out that there’s a lot of good data that it’s safe. I think safety would be my main reason for not getting it—safety of the vaccine. If it’s not looking very safe—cause even if it reduces the risk a little, I don’t need the risk reduction to be huge, I just need the safety to be huge. ‘Cause you know all the vaccines—she’s not going to die from the measles, the mumps, chickenpox, but I get her all those things cause why not stay healthy. And the vaccines to me seem safe so that’s sort of my equation.*

In a subsequent chapter, I will examine how notions of sexuality and parental knowledge shape assessments of safety and risk. In addition, parents’ relationship with and trust regarding doctors also mediated these considerations.

## VI. DOCTORS KNOW BEST...SOMETIMES

In our conversations, parents discussed a variety of sources—friends, family members, websites, and media sources—from which they drew upon to inform themselves regarding risks and benefits of HPV vaccination. Of these sources, doctors (not surprisingly) emerged as having a key role in vaccination decisions, particularly among those who expressed trust in doctors in general.<sup>17</sup> In the questionnaire, I asked parents to complete five-items, adapted from Hall and colleagues' Trust in Medical Professionals scale (2002), to assess parents' general trust in doctors. I also summed the five items (score 5-25, lower scores indicating higher trust), and examined the relations between the individual items, summed score, and vaccination status. Internal consistency for the overall scale was high (Cronbach's  $\alpha=0.828$ ). Table 2 includes the results of each item:

Item <sup>18</sup>	Unvaccinated <i>Mean (SD)</i>	Vaccinated <i>Mean (SD)</i>	Independent Samples t- test	95% CI
I trust doctors' decisions about which medical treatments are best.	2.89(.809)	2.48(.665)	t(40)=1.831, p=.075	-.043, .876
I trust doctors to tell me all the risks and benefits of medical treatments.	3.32(.885)	2.48(.790)	t(40)=3.238, <b>p=.002</b>	.315, 1.360
I trust doctors to put the needs of patients before what is most convenient or best for them.	2.68(.820)	2.78(.795)	t(40)=-.394, p=.696	-.604, .407
I trust doctors to tell me if they are not certain about the risks and benefits of a certain medical treatment.	2.79(.976)	2.52(.846)	t(40)=.952, p=.347	-.300, .836
All in all, I trust doctors completely.	3.63(.955)	3.13(.757)	t(40)=1.898, p=.065	-.033, 1.035
Sum Score of 5-items	15.61(3.63)	13.39(2.888)	t(39)=2.272, <b>p=.029</b>	.244, 4.196

<sup>17</sup> In interviews, I asked parents about their relationship with their child's doctor and in general, most described having access to consistent, quality care for their child, often stating that their child had been with the same pediatrician since birth. A few parents did describe lower quality of care (rushed communication, inconsistency in doctors seen) for their children, but still reported having access and generally good care.

<sup>18</sup> Responses ranged from 1=Strongly Agree to 5=Strongly Disagree.

Parents who had vaccinated at least one child reported significantly higher levels of trust than those who had not vaccinated. Additionally one item regarding trust in doctors to tell patients all the risks and benefits also was independently related to vaccination status, whereby parents who had vaccinated were more likely to agree with this statement than those who had not. Beyond quantitative data, the following quotes also highlight the powerful role trust in medical professionals (and their expertise) had on vaccination decisions:

*Debra: Maybe more people might have researched it. I just kind of – I did trust what the doctor was telling me and went with it. So I want to say it's more of an easy going kind of way of dealing with it as opposed to – maybe if my husband would have done it he would have done a lot more research (Mother of 14- and 19-year old vaccinated daughters).*

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*Krista: I guess that to a certain extent I assume that by the time my doctor tells me that it's there that all the normal tests have been done (Mother of 14- and 16-year old vaccinated daughters).*

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*Jessica: I think that if the doctor recommends [vaccination for my son]...either he would bring it up, or if I were thinking about it, I might say, 'Is that something we should do?' and if he says yes, I probably will do it (Mother of 17-year old vaccinated daughter, three unvaccinated daughters (aged 7, 9, 12), and one unvaccinated 14-year old son).*

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*Michelle: I was persuaded by the doctor [to vaccinate]. Yeah, and I had never been against the vaccine before even though when they were younger, the physician was saying that you can either do chickenpox or not. I think it's chickenpox; I think it's that one. Then you can let the child develop naturally...I had chickenpox when I was in third grade myself and then you become immune you know later on. So that time the doctor was not very insisting on getting it...When now it seems so, that the doctor said that you still have the choice not to do it but it's the best for you. Things like that. So I think for the HPV, now that I think about it, it's because she persuaded me to do that (Mother of vaccinated 12- and 15-year old daughter and 11-year old unvaccinated daughter).*

Although these patterns are informative, trust in biomedicine and its expertise is a

complex concept shaped by understandings of how and why we become ill (explanatory models), epistemological understandings of how we know (knowledge production), and lived experiences beyond health and affliction that cannot be easily reduced to survey measurement (illness narratives). In an effort to show these complexities, I will compare the experiences and decisions of two parents—each of which made opposite decisions than one might guess based on identified patterns. This is not to argue that identifying patterns is not a useful endeavor, and from a practical standpoint, identifying patterns might be necessary to begin to translate findings into structural, individual and group level interventions to improve public health. Rather, this is to argue as many have for why "ethnography matters" (Fassin 2012).

## **VII. UNMAKING MODELS**

At the onset of our interview, Marilyn, a full-time working mother of five daughters, aged 11 to 21 (four of whom had been vaccinated), immediately disclosed that, "I didn't really investigate the risks and benefits of the vaccine because we just generally vaccinate." 'We' in this case includes herself and her husband, a family practice physician who works in community health clinics in the Bay Area. Like Marilyn, other parents had felt the need to give a confessional of sorts during the interview, whereby they apologized or divulged their lack of knowledge regarding HPV vaccination. However, in this case, I was not surprised that she had not done much research and just followed the recommendations of her child's doctor because in this case, the doctor was her husband. What did surprise me is that during our conversations she also explained that she herself was a bit surprised that she did not do more research due to her personal experience with the potential harm of vaccines.

*Marilyn: That's where I feel uninformed like maybe I should have looked more into it. You know like the whole MMR thing, I actually have a person in my family who had a bad outcome with MMR, my younger brother. But I just never heard maybe much about Gardasil having any downside, so I just didn't bother to even investigate that when the time came up.*

*Kate: Did your brother have a bad reaction to the MMR shot?*

*Marilyn: Well, he developed encephalitis, where he almost died actually at age 10 and he was in a coma for 3 months. And they don't know for sure if it's the MMR but that's the theory...He was one of those cases that you hate to hear about. So it's just had different repercussions in my family, like my older sister does not vaccinate, but myself and my younger sister, she's also a physician, we never hesitated to vaccinate. So it's kind of like my older sister's thinking her kids could be that one in a million like my brother was and end up brain damaged. And I think the rest of us are thinking, well that's so unlikely and the medical reasons are overwhelming in favor, so let's just do it and just trust that.*

For Marilyn, despite living through "one of those cases" where vaccination results in serious harm, she did not hesitate to vaccinate based on a trust in both medicine and statistical probability that it would not happen to her and her family. In contrast, another parents expressed strong resistance to vaccination, despite seeing (and expressing gratitude for) the positive effects of biomedical intervention.

I met Autumn on a rainy day at a coffee shop near the local university where she worked as a finance administrator. Full of energy despite the gloomy day, Autumn described the intensity and closeness of her relationship with her two daughters (aged 15 and 17), stemming in part from her experience as a single mother.

*Autumn: I can read my kids, I separated from their dad when they were pretty small, seven and four, and had them, have them eighty percent of the time. And I've had them eighty percent of the time for the last ten years, so to read them is pretty, is pretty easy. And the youngest is like an open book sometimes, and when my oldest gets a little too chatty and that's when I know.*

This closeness also came from her experience caring for her younger daughter, who was diagnosed with childhood leukemia at age five. Nearly 10 years later, she described her daughter as a "survivor" and expressed gratitude for her child's pediatrician for identifying

the illness and helping to care for her daughter. However, despite this positive and long-standing relationship with her child's doctor, Autumn "fired" her doctor due to her doctor's insistence to have her daughter receive the HPV vaccine. As she explained:

*Autumn: I fired their first primary care physician. Because at my soon to be twelve-year-old's well check or at an appointment we were at, she says, 'Well I guess when she comes into her well check, we'll be setting her up for the HPV.' And I said, 'No we won't.' And she says, 'Oh sure you will.' I said, 'No we won't.' And she got really in my face and I said, 'You will hear me about this. I am not interested in my child who doesn't even know what sex is to be inoculated for something that is not in her next three year window, I assure you.' [The doctor] wanted nothing, absolutely nothing to do, she basically put her hand up to me and said, 'Fine we'll talk about it later.' And I said, 'No we won't.' And I turned around, called my oncologist, and said, 'Who can you recommend? Who is your PCP for your kids because I'm ready to fire mine.' And I told her why and she says, 'Wow.' I said 'You know, you don't tell a mom, whose other kid has been shot up with every chemotherapy drug known to man it feels like and every drug under the sun that you're gonna just 'Because I said so' put poison into my kids body. No you're not...I had been hearing about [the vaccine] and reading about it and I thought, 'This is ridiculous.' They're using little girls as guinea pigs. It's that simple.*

Despite a personal history and use of "every chemotherapy drug known to man", she considers the HPV vaccine to "poison" due to novelty and initial target audience of the vaccine. Her resistance to the vaccine overrode her trust of—and ultimately her relationship with—her child's doctor.

In the case of both of these mothers, based on my own identified patterns, it would be predicted that each would have chosen a different vaccination decision. Personal experience of seeing the harms of vaccination would lead one to predict that this individual would be resistant or at least critical of new vaccines. In contrast, expressed trust and gratitude with doctors and personal experience of seeing the positive impact of biomedical care would be predicted to lead to decisions to vaccinate. In each of these cases, however, other aspects of life overpowered these predictors, pointing to the way in which ethnography can complicate and enrich health behavior and risk models. In the final section, I will examine the ways in

which my time in the field also unmade my own theoretical approach and understanding of the project.

### VIII. LOCATING PEOPLE AMID THEORY

*In their relentless drive to theorize, anthropologists run the danger of caricaturing complex realities, neglecting key realms of experience, and missing lived ironies and singularities that might complicate and enrich analytics. People are missing, in multiple senses (Biehl and Locke 2010:319).*

My original framing of my dissertation built upon theories and frameworks of how subjects are produced through various mechanisms and practices—informed in large part by the work of Foucault and those speaking to his work on biopolitics, governmentality, and subjectification. Underlying much of this work are concerns regarding how articulations of power come to make (and unmake) who we are and how we engage with the world. In the context of HPV vaccination, I do believe these practices are at play, particularly in the realm of moral politics and pharmaceutical marketing. However, what I have learned from speaking with parents is that decisions regarding HPV vaccination are not solely a result of powerful, biopolitical institutions, but rather are evaluated through their *desire* to care and parent in particular ways.

Drawing from the philosophical work of Deleuze on desire and Foucault on power (and their debates), Biehl and Locke (2010) argue for an "anthropology of becoming", which allows for an examination of how power and knowledge guide action and existence while simultaneously acknowledging the complexities of lived experience that emerge during fieldwork. To bring these complexities to light, I will use the cases of three mothers who have all made different decisions regarding HPV vaccination for very distinct reasons. Within each case, the desire to care guides and shapes each decision. However, exactly

how—and for whom—this desire is articulated and mobilized is quite different, and highlights the role of both lived experience and power of normative constructions of risk, sexuality, and social obligation.

### *Latrice*

As her nine-year old son played on a nearby playground, Latrice, a 32-year old African American Oakland Native, detailed the struggles of her life as a single mother who has worked to become educated in order to escape the poverty and crime of West Oakland. As a first generation college student, earning her Master's in Education, she is remarkably sensitive to the challenges of escaping poverty and the impact of institutional processes on daily life. She laughed as she explained, “[The paperwork] depletes a lot of my time. I only can work part-time because I find I spent a lot of my time at the housing authority—that’s like my home away from home.” She is dedicated to caring for her son—by promoting healthy living and education—but worries that the unsafe environment where they currently live is contributing to her son’s obesity, high cholesterol, and borderline diabetes. “When you live in a bad neighborhood,” she said, “if you don’t feel safe, you know walking around the neighborhood, you cannot get those physical activities.”

Although she has many other concerns, she is adamant that her son receives the HPV vaccine when he is of age. This persistence stems largely from her experiences with the virus herself that resulted in increased medical surveillance and many invasive procedures. She believes she contracted HPV from her son’s father—another actor who heavily influences how she cares for her son, but not necessarily in expected ways. In asking about her vaccination decision for her son, she gave great detail of her desire for her son to be



vaccinated so he would not spread the virus to other women. When I asked what she hoped her son would be like when he was an adult, she said, “Number one: Not like his father.” For this mother, her desire to care and subjectivity as a parent has intersected with institutional processes more than most. Through these experiences, she has shaped a particular understanding of risk and responsibility guided by personal experience with HPV, and the material and social realities of her daily life. For her, the decision to vaccinate her son is embedded within a larger desire to care for the community of women at large by raising a healthy and educated son.

### *Lorraine*

I met Lorraine on an early rainy morning in Berkeley after she had just dropped off her two daughters at school. Her daughters hoped the rain would clear in time for soccer practice, but she secretly hoped the rain would stay so they could all go home and avoid the muddy fields. Although an older mother by national standards—in her late fifties—she very much fits the stereotyped profile of a Berkeley mother—liberal, educated, and very informed. As she put it, “I listen to public radio—I am a Berkeley person, what can I say [laughter].” In the case of the HPV vaccine, these desires to be informed and search for information, however, were trumped by a specific personal experience.

Early on in our conversation, Lorraine disclosed, “We have a personal connection to a story which has certainly added to my negative views of [the vaccine]...A girl who died in our community...I don’t know if—and I don’t know if they know, but they certainly believe it was from the vaccine.” The story is one I would hear again—of a girl (Jenny Tetlock) who died from an autoimmune disorder that is believed by some to have been triggered by the

vaccine. Lorraine explained that hearing the story made her question the safety of the vaccine not because she lacked comprehension of probability statistics, but rather because the closeness of the story amplified the potential for risk. “I know the numbers are very small. I’m sure that the cases that might be even attributed to it must be [minute] ...so I’m not like ‘wow this is horrible, everyone’s dying’. But I do think there could be cause for concern.” Her experiences have placed the risk of the vaccine at a greater weight than the current risk of her daughter catching the virus. However, for her there is something particular about the HPV vaccine, which makes these risk calculations more understandable.

Lorraine is not anti-vaccine. As she explained:

*I think there is a certain selfishness in deciding ‘oh I’m not gonna vaccinate my kid because there is enough protective immunity in the rest of the community—that I don’t have to’ but if everyone starts to do that, then obviously that’s gonna breakdown. I’m sure that there are harms caused by vaccines for some people, but probably the bigger picture is that overall it has improved our health. But I feel the HPV one is different in character.*

When I asked her why, she responded, “Well, because we are talking about a behavior that leads to some diseases. And the case of chicken pox or polio or whatever, you’re talking about exposure and it’s just you know, you cannot avoid the diseases by avoiding behaviors.” The behaviors she is referring to are sexual behaviors. While it could be argued all communicable diseases are in some ways linked to behaviors—riding the bus, living in certain areas, or traveling abroad—the act of sex remains for Lorraine, and for many other parents, something distinct that can be avoided—or taught to be avoided—in order to protect their children from HPV.

For this mother, the visceral experience of knowing someone who potentially died from receiving the vaccine, amplified and altered her construction of the risk of the vaccine. Additionally, the way she understood HPV as distinctly different from other communicable

diseases—as something that could be prevented by avoiding certain behaviors—solidified her calculations. For her, the more pressing risk came from the vaccine rather than from the virus. Although she greatly desired to care for her children by making them healthy and protecting them from risk, she believed she could reduce the risk of HPV transmission by teaching them safe sexual behaviors; whereas, the risk of the vaccine seemed uncertain and out of her hands.

### *Sarah*

I met Sarah, a divorced, single mother of two teenage children, at a small café while her daughter attended violin lessons in a nearby school. Immediately, I was struck by her ability to clearly define who she was as a parent, particularly in contrast to the liberal community around her. “[I’m] more authoritarian. I’m the boss.” Her strictness also shaped her views on vaccination—or rather on those who decide not to vaccinate. As she explained, “Parents who are not in favor of vaccines—for me, their reasons don’t seem very sound. I don’t feel like they have a legitimate grievance.”

Responsibility also seemed to hold significant meaning for how she defined herself as both a parent and citizen. She views herself as primarily responsible for her children’s health. As she stated, “I have been entrusted with the responsibility of keeping them healthy.” This very much guided her decision to have her children vaccinated against HPV. However, when I asked her what the primary reason was, she answered:

*You’re gonna laugh. It’s not even to protect my kids from getting sick. It’s because I buy into the whole subject of herd immunity so strongly I want my kids to be vaccinated more for the good of society. I want to be part of the legion that protects people who cannot get [vaccinated]...I really strongly believe that. I know the chances of them getting [cervical cancer] aren’t very high. But I really think the more people that have [the vaccine] the better. I’m gonna do my part.*

For Sarah, her personal desire to protect the collective drove her decision to have her children vaccinated.

However, she felt some internal conflict between her views on vaccines and her general political views. As she explained, “I kind of lean libertarian or moderate so therefore I...am in favor of a smaller government. But on the other hand, there’s a few—like the topic of vaccines, I feel like vaccines should be mandatory for everyone that can get them. So in that area, I’m more in favor of a large government. So I realized that I have an internal conflict there.” While Sarah very much desired to care for her children—and viewed it as her responsibility, the decision to vaccinate her children was driven more by the desire to care for the collective societal whole. For Sarah, the decision to not vaccinate ones children is not only an act of poor parenting, but bad citizenship.

In conclusion, as indicated by the thoughtful considerations of each of these parents, a consistent reason underlying their decision to vaccinate or not to vaccinate their children against HPV is a strong desire to care. Beyond caring for their child, the desire to care is reflective of relationships between a variety of actors (individual and collective) as well as norms, values, and assumptions. This desire may in some ways be an inescapable result of the powerful material, legal and moral requirements of parenthood and biological citizenship in the United States. However, how this desire is articulated varies significantly, and is shaped by the particular ways each parent constitutes risk, responsibility, gender, and sexuality. Lived experiences such as Latrice’s experience with HPV and her son’s father or Lorraine’s proximity to a child’s death as well personal values—exemplified most clearly by Sarah’s devotion to being a good citizen—are at the foundation of these constructions. In these ways, the decision to vaccinate becomes much more than an evaluation of risks and

benefits, but rather is entangled with ethical considerations of how one should live—and parent—amid technological transformation.

### CHAPTER THREE: EMPOWERMENT, AMBIVALENCE, AND PHARMACEUTICAL MARKETING

*Pharmaceuticalization functions as a three-way bridge among the universalizing assertions of biomedical science, the moral imperative to treat the world's sick, and the subjective experience of illness. The pharmaceutical industry claims privileged access to each of these three domains.*

–Kalman Applbaum<sup>19</sup>

Since the FDA regulatory change allowing for direct-to-consumer (DTC) advertisements, a disorder, like depression or erectile-dysfunction, is frequently marketed in conjunction with a new drug claiming to cure or alleviate its symptoms (Fishman 2004; Healy 2006; Potts et al., 2004). In the United States, human papillomavirus (HPV) and the vaccine followed a similar progression, emerging concurrently into the public sphere through direct-to-consumer (DTC) advertising backed by public awareness campaigns and an aggressive (albeit hidden) lobbying campaign by Merck to have the HPV vaccine added to the list of mandatory vaccines for 6<sup>th</sup> grade girls<sup>20</sup>. In this chapter, I will provide detailed analysis of initial marketing campaign employed by the pharmaceutical company, arguing that the initial campaign utilized a feminist empowerment model in an attempt to avert public backlash. Following, I will present an overview of more recent public health and pharmaceutical marketing approaches, as well as highlights from the larger political and

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<sup>19</sup> [http://somatosphere.net/2009/02/pharmaceutical-marketing-and-capitalism\\_28.html](http://somatosphere.net/2009/02/pharmaceutical-marketing-and-capitalism_28.html)

<sup>20</sup> Merck also worked with public health departments and patient advocacy groups to garnish support and increase public awareness of and for Gardasil (See Gottlieb (2013) for further discussion).

cultural debates regarding HPV vaccination. I will then situate these discussions in the thoughts and decisions of parents with whom I spoke, drawing from Emily Martin's work on ambivalence and meaning in pharmaceutical practices, and arguments from Biehl and others regarding the "pharmaceuticalization of public health" to highlight how vaccination decisions are scripted with and come to reflect political and economic values and practices in the United States. Lastly, I will discuss novel ways social workers can assist in clinical efforts to understand and communicate how particular lived experiences of patients, including structural, social, and economic conditions, influence health outcomes and practices (beyond individual-level factors or "cultural variables") amid recent shifts in the healthcare system (Metzl & Hansen 2014).

## **I. PHARMACEUTICAL INTERESTS AND VACCINE DEVELOPMENT**

Since the widespread support of the polio vaccine in late 1950s, pharmaceutical companies' interest in developing vaccines has greatly decreased, resulting in repeated vaccine shortages across several of the recommended childhood vaccines and the flu vaccine (Offit 2005; Cohen 2002). Several factors contribute to pharmaceuticals reluctance to develop vaccines. In comparison to other drugs—for example, cholesterol-lowering agents that need to be taken daily—vaccines are only used several times across one's lifetime, resulting in a much smaller market, and much smaller potential for revenue (Offit 2005). Additionally, the 1994 enactment of *Vaccines for Children*, a federally funded program that provides free vaccines for all underserved children, has greatly reduced the private market for vaccines. In addition to smaller financial benefit, vaccines also carry additional risk,

regulatory burden, and potential product liability<sup>21</sup>. While many decry public health's reliance on the private market to produce what is framed as a public good, the practice remains, indicative of both the power of the pharmaceutical industry in the United States, and growing reliance on "magic bullet" solutions for both illness and prevention (Abraham 2010; Biehl 2007).

However, beginning in the late 1990s, the vaccine industry entered into a renaissance of sorts. Between 1995 and 2008, the total number of vaccines in development more than doubled globally, and, although the number of pharmaceutical companies remained relatively the same, three of the four major manufacturers active in the U.S. market increased the proportion of their product portfolio dedicated to preventive vaccine development by three-to-four fold (Davis et al. 2010). In the case of Merck, the company also began investing heavily into the production of preventive vaccines, including Gardasil, in the early 1990s. This investment seemed to pay off as Merck earned 1.5 billion in revenue from Gardasil in 2007 (Herper 2012). Although in 2010 sales dipped to about \$1 billion, sales again increased to \$1.6 billion in 2012 following the expansion of licensure to include young boys. This is in comparison to their competitor, GlaxoSmithKline (and their bivalent vaccine, Cervarix), who "only" earned \$408 million in 2012 sales (Silverman 2013). In addition to gaining U.S. FDA approval and licensure first, many credit Merck's expansive marketing and lobbying campaign for their initial and continued success over their competitor.

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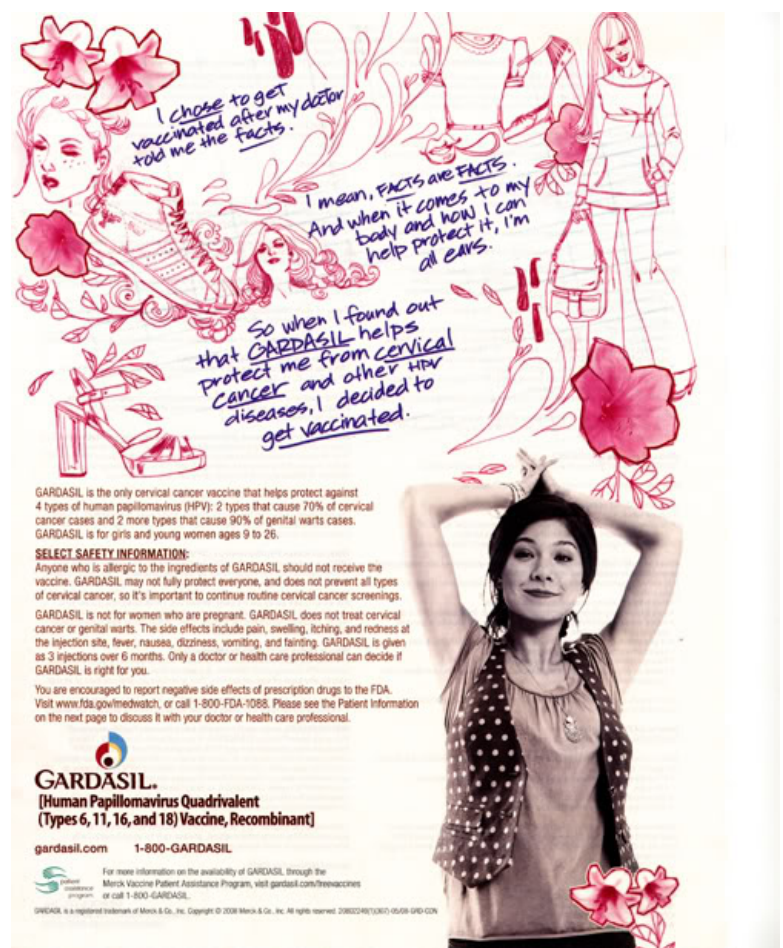
<sup>21</sup> Following numerous lawsuits against pharmaceutical companies claiming harm inflicted by the pertussis vaccine, the United States Congress passed the National Childhood Vaccine Injury Act (NCVIA) of 1986, which nearly eliminating liability of vaccine manufacturers for any potential harm resulting from vaccination (thus encouraging them to continue to manufacture vaccines), and created a no-fault, federally funded compensation program (National Vaccine Injury Compensation Program) for children who suffer a scientifically-proven reaction to a vaccine. This act also established regulations regarding the reporting of adverse events following vaccination, centralizing these reports in the Vaccine Adverse Event Reporting System—VAERS. In 2011, in the case of *Bruesewitz v. Wyeth*, the U.S. Supreme Court upheld the NVCIA, reaffirming that pharmaceutical companies cannot be held liable for adverse vaccine effects, unless they actions are proved to be negligent in some way.



## II. PROMISE OF EMPOWERMENT: INITIAL MARKETING OF THE HPV VACCINE

Following the initial FDA approval of Gardasil in June 2006 for young girls and women, Merck employed a widespread marketing campaign, known as the "One Less" campaign (See Figure 7). The campaign was directed primarily at the initial target population, young women between the ages of 11-26 and their mothers<sup>22</sup>. Simultaneously, Merck also launched an aggressive lobbying campaign (funded through a third party advocacy group, *Women in Government*) to enact legislation that would require HPV vaccination for 6<sup>th</sup> grade girls. On marketing alone, Merck reportedly spent \$100 million to promote Gardasil in 2007 (Taylor 2013), followed by \$96 million in 2008 (Silverman 2013). The One Less campaign, designed in part by two worldwide advertising agencies,

Figure 7 : Gardasil poster targeting young women  
Source: [www.gardasil.com](http://www.gardasil.com)



DDB and RAPP, received critical acclaim, winning top honors for *Best Branded TV*, *Best Branded Print* and *Best Integrated Campaign* at the 2008 Pharmaceutical Advertising and

<sup>22</sup> Merck simultaneously ran a Spanish version of the One Less campaign ("Una Menos"), which some believe helped to drive high rates of vaccination among Hispanic adolescents in the United States.

Marketing Excellence (PhAME) awards (Arnold 2008). In addition to receiving critical acclaim, the marketing campaign seemed to pay off, boosting sales of the vaccine from \$235 million in 2006 to \$1.5 billion in 2007.

The architects behind the initial campaigns carefully designed the approach to encourage the target audience of young women (and their mothers) to identify with the projected message: “choose to be one less, choose to be vaccinated.” In a seeming effort to avoid cultural backlash and promote consumption, public awareness and media campaigns were constructed to produce a social identity that reconciled the precarious link between the limits of acceptable public discussion of female sexuality and sexual health, and the need to connect with the collective intimacy of women and young girls in the United States (Appadurai, 1986; Shryock, 2004). In this section, I will examine the ways in which the initial marketing campaign of Gardasil employed cultural markers and discourses of female empowerment to attempt to engender acceptance among the target population and to (unsuccessfully) evade scrutiny and resistance among this public.

The female empowerment model projected in HPV vaccine advertisements and public awareness campaigns drew from extant feminist rhetoric to frame vaccination as an empowered “choice” and for many young women and parents, vaccination may be. However, the “choice” to be vaccinated against HPV is an embodied practice, which reworks subjectivities and is situated within networks of power (Foucault 1979). Governing institutions and disparities in healthcare access, which are influenced by social and structural factors, regulate access to this practice, restricting (but not removing) the ability of individuals to freely “choose”. Examination of marketing materials gives clear insight into how HPV is being formatted and visualized as a disease that is ubiquitous and curable,

especially in contrast to other (less visible) sexually transmitted diseases associated with the virus. This formatting excluded discussion of structural barriers to vaccination including the high cost of the vaccine and disparities in access to healthcare, and simultaneously created parents and young women as moral subjects of the vaccine (Mamo, Nelson & Clark 2010). Through this process, the vaccine became emblematic of a certain type of mother, daughter, woman, and biological citizen. The examination of HPV and the HPV vaccine as a formatted, constructed phenomenon does not discredit claims of medical potential or seek to exclude the possibility that the vaccine can possibly save thousands of lives. Understanding the formatting of HPV does, however, illuminate how cultural ideologies and power relations give meaning to social life of medical technologies.

**Figure 8: Print images from Merck's One Less campaign**  
**Source: Rosenthal 2008**



### *One Less Campaign*

The One Less campaign employed a variety of print, electronic, and social media pathways to market its message (Figure 8), including a highly designed and interactive website, which more resembled a social networking site than other pharmaceutical websites. Beyond online tools, between 2007 and 2009, two commercials, modeled after the messaging campaign, aired frequently on national television stations across the United States as well as on the official Gardasil website and YouTube.

The commercials matched the framing of the initial website and projected an image of vaccine as connected to modernity, beauty, and empowered femininity. The invisible side

**Figure 9: Gardasil commercial targeting adolescents: Screenshot A**  
Source: [www.gardasil.com](http://www.gardasil.com)



of HPV, presented as the “other HPV diseases” in the commercial and on the website, acted as a buffer to absorb the negative associations between the vaccine and stigma of sexually transmitted diseases (Brandt 1987). Each commercial had a primary audience, one targeted mothers of young girls and the other targeted young women, and both stressed the empowerment of those who choose to be vaccinated against cervical cancer.

The commercial aimed at mothers begins with a white woman stating: *I chose to get my daughter vaccinated because I want her to be one less woman affected by cervical cancer*. She and her daughter are sitting on a couch, with a skateboard, laughing (Figure 9). The daughter is presented as the classic teen rebel, dressed in baggy, skater clothes with a flawlessly disheveled haircut. The mother closes the frame with a kiss on her daughter's head. This interaction illustrates that the commercial is selling the vaccine as socially desirable, and Merck is attempting to align HPV vaccination with modern idealizations of hipness and individuality.

The next frame is of a Black mother who is putting braids in her daughter's hair as she sits at the kitchen table (Figure 10). She states: *I chose to get my daughter vaccinated when her doctor told me the facts. Like other vaccines, it's about prevention*. The frame closes with her daughter looking up at her and saying, *I like it*, which the audience can assume refers to the braids, but also to the vaccine.

**Figure 10: Gardasil commercial targeting adolescents: Screenshot B**  
Source: [www.gardasil.com](http://www.gardasil.com)



**Figure 11: Gardasil commercial targeting adolescents: Screenshot C**  
Source: [www.gardasil.com](http://www.gardasil.com)



The next white mother and daughter team are situated in the kitchen (Figure 11). The daughter is doing her homework, while the mother prepares dinner and reiterates that HPV vaccine protects against four types of HPV, saying: *Two types that cause 70 percent of cervical cancer and two more types that cause other HPV diseases.* Another white teenager adds: *I chose to get vaccinated after my doctor told me Gardasil does more than help prevent cervical cancer.* Her mother, with whom she is playing checkers, confirms: *It helps prevent other HPV diseases too.* The actors allude to the “other HPV diseases,” but the commercial is carefully formatted to exclude the verbal use of “genital warts”. The commercial continues with the disclaimer describing potential side effects and limits of the vaccine and ends with quick frames of each group of women and girls, spelling out: *O-N-E L-E-S-S, One Less, Gardasil, Gardasil, Gardasil. You have the power to choose.* This is audible over the last frame, which reiterates the slogan, “choose to be vaccinated”.

The second commercial is aimed at the other initial target population: young women aged 18-26. There are similarities between the two commercials; however, the second commercial portrays the empowered young woman, rather than the empowered mother. The commercial begins with the statement: *I chose to get vaccinated because I will do everything I can to help protect myself from cervical cancer.* A young woman in her early twenties says this while sitting on a couch, making jewelry (Figure 12). The next character, a cheerful, thin



Figure 12: Gardasil commercial targeting young adult women: Screenshot A  
Source: [www.gardasil.com](http://www.gardasil.com)

woman  
with dark  
hair who  
speaks  
while she  
pets her  
toy dog,  
states: *I  
chose to  
get*

*vaccinated when my doctor told me HPV can affect women my age and how Gardasil can help protect me.* This character sits in a fashionably decorated room, with a bicycle and helmet visible in the background. These cultural cues provide the audience with information about the identity of the character, a modern woman (of all races) who is active, creative, and vaccinated against HPV. The commercial ends with the first actor restating: *I chose to get vaccinated because my dreams don't include cervical cancer. Gardasil, Gardasil, Gardasil. You have the power to choose* (Figure 13).



**Figure 13: Gardasil commercial targeting young adult women: Screenshot B**  
Source: [www.gardasil.com](http://www.gardasil.com)

Throughout the commercials, the theme and rhetoric of choice is reiterated. This tactic is reminiscent of the strategies employed by reproductive rights activists who, beginning in the 1980s, reformatted abortion rights as the right to choose (Gordon, 2002)<sup>23</sup>. *Choice* is connected to a larger individualistic and mainstream feminist ideology in the United States, and as such, carries considerable cultural authority and familiarity. Each character depicted in this commercial is linked to a certain cultural identity that projects modern idealized traits including health, beauty, individuality, creativity, independence and empowerment. Gardasil is formatted as a feminist, modern vaccine that transcends race.

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<sup>23</sup> Second-wave feminism in the United States has been highly criticized for ignoring how other factors—such as race, class, and sexual identity—intersect with gender to impact the experience and discrimination of women (Collins 1999; hooks 1981; Roth 2004). In the context of these commercials, I believe Merck attempted to transcend race by carefully depicting women of all diverse ethnicity to expand its market. However, the message largely ignores historical structural and social barriers or experiential dissonances invoked by choice rhetoric.



The message is clear: Take this vaccine if you are a young woman who chooses to fight back against the repression of disease.

As anthropologists working in media studies have pointed out, the producers of media and mass culture should not be viewed simply as projectors of hegemonic images and messages, but as creative individuals that are both encompassed by and contributing to the development of formatted ideas (Dávila, 2001; Ginsburg, Abu-Lughod, & Larkin, 2002). The “Behind-the-Scenes” video clip on the initial Gardasil website gives some insight into the formatting work that is being done with the HPV vaccine. This episode gives the viewer an “insider” look into the making of the commercials, which is supposed to give the audience the feel of spontaneity and lack of formatting. However, it is clear that as much formatting is put into the “Behind-the-Scenes” episode as is put into the commercials.

One interaction is particularly illuminating in which the two actors, a mother and daughter, reflect on their roles and the perception that they are representatives of the vaccine (depicted in Figure 10). The audience learns that the Black actors (who are shown braiding hair in the commercial) are named Ashley (mother) and Kammie (daughter).

*Mother: It's something that is going to help people. You know, it is good to be a part of it.*

*Daughter: And it is like you are representing it. So, if you know that it is that important, and then you see it, and it's like, wow, I am representing something that is that important. It makes you feel good inside.*

The actor, Kammie, is cognizant of the fact that she, by being part of the marketing campaign, will be viewed as representing the type of young girls who choose to be vaccinated. She is visibly proud of this fact, as is the mother, Ashley, as they both interpret their actions as helping other women. It is unclear if this aspect of the “Behind-the-Scenes”

episode is scripted, but it indicates how the media creates a formatted image for public consumption.

Pharmaceutical companies, through advertising, construct an image, which is connected to larger cultural ideologies and backdrops. The formatting, beginning with the clinical trials and the direct-to-consumer “public awareness” campaigns, proffers HPV and its vaccine as a trimmed product available for consumption, accompanied by a productive and transformative quality. The representation of a disease and its cure has drastic implications for the cultural acceptance or rejection of not only the disease, but of those persons inflicted with it. An historic example of this is the ongoing battle fought by HIV/AIDS activists against the stigma first associated with the disease (Epstein 1996). In contrast, although it is also preventing against a sexually transmitted disease, the HPV vaccine is being framed (or attempted to be framed) by the pharmaceutical industry with desirable traits such as modernity, independence, and beauty.

The formatting of HPV and its associated vaccine offers the illusion of access to a safe, healthy, empowered sense of being that is connected to modern views of control over the “natural world” through technological advances and employs discourses of womanhood and sexuality to connect to its audience. The empowered female is resisting viral power through vaccination. This view plays off normative views of gender, sexuality, and womanhood that maintain boundaries of legitimacy and normalcy. Individuals who do not conform to these cultural norms will be excluded from the benefits of vaccination; moreover, relying on gendered notions of empowerment including beauty and charisma inevitably perpetuates hierarchies that serve to exclude individuals who do not fit gender roles. The rhetoric of choice ignores structural and cultural boundaries that inhibit (or mandate) certain

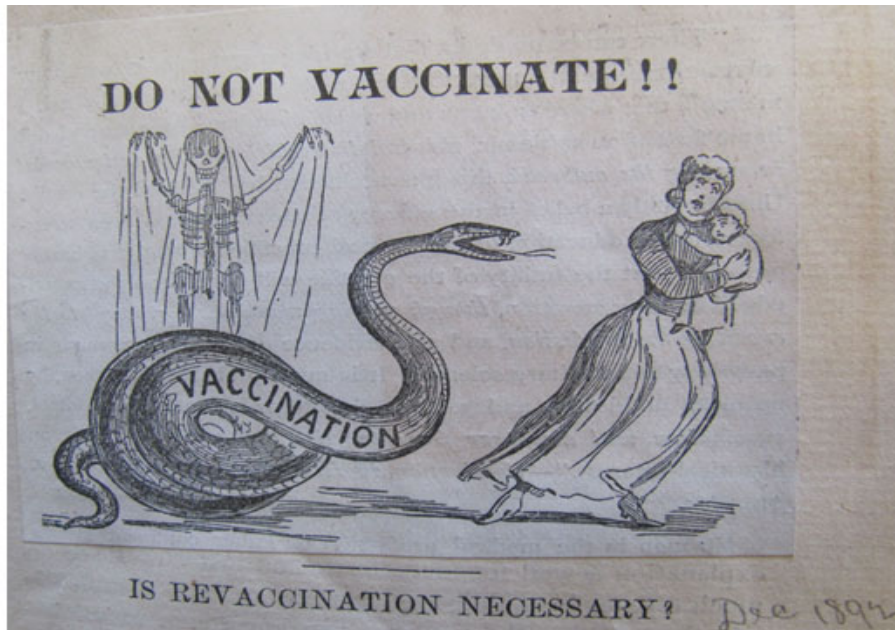
individuals from being vaccinated, and reifies the notion of the informed health consumer. However, despite the initial marketing and formatting by Merck, the HPV vaccine has been plagued by cultural critique and debate, tied in part to cultural anxieties regarding female sexuality, pharmaceutical and government distrust, and uncertainty regarding the safety of the vaccine.

### **III. PUBLIC DEBATES, CONTROVERSIES AND RESISTANCE TO HPV VACCINATION**

Since its licensure, the HPV vaccine has been shrouded in public debate, controversy, and political attention. These debates are part of a seemingly growing public distrust of the need for and risk of vaccines in the United States, stemming in part from (scientifically) unfounded claims of the causal link between autism and MMR vaccination (Kaufman 2010) as well as lack of lived experience with diseases such as measles and polio that vaccines have nearly eradicated from the U.S. population<sup>24</sup>. However, debates have followed vaccines since their inception (Figure 14), beginning with the small pox vaccine and continuing through to the HPV vaccine (Colgrove, 2006).

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<sup>24</sup> A number of outbreaks of vaccine-preventable diseases including whooping cough (pertussis) and measles have occurred in the last ten years in the United States that many believe are fueled by vaccine fears and increased numbers of parents “opting out” of childhood vaccination. In California, the whooping cough outbreak resulted in 2011 legislation (AB 354) mandating that all 7<sup>th</sup> graders receive the pertussis vaccine booster (Tdap). Worldwide outbreaks of polio and measles (mostly due to lack of access to vaccines not opt out policies) have resulted in global initiatives, most notably the Global Alliance for Vaccines and Immunizations (GAVI), to provide vaccines to impoverished nations at lower costs. In 2013, Merck recently agreed to provide Gardasil to GAVI at a significantly reduced rate (\$4.50/dose in contrast to its U.S. market value of over \$100/dose).



**Figure 14: Anti-vaccination poster from 1890s.**

**Source: The Historical Medical Library of The College of Physicians of Philadelphia (www.historyofvaccines.org)**

vaccine, these debates have taken various forms including concern over parental rights, religious convictions, sexuality of young women, and governmental distrust. What may be novel to the current public controversies is the speed at which news stories and subsequent controversies can spread across the nation (and world) through the range of devices ubiquitous in the digital age. In this section, I will review highlights of media coverage (and corresponding controversies) that have followed the HPV vaccine since its licensure.

*Initial Reactions: Parental Rights, Sexual Promiscuity, and Legislative Mandates*

As discussed previously, Governor Rick Perry of Texas caught much media spotlight early on due to his decision to circumvent normal legislative pathways, and pass an executive order to mandate HPV vaccination for young girls in the state of Texas (Perry 2007). This act received much media attention in political and popular media sources. A story published in *People* magazine in April 2007 highlights some of the central public reactions to the

In each epoch, public reception regarding vaccines is couched within larger societal concerns of the time. In the case of the HPV

proposed Texas law and the vaccine in general. Jan Gustafson, a mother of three shows hesitation to vaccinate due to the novelty and unknown long-term efficacy of the HPV vaccine. “We just don’t want to rush into anything...since it’s a new vaccine, we want to give it time and not let our daughter be a guinea pig. After all, she is just 12, and we are confident she is not having sex” (Lang 2007:89). Another mother, Cheryl Swope Lieck, a cervical cancer survivor, plans to vaccinate her daughter, as she feels it is her responsibility as a parent to protect her children. “Am I teaching my kids abstinence? Absolutely. Do I think abstinence is the main way to prevent HPV? Absolutely. But what are you going to say to women who get HPV from their husbands, even when those women were virgins when they married?” (Lang 2007:90). Both of these mothers expressed concern over how HPV vaccination would influence her daughter’s sexual behavior.

The concern of some parents is that the HPV vaccine will encourage young females to have sex, as it will take away one of the potential “consequences” of engaging in sexual behavior. Ellen Rossini, a mother of two daughters, exemplifies this view. “Our daughters are being raised in the moral tradition of chastity...Julia [her daughter] has a purity of heart and confidence that practicing moral traditions will lead to true happiness—chastity, followed by monogamous marriage. It’s not a dream. Her dad and I have lived it” (Lang 2007:90). Each of these viewpoints highlights initial moral arguments over the use of the HPV vaccine. Running through each of these viewpoints are cues into how individual bodies (namely, those of adolescent females) became the subjects of not only physical vaccination, but subjects upon which moral and cultural arguments over the rights of parents, sexuality, and public health are scripted.

The following cartoon<sup>25</sup>, written by Mike Adams, the “Health Ranger,” highlights some of these concerns (Figure 15):

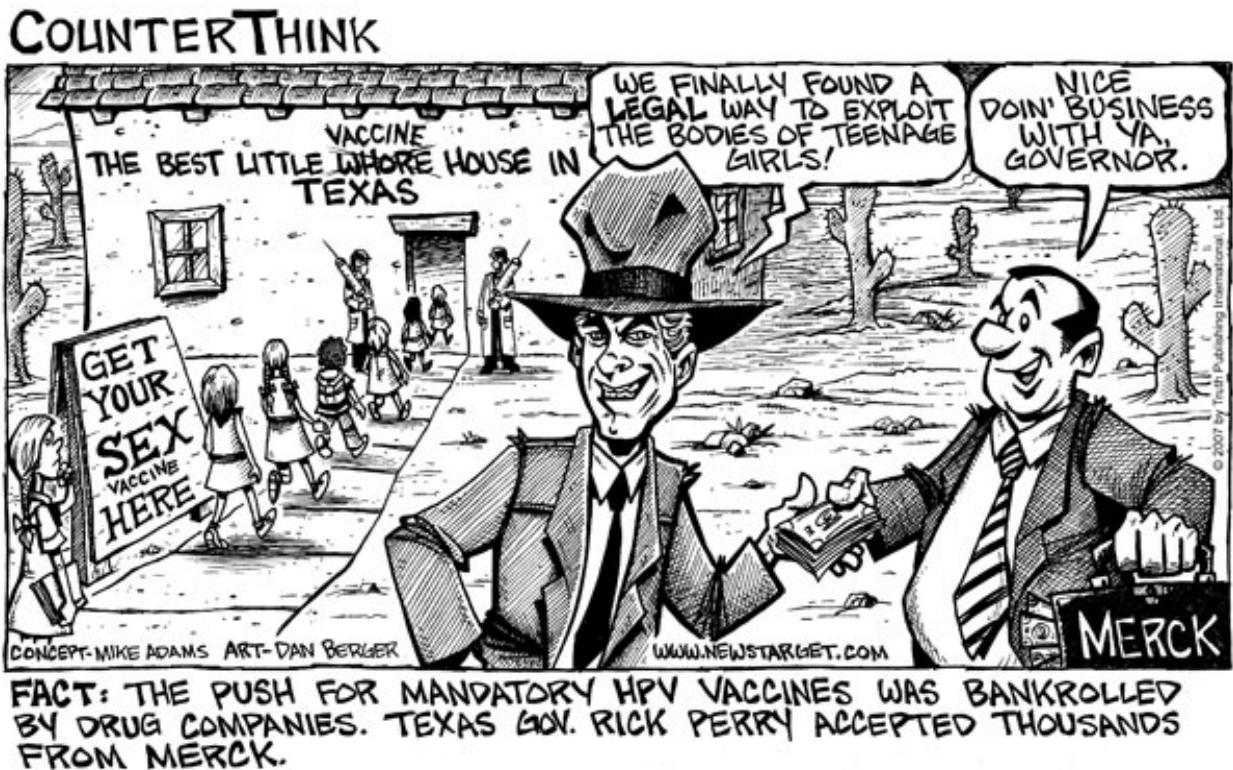
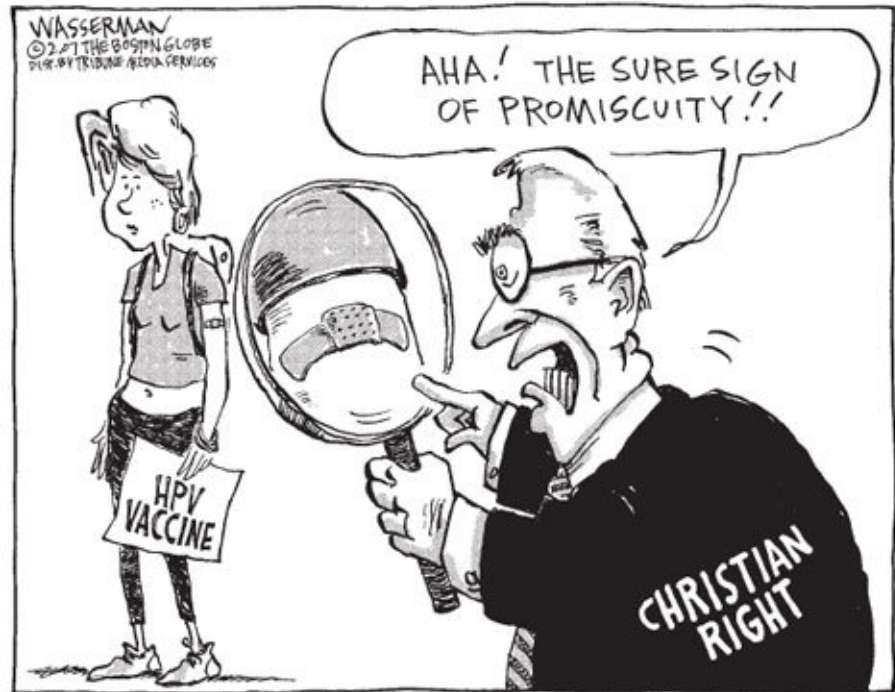


Figure 15: CounterThink editorial cartoon  
Source: [www.naturalnews.com](http://www.naturalnews.com)

The message here argues that the HPV vaccine, rather than empowering young women and girls as indicated by Merck, exploits their bodies for the goals of private corporations and politicians. Also represented in this comic is the view that the vaccine is a “sex vaccine” rather than a cancer vaccine as framed by public health and pharmaceutical marketing.

<sup>25</sup> This comic was published on the Natural News website, a website which advocates for healthy, homeopathic alternatives to pharmaceutical drugs.

Social or religious conservatives echoed concerns of the sexual implications of HPV vaccination, often using religious belief to frame HPV (as in the case of other STIs) as indication of the need to remain abstinent until marriage. In these ways, vaccination, as this comic



indicates, becomes a **Figure 16: Wasserman editorial cartoon**  
**Source: Wasserman 2007**

sign of promiscuity (Figure 16). For example, *Focus on the Family*, the Colorado-based Christian group that promotes socially conservative public policy, released a position statement on HPV vaccination in which it urged abstinence:

*The seriousness of HPV and other STIs underscores the significance of God’s design for sexuality to human wellbeing. Thus, Focus on the Family affirms – above any available health intervention – abstinence until marriage and faithfulness after marriage as the best and primary practice in preventing HPV and other STIs.*  
 —Focus on the Family<sup>26</sup>

The Family Research Council, another Christian-based, social conservative and lobbying organization, also promoted the message that abstinence is the best way to protect against HPV, even using the CDC to support their claims:

<sup>26</sup> Focus on the Family Position Statement: HPV Vaccine ([http://media.focusonthefamily.com/topicinfo/position\\_statement-human\\_papillomavirus\\_vaccine.pdf](http://media.focusonthefamily.com/topicinfo/position_statement-human_papillomavirus_vaccine.pdf)), accessed December 10, 2013.

*According to the CDC, limiting sexual activity to the context of a “monogamous relationship” with an uninfected individual is the surest way of preventing future HPV infection. Therefore, practicing sexual abstinence until marriage and fidelity within marriage are the best ways to avoid genital HPV infection. However, in some cases HPV infection may result from involuntary sexual activity, such as abuse or assault, and/or if a woman marries someone who is carrying HPV. Therefore it is possible that even someone practicing abstinence and fidelity could benefit from vaccines designed to prevent HPV infection*

—Family Research Council<sup>27</sup>

Despite urging abstinence, surprisingly, both Focus on the Family and Family Research Council did not oppose widespread availability of the vaccine, arguing that even a (virtuous) girl who was abstinent may be exposed to HPV if she "marries someone who is carrying HPV." Both organizations did, however, strongly oppose mandatory vaccination due to concerns over its infringement on parental rights.

*We feel that a mandate infringes on the right of parents to make decisions regarding their children’s medical care. Since genital HPV is not spread by casual contact, there is insufficient public health justification to require vaccination for school attendance. A mandate may also lead parents to believe that the vaccine is the only available way to reduce the risk of cervical cancer and HPV infection, which is untrue*

—Family Research Council<sup>24</sup>

Although these sources position HPV vaccination in an opposite manner than the pharmaceutical company, they invoke similar cultural norms regarding appropriate sexual behavior and gender roles to encourage abstinence, as well as values regarding parental and individual rights that are common discourse in the United States.

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<sup>27</sup>Gaul, Moira (2007) Gardasil: What every parent should know about the HPV vaccine. Washington, DC: Family Research Council (<http://www.frc.org/content/gardasil-what-every-parent-should-know-about-the-hpv-vaccine>, accessed December 10, 2013)



### *Impact of Public Response*

Due to growing pressure from advocacy groups and negative public reaction, Merck announced in February 2007 that it would be suspending lobbying for the school-mandated vaccination. Dr. Richard Haupt, executive director for medical affairs in Merck's vaccine, stated: "Our goal is to prevent cervical cancer. Our goal is to reach as many females as possible. Right now, school requirements and Merck's involvement in that are being viewed as a distraction to that goal" (*Quoted in Pollack & Saul 2007*). The executive secretary of the Advisory Committee on Immunization Practices (ACIP), Dr. Larry K. Pickering, applauded Merck's decision noting that lobbying "has been somewhat counterproductive. Anything that takes away from the process of getting vaccine into people is deleterious to the whole process" (*Quoted in Pollack & Saul 2007*). Merck's decision to end lobbying, in addition to the growing public and scientific resistance to mandatory vaccination, effectively halted all public discussions of legally requiring young girls to be vaccinated.

In 2006-2007, 24 states (California) introduced legislation that would require young girls (usually 11-12 year olds) to be vaccinated against HPV unless parents opted out (which depending on the state could be on religious, philosophical, or medical grounds). Of these states, only two<sup>28</sup>, Virginia and District of Columbia, have enacted legislation that requires HPV vaccination—Virginia in October 2008 and District of Columbia in 2009<sup>29</sup>. More recently, the issue has been introduced again into some state legislatures (for example New York in 2013), stemming potentially from growing scientific evidence that the vaccine is safe (Chao et al. 2012; Gee et al. 2011; Klein et al. 2012), and early evidence that it is effective in

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<sup>28</sup> Texas also temporarily required HPV vaccination following an executive order by Governor Rick Perry in February 2007; however, congress quickly reversed this order in May 2007 (HB 1098), removing the requirement.

<sup>29</sup> <http://www.ncsl.org/research/health/hpv-vaccine-state-legislation-and-statutes.aspx>

preventing precursors to cervical cancer (Gertig et al. 2013) and the spread of the virus (Markowitz et al. 2013). However, discussions over mandating vaccinating have not resurfaced publically as markedly as they did following initial licensure.

### *Adding Boys: Shifts in Marketing Content and Volume*

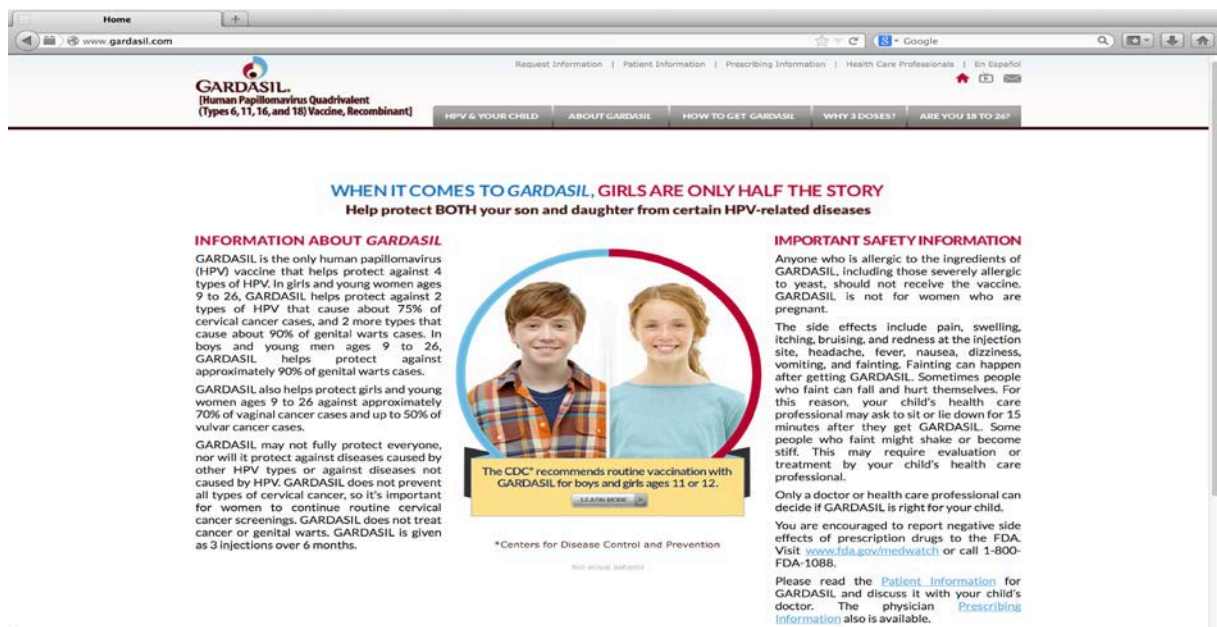
Since the initial marketing campaign, much has changed in both the money spent on advertising and the approach by Merck (including elimination of their television campaign in 2009) in large part due to the shifts in the licensures and reaction of the vaccine itself. In contrast to the nearly \$100 million spent by Merck in 2008 on advertising, Merck *only* spent \$44 million in 2012. Additionally, following the 2011 expanded recommendation by the ACIP to also routinely vaccinate young boys, Merck dramatically shifted its marketing campaign towards a more gender-neutral approach. As shown in the image, below, taken from the most recent version of the official Gardasil website (accessed January 2014), Merck has removed its choice-laden language, and replaced with an approach that utilizes a symbol—which combines both the male, Mars symbol and the female, Venus symbol—that



Figure 17: Gardasil poster targeting adolescent boys and girls  
Source: [www.gardasil.com](http://www.gardasil.com)

has been historically used to indicate gender equality or transgender identity (Figure 17).

Furthermore, the website (Figure 18) has been transformed from the interactive, playful website of 2007 to a much more text laden—or scientific—website that is more reminiscent of a pharmaceutical pamphlet than a social media site (as the initial website was). While marketing has substantially been reduced and reformatted arguably to invoke gender neutrality, the debates over sexuality, safety, and political influence have continued.



**Figure 18: Image of Gardasil website**  
Source: [www.gardasil.com](http://www.gardasil.com)

#### IV. CONTINUED CONTROVERSIES: PERRY, BACHMANN, AND DR. MERCOLA

Nearly eight years after the initial FDA licensure, controversies<sup>30</sup> around the HPV vaccine remain, exemplified by a series of media events surrounding the 2011 Republican

<sup>30</sup> Although not discussed in detailed due to its recent development, on December 4, 2013, Katie Couric (on her daytime talk show, *Katie*) aired a segment titled "The HPV Vaccine Controversy" that has been highly criticized for unfairly exaggerating the potential risks of the vaccine. In the episode, she interviewed a mother who claimed her daughter's death was caused by the HPV vaccine. Following the high criticism by public health officials calling it "alarmist", on December 10, Couric issued apology for spending a disproportionate amount of time on claims of adverse effects, stating, "We simply spent too much time on the serious adverse events that have been reported in very rare cases following the vaccine. More emphasis should have been given to the

Presidential debates. In February 2011, at a CNN debate moderated by Wolf Blitzer, an exchange occurred between Republican Governor Rick Perry of Texas, and Congresswoman and staunch Tea Party supporter, Michele Bachmann that had lasting impact not only the final selection of a Republican Presidential Nominee, but HPV vaccination in general. The exchange<sup>31</sup> began with Blitzer asking Governor Perry if signing the executive order requiring "little girls" to get a vaccine was a "mistake." Perry answered:

*Perry: It was. And indeed, if I had it to do over again, I would have done it differently. I would have gone to the legislature, worked with them. But what was driving me was, obviously, making a difference about young people's lives. Cervical cancer is a horrible way to die. And I happen to think that what we were trying to do was to clearly send a message that we're going to give moms and dads the opportunity to make that decision with parental opt-out. Parental rights are very important in state of Texas. We do it on a long list of vaccines that are made, but on that particular issue, I will tell you that I made a mistake by not going to the legislature first.*

Blitzer then asked Bachmann if she had anything to say—as a mother herself.

*Bachmann: I'm a mom. And I'm a mom of three children. And to have innocent little 12-year-old girls be forced to have a government injection through an executive order is just flat out wrong. That should never be done. It's a violation of a liberty interest. That's—little girls who have a negative reaction to this potentially dangerous drug don't get a mulligan. They don't get a do-over. The parents don't get a do-over.*

In response, Blitzer asked Perry to react to suggestions by his critics that his order mandated or "forced" vaccination. Perry responded that it had not, as "it had an opt- out. And at the end of the day, this was about trying to stop a cancer and giving the parental option to opt out of that." Perry and Bachmann both used parental and individual rights as a way to distinguish themselves from President Obama and healthcare reform, which was framed as an infringement on individual rights.

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safety and efficacy of the HPV vaccines." ([http://www.huffingtonpost.com/katie-couric/vaccine-hpv-furthering-conversation\\_b\\_4418568.html](http://www.huffingtonpost.com/katie-couric/vaccine-hpv-furthering-conversation_b_4418568.html)). This event happened after my time in the field; however, it indicates the continued controversies regarding HPV vaccination in the United States.

<sup>31</sup> See Appendix E for transcript of the full exchange.

The conversation continued with Bachmann reminding everyone that "in the midst of this executive order, there is a big drug company that made millions of dollars because of this mandate" and strongly suggested that Perry signed the order not to save lives, but to gain political capital through campaign donations:

*Bachmann: The drug company gave thousands of dollars in political donations to the governor, and this is just flat-out wrong. The question is, is it about life, or was it about millions of dollars and potentially billions for a drug company?*

The conversation moved onto another topic after Perry responded that he only received \$5,000 from Merck and it is "offensive" that this amount of money could sway his actions.

Within this exchange, Congresswoman Bachmann invoked her credibility—as a female and a mother—to discredit Governor Perry’s decision to pass the executive order regarding HPV vaccination, positioned as a “potentially dangerous drug” that infringes upon parents’ liberties. Bachmann also insinuated (strongly) that Perry made this decision due to political contributions made by Merck to his campaign and his close connection to the chief lobbyist. Perry attempted to circumvent her argument, agreeing that this was a mistake, but a mistake made with good intention of preventing cancer.



**Figure 19: Branch editorial cartoon**  
**Source: Branch 2011**

Despite his attempts, many media analysts claimed this debate as a victory for Bachmann, greatly damaging Perry's ultimately failed attempt to become the 2012 Republican Presidential nominee (Figure 19). However, the debate did not ultimately prove to be a success for Bachmann either, stemming in part from the statements she made in the days following the debate.

During an interview with *Fox News* the day after the debate, Bachmann continued to criticize Perry for his involvement with Merck. However, she made a crucial political error when she made claims that the HPV vaccine is not only unnecessary, but also causes serious mental harm. Bachmann stated, "There's a woman who came up crying to me tonight after the debate. She said her daughter was given that vaccine. She told me that her

daughter suffered mental retardation as a result. There are very dangerous consequences” (Stein 2011). She reiterated these comments on the *Today* show as well.

Although Bachmann’s comments of the “very dangerous consequences” of the vaccine prompted immediate dismissal by medical groups (Burton 2011), her statements did resonate with public discussions of the uncertain risks and benefits of HPV vaccination. Most of these debates have occurred in the expert realm of scientific conferences and journals (Huang 2009; Tomljenovic & Shaw 2011); however, Dr. Diane M. Harper, who conducted early clinical trials for the HPV vaccine, has been outspoken in her opinion that the promotion of HPV vaccination has glossed over many of its potential risks. “*Gardasil is associated with serious adverse events, including death. If Gardasil is given to 11 year olds, and the vaccine does not last at least fifteen years, then there is no benefit—and only risk—for the young girl*” (Harper quoted in Yerman 2009) More than mere words, these claims of risk and danger are thought to be having a direct effect on the uptake the HPV vaccine as public health officials argue “misinformation” and “myth” are the central reasons behind lagging numbers of vaccination rates in the United States (Tucker 2011).

#### *Dr. Mercola and Growing Public Distrust of Vaccines*

In addition to claims in the medical community, continued attacks by alternative medicine “experts” or critics of biomedicine—most notably Dr. Joseph Mercola—have spread concerns over the potential risks of HPV vaccination. Between 2006-2013, on his website, Mercola ran 38 different articles that centered on the potential physical harms and lack of social benefit of HPV vaccination<sup>32</sup>. Three recurrent themes are used by Mercola to

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<sup>32</sup> In the Appendix F, I have included a list of the titles of the 38 articles to document the range of framing used by the website.

discredit scientific claims and promote a negative view of HPV vaccination: 1) pharmaceutical companies are profiting from and promoting the vaccine; 2) there is scientific evidence (or uncertainty) of the risks and lack of benefit from HPV vaccination; and 3) HPV vaccination is an attack on parental and individual rights in the United States. For example, in the following article, Mercola (and his team) frame the vaccine as harmful due to its association with the pharmaceutical company, Merck, due to its past handling of the now-recalled arthritic drug, Vioxx, in early 2000s, and then substantiates claims by using scientific knowledge strategically to show evidence of the lack of necessity of HPV vaccination:

*Merck, maker of the notorious Vioxx, now wants to make their needless human papillomavirus (HPV) vaccine Gardasil a requirement for young women. Although Merck openly admits its lobbying ties with Women in Government, the mega-drugmaker won't say how much money they're funneling through the non-profit. But here's a possible measuring stick: With Merck doubling its spending on lobbying, just in Texas, to some \$250,000, multiply that by 18 and you get almost \$5 million. Spending \$5 million (or some \$12.5 million if you're considering the whole country) is mere chump change compared to the \$1 BILLION Merck could earn annually from Gardasil, says one drug industry analyst. A New England Journal of Medicine study found the use of condoms reduces the incidence of HPV by 70 percent. And just a reminder, more than 6 million women contract HPV annually, but a woman's immune system is often strong enough to clear up this infection on its own; it's virtually 100 percent avoidable without a vaccine<sup>33</sup>*

While this presentation is factually true (although claims of the money spent on lobbying are not documented), it utilizes extant cultural tropes regarding growing distrust of the power of pharmaceutical companies with a well-known scientific journal to invoke both fears of parents and trust in scientific knowledge to substantiate its claims. These discussions highlight the tensions between pharmaceutical use, governmental distrust, and media

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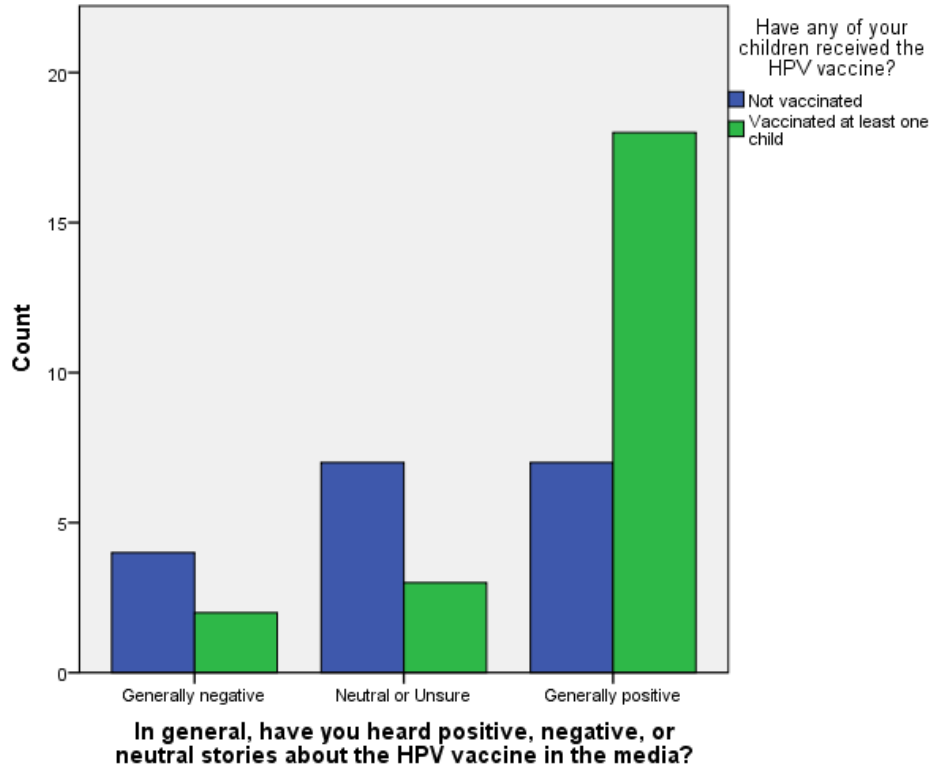
<sup>33</sup> “Will the HPV vaccine soon be mandatory for schoolgirls? Article published February 17, 2007 on [www.mercola.com](http://www.mercola.com).



influence in the United States, and the uncertainty parents' face in making decisions regarding HPV vaccination.

## **V. IMPACT OF MEDIA ON HPV VACCINATION DECISIONS**

The influence of media, including pharmaceutical marketing, on health behavior changes is increasingly becoming a focal point within public health and allied health fields; however, it is difficult to measure its specific impact due to challenges in tracking individual media exposure as well as the potential role of mediating factors (such as access) in information-seeking behaviors or practices. As described earlier, political debates regarding mandatory HPV vaccination or perception that HPV vaccination would lead to sexual promiscuity did not seem to greatly impact parents' decisions whether or not to vaccinate their son or daughter. Most parents disregarded these debates (and often their supporters) as not credible or even rational. However, media exposure did seem to play some part in parents' vaccination decisions.



**Figure 20: Parental responses to “In general, have you heard positive, negative, or neutral sotries about the HPV vaccine in the media?” by vaccination status**

In the questionnaire, I asked parents to reflect upon the general tone, positive, neutral or negative, of media coverage that they heard regarding HPV vaccination (Figure 20). A chi-square test of independence was conducted to compare framing of media exposure in parents who had vaccinated and not vaccinated at least one child aged 11 or above, and not surprisingly, I found a significant relation between responses and vaccination status,  $\chi^2(2, n=41) = 6.595, p=.037^{34}$ , whereby parents who remembered hearing more positive media were more likely to have vaccinated at least one of their children. During interviews, parents elaborated upon the influence of media, explaining that hearing negative or positive stories regarding the risks and benefits of HPV vaccination did have some impact on their decisions—however, the level of impact often depended on from *what* source they heard the

<sup>34</sup> Due to the small sample size, not all chi square assumptions were met, and therefore, these results should not be viewed as conclusive without further data and analysis.

information. As Charlotte who vaccinated her 12-year old son as soon as he turned 11 described:

*Charlotte: There's always the crazies who weigh in, in the letters to the editor, afterwards. No, in my reading of it, [the media] portrayed it as a necessary and positive development—improvement. I'm in the camp that vaccines are good though.*

While aware of negative media or marketing, these claims did not seem to make much impact on her decision due to evaluations of the sources ("crazies), and her general support of vaccinations. For others, the more recent discussions, and expansion of vaccination to boys as well as girls, made a positive impact on their perception of the vaccine. As Sadie, a mother of an unvaccinated 19-year old son and vaccinated 17-year old daughter, explained:

*Sadie: I thought it was great that they started promoting it for boys and girls, and I thought that was great, to make it as visual as possible and present to people's daily life, to disseminate the importance of the vaccination.*

Cristina reiterated these sentiments when I asked her if she had seen any public health or pharmaceutical marketing:

*Cristina: Yeah, I certainly—both probably at the time that I was looking and at other times I know that I've seen it on billboards, I've see it in magazines, although probably not print piece magazines. It was probably something I was looking at online, but the magazines still had the same ads on their pages. The ones that really stuck out for me, cause I just hadn't thought about it, was when they started having more media about having boys vaccinated for it. I remember thinking, oh yeah, that's a kick ass idea. That totally makes sense (Mother of 13-year old vaccinated daughter).*

For others, hearing about those who had resisted the vaccine or general controversies regarding the safety of the vaccine served to further solidify their decisions. As Krista explicated:

*Krista: If anything, [hearing about public debates] made me more happy that I made the decision. I mean I'm hearing a lot more...about people who refuse to vaccinate and just feel so horrified and upset. So I feel happy (Mother of 14- and 16-year old vaccinated daughters).*

Beyond feeling happy about their decisions, Sarah explained that media coverage of vaccine safety or controversies actually drove her to want to vaccinate her son and daughter more.

*Kate: Did any of the media coverage or marketing impact your vaccination decision in any way?*

*Sarah: You know in a reverse way because so much of the media around here is, not necessarily anti-vaccine, but they always give that, that view time in the articles, equal time. When you read an article about vaccines, they give equal time to both sides and I don't really think it should be equal time to both sides. So sometimes I get so annoyed by reporting or media that, in disgust, it'll make me feel more strongly about being vaccinated, if that makes sense. It's a pet peeve of mine (Mother of vaccinated 14-year old son and 17-year old daughter).*

David, a father of an eight-year old unvaccinated son, also reflected upon the general presentation of vaccines in the local media, identifying how the "mass hysteria"—even if a parent does not completely agree—can begin to influence one's thinking.

*David: The more I hear about it, it does put a little more of an inkling in my head. Is there some sort of truth to it? But then it always seems like its 'mass hysteria'. It's one person saying it. And then another person saying 'Yeah, I sort of got that too.' And then a third person—my wife actually put it this way. She said, 'This is how riots start. It's one person in a crowd going down with this, and then one person throws a rock through a window and then the next thing you know, cars are flipped over and trash cans are on fire and then you have a full riot.' She says, 'It only takes one instigator in a crowd to just go—DO IT'! And then a rock gets thrown and that's all it takes, just that one little rock through a window. The next thing you know a whole city block is on fire. I think it's like that. It's one person says, 'Hey, my son got sick', and then she turns around and then another guy says, 'Yeah I think my son got sick to.' And then this mass hysteria builds up. I think that's how it happens and it is like a virus where people start building on that.*

For Mona, rather than mere hysteria, these stories—and the initial marketing of the vaccine—greatly shaped her perspectives of the vaccine:

*Mona: If I'm remembering the commercial right, it talked about four of the possible strains for HPV, Gardasil only had four. And I remembered listening to that and remember thinking that was a very small number to go against the vaccine. So it's like why four? That seemed small. So that was weird, and I think around that same time, maybe within a year of then, I started seeing articles of people who were having adverse reactions. So right off the bat the very first knowledge of this vaccine I was suspicious. I wasn't, like oh, this sounds like a fantastic idea (Mother of 9-year old*

unvaccinated daughter).

While for some parents media exposure did seem to play a role in their vaccination decisions, many parents did not describe media as having a significant impact on their decision, which often reflected distrust or suspicion of pharmaceutical marketing in general, as these quotes indicate:

Thomas: *I took a neutral stance on it, where I took it with a grain of salt that the reporting is correct. But I'm not going to believe everything that's in there* (Father of unvaccinated 8-year old daughter and 10-year old son).

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Lorraine: *I'm aware of them. I didn't focus on them a lot. I'm skeptical of this vaccine so I put a little less stock in the advertising. I'm skeptical of advertising in general, but I have been aware of it, I've seen it. When it first started to come out my niece, my sister was trying to decide. My kids were quite a bit younger at that time; I don't know what year it first emerged. And my niece was considering what to do, should she have it or not. I think they decided not to do it. At that time was the first I had heard about it and she asked what I thought, and I remember looking it up and reading about it and being skeptical then and remaining skeptical* (Mother of unvaccinated 10-and 15-year old daughters).

Reflections of skepticism, suspicion, and distrust emerged not only specific discussions regarding the marketing of the HPV vaccine, but in reflections regarding the role and power of the pharmaceutical industry in the United States.

## **VI. HOPE AND HARM: REFLECTIONS ON THE PHARMACEUTICAL INDUSTRY**

*Hope and harm—the balance of hope and harm. Reminds me of a see-saw where someone has to slide forward depending on how heavy the other side is—that as a parent or as a user of pharmaceuticals, one has to balance that* (Alice, mother of 12 year-old unvaccinated daughter).

As part of my conversations with parents, I explicitly asked each individual to give me their general opinion of pharmaceutical companies. The majority responded with mixed feelings—or ambivalence—illuminating tensions between positive feelings regarding the

potential for the pharmaceutical industry to improve the health of the population, and negative feelings of distrust regarding their financial motives and unmitigated influence over politics. In her examination of pharmaceutical pills, Emily Martin (2006) also identifies this ambivalence—or how “people surround the same object with two sets of social meanings—one positive and one negative” (274) surrounding pharmaceutical practices in the United States. Using the Greek word, *Pharmakon* (which invokes meanings of both remedy and poison), Martin examines the social process by which the negative parts of pills are “displaced” from primary view. “In the American *Pharmakon*, pills are split into good and bad parts: the bad parts with their negative meanings can thus be displaced to the side and kept out of awareness, or so it might seem” (Martin 2006:274). While attempts are clearly being made to displace the potential negative effects of the HPV vaccine, I did not find that parents were keeping these effects “out of awareness,” but rather held each (albeit precariously) in their viewpoint of the positive and negative *potential* of pharmaceuticals (Taussig, Hoeyer & Helmreich 2013). Within these tensions, emerged notions of economic and political values, as well as articulations of parental responsibility to balance the “hope and harm” of pharmaceutical use.

### *Ambivalence*

Many parents expressed mixed feelings regarding pharmaceutical companies, reflecting tensions between good allotted to the industry for their role in advancing health, and potential evil due to their driving desire to earn profits. As these two parents explained:

*Florence: I'm a bit jaded about – I mean on the one hand we've gotten some marvelous inventions and vastly improved our quality of life. Then on the other hand I think they are largely motivated by profit and they need to be regulated* (Mother of

unvaccinated 9-year old daughter, and vaccinated 12- and 16-year old daughter, and 14-year old son).

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Thomas: *When I think of a pharmaceutical company I think of—they definitely play a huge role on society in terms of, hopefully, developing vaccines and medicines that can further our lives or prevent a lot of diseases. But at the same time too, they're beholden to their shareholders. So their goal a lot of times is to maximize their profits, which is at the detriment of patients, and with healthcare costs escalating, especially with pharmaceuticals, you get mixed feelings about it* (Father of unvaccinated 8-year old daughter and 10-year old son).

For some, framing pharmaceutical companies within the lens of free market, capitalist values, helped to make sense of tensions between public good and economic profit. As Rebecca stated plainly: “I think nothing different about a pharmaceutical for profit multi-national corporation, any other business in it to make money” (Mother of unvaccinated 11-year old daughter).

Another father went further to place these values as not only reflective of economic values, but at the center of the "American way":

David: *It's a business. They're in the business to make money. That's what a business does. It's not a non-profit organization; it's a for-profit organization. So they're there to do things to make a profit to keep their company going—to make more profit. That being said, that's the American way. A drug company is the same thing. They're providing a service or a product to help society—and this is drugs. It's more important than a tire or a toothbrush necessarily, but it's still providing something* (Father of 8-year old unvaccinated daughter).

The motive driving the pharmaceutical industry may be profit, but this motive is evaluated through values inherent and representative of the American—or capitalistic—way, and as such, is not only understandable, but desirable. However, as David went on to explain, these motives are also subject individual greed, highlighting the limits of economic profit as an American value:

David: *I guess my answer to your question—pharma companies, biotech companies are just like any other company, there's going to be good and bad to it. In general, I*

*think they're a positive to society where they are creating products that are going to help us live longer and healthier lives. But there's going to be bad apples; they're humans. And humans are flawed and dirty and greedy and filthy people that have bad tendencies. They fall into what's easy and not what necessarily what's best.*

Invoking images of the original sin, profit is understandable as an economic motive, but must be regulated due to the potential flaws or weakness inherent in all humans. For other parents, the economic profit gained by pharmaceutical companies is beyond what is necessary—or morally just. As Antonia explained:

*Antonia: I, of course in general, think that it is very wrong that somebody is making a lot of money on pharmaceuticals. Having said that I also, I guess it's my 'middle of the road-ness'. I don't think it's so simple. I think the whole development, I think it's just part of our entire decisions about resources. It is resource intensive to develop drugs, and of course, I think everyone should have equal access to the drugs and of course, I think nobody should be getting rich off of drug. On the other hand, I believe people who are supporting the development should have a good living. They should be well supported so that they can do this valuable work—of course so should teachers—And I do think it's wrong when pharmaceuticals are sold when they shouldn't be, when the decisions on when to take something aren't so influenced by somebody's ways to make money. But I think it's really complex. The simple truth is I do not think somebody should be getting rich on pharmaceuticals (Mother of unvaccinated 11- and 19-year old daughters).*

Anthropologists and others have criticized the use of "magic bullet" solutions proffered by pharmaceutical industries to cure or prevent disease, rather than address larger structural factors that impact health and perpetuate inequalities (Appelbaum 2009; Nguyen and Peschard 2003). This "pharmaceuticalization" of society is based in part on the pharmaceutical industry's ability to obtain funds allocated for promotion of public health (often over other organizations and industries)—and governmental support for their endeavors in the United States and globally (Abraham 2010; Biehl 2007). In the United States, as noted earlier in the chapter, the federal government not only gave funds, but passed legislation protecting pharmaceutical companies from liability lawsuits (NCVIA) to ensure pharmaceutical companies would continue to make vaccines. This act created a direct link between—and



reliance upon—the pharmaceutical industry to supply vaccines. In the context of HPV vaccination, the public and moral discomfort between the development of public health policies and power of pharmaceutical influence entered the public stage, exemplified by criticisms of Merck's lobbying efforts and HPV vaccine legislation. While unnerving for most parents, most did not argue that pharmaceutical companies should not be able to make a profit, but rather their power—and potential evil—should and *must* be checked through governmental (FDA or otherwise) regulation. As Kelsey explained:

*Kelsey: I guess they're one of our new safe evils. I'm skeptical of them. I do think profit making is their primary motive, so it has to be monitored. And I think there needs to be oversight, which I guess means regulation. But I think on the other hand, we have to have companies that do the research and make the product, so they can't be a pure evil. They perform a needed service and they need to be heavily overseen. I wouldn't trust them. I mean it's not enough for them to say my product is excellent. That's like McDonald's saying my hamburger is delicious. But I still appreciate that they make the product as long as someone is watching over their shoulder with some care, which I'm not sure we are – cause they have a pretty strong lobby in Washington I'm sure, and probably every state capital (Mother of unvaccinated 12-year old son).*

In the digital age, the circulation and impact of media and marketing is increasingly difficult to understand and measure. The rapidity at which information emerges, circulates, and vanishes makes understanding its meanings and influences a daunting task indeed. Despite its elusiveness, public discourses (whether through media, marketing or controversy) are scripted and re-scripted using extant—often normative—beliefs, practices, and relationships of power. In the context of HPV vaccination, these norms are guided in part by historic constructions (and limits) of sexuality, science, and the nation-state. Throughout these public debates—whether it be by the pharmaceutical industry or Tea Party activists—information technologies are being harnessed to promote certain understandings of what it means to live and be healthy. However, these strategies are not merely implanted onto the

minds of parents and other collectives, but resisted and reworked through ethical and experiential practices occurring in everyday life. Beyond mere intellectual or ethnographic inquiry, these practices have direct connection to the health and wellbeing of the nation. In conclusion, I will consider how social workers and other care professionals working the field of health promotion or healthcare may help parents to make sense of the cacophony of voices claiming to know what is best for the health of children.

## **VII. GROWING OPPORTUNITIES FOR SOCIAL WORKERS IN HEALTHCARE**

The paternalistic model of healthcare in the United States—in which the physician is viewed as the primary decision maker—has long been challenged by medical social workers who have fought to bring a more person-centered approach to healthcare since the early 1900s (Gehlert 2006). Recently, national healthcare organizations and legislation (including the Affordable Care Act) have also shifted to promote a more balanced, patient-centered medical model (Institute of Medicine 2001; Shafir & Rosenthal 2012). This shift toward patient-centered care is not only happening in the United States, but also worldwide with similar policy and intervention efforts occurring throughout Europe, Asia, and Australia (Légare et al. 2012).

Patient-centered care prioritizes the values and preferences of patients, and positions healthcare providers as collaborators rather than dictators in determining the best treatment option. Medical decision-making in this model is viewed as a shared or collaborative process between the patient and his or her healthcare team—often referred to as shared decision-making (SDM) (Charles, Gafni & Whelan 1997). SDM incorporates the patients' preferences and values into treatment decision-making, and is reliant upon clear, open communication

between the patient and his or her healthcare team. Patient-centered care and shared decision-making have been shown to have a positive impact on patient satisfaction as well as health outcomes in both acute and chronic conditions (Stacey et al. 2011).

Although the patient-centered model is increasingly becoming the ideal standard of care, it has been difficult to incorporate shared decision-making into routine medical care. This is due in part to the values, practices and structure of the healthcare system in the United States that discourages patient-centered care in many ways. For example, systemic policies may impede patient-provider communication by the placing strict time limits on appointments. Additionally, time spent engaging in the behaviors necessary for shared decision-making including asking about patient's needs and listening attentively to patient concerns is not often reimbursed by private and public insurance companies (Légare et al. 2012). There may also be cultural attitudes among patients and practitioners that act as barriers including traditional views that place physicians as unquestioned experts and patients as passive recipients of their knowledge (Frosch et al. 2012). Patients also face a variety of barriers to engaging in shared decision-making, particularly patients with low health literacy or those who do not have access to regular preventive care (Galesic & Garcia-Retamero 2011). Furthermore, there has been some indication that patients of different racial or ethnic backgrounds have different preferences for the level in which they want to be involved in medical decision-making (Levinson et al. 2005); however, these may be more a reflection of structural inequalities than cultural. Marginalized populations also may not have access to information about the risks and benefits of treatment options in a format that is linguistically and culturally appropriate (King, Eckman & Moulton 2011)

A growing amount of research in health services, medical decision-making, and related fields have focused on developing tools for both patients and providers to support shared decision-making—most notably in the form of decision aids, which have been proven to be efficacious for promoting patient engagement (Stacey et al. 2011). However, decision aids have been difficult to incorporate into routine medical care outside of clinical trials, and very few have been tested among or adapted to the needs of low-income patients or people of color. As well, decision aids are only modestly successful without institutional support by doctors and healthcare team members to encourage patients to voice their preferences (Lin et al. 2013).

In this shifting environment and increased focus on expanding communication between patients and providers, social workers have the potential to help fill the gap between the ideal of shared decision-making and the variegated and often absent practice in routine healthcare, particularly among vulnerable populations. Although subject to the dominant medical model, medical social workers have always pushed to place the contextual needs of patients within the clinical encounter. Much of the attempt to elicit patients preferences focus on values (which is not often defined, but often infers quality of life concerns) and communication of risk and benefit. In a previous article, my colleagues and I argued that communication regarding the everyday experiences—meaning structural, lived barriers—and strategies of low-income patients needs to be central to clinical decisions regarding diabetes self-management (Rendle et al. 2013). For example, in the context of diabetes care, recent guidelines have argued that clinical flexibility in determining target A1c levels based on individual circumstances may actually lead to better self-management (“adherence”) than rigid standardization. Without direct communication regarding structural conditions, the

physician would not be aware of how factors, such as access to fruits and vegetables, are shaping health outcomes among ethnic minorities or impoverished groups, and not be able to consider how to tailor recommendations to match the context in which the patient lives.

In the context of HPV vaccination, while most of my sample did not face structural factors to care, they did face communication barriers to discussing the risks and benefits of HPV vaccination, and often barriers to discussing the sexual activity of their child. Also, the literature shows that most of the barriers to HPV vaccination among underserved populations are structural—such as lack of health insurance or lack of healthcare provider recommendation. While it is essential that physicians directly communicate with patients and engage in extra-clinical efforts to reduce structural inequalities that patients face, I argue that social workers have a role to play to assisting in this communication, particularly due to increased structural limitations facing physicians' time in medical appointments. In some healthcare care settings, shared medical appointments or information sessions offer opportunities for patients to ask questions and communicate concerns, whether they are structural or otherwise, regarding a particular treatment decision or condition, and these are often run by medical social workers or health educators. Due to their training and commitment to social justice, social workers are trained and capable of assisting efforts to incorporate structural competency as part of medical care, as well as continue to lead efforts outside the clinical encounter to eliminate social, economic, and structural conditions that lead to health inequalities in the first place (Metzl & Hansen 2014).

## CHAPTER FOUR: TEMPORALITY, SEX, AND DESIRES TO DELAY

In this chapter, using fundamental cause theory (FCT), I will explore how the theoretical concept of countervailing mechanisms may help to explain HPV vaccination patterns that document both disparities by race and socioeconomic status, *and* low uptake among high-resource populations (Link & Phelan 1995). Following a brief explanation of the core components of FCT, I will examine patterns in HPV vaccination rates among different populations in the United States to give an overview of who is being vaccinated from a national standpoint. Then, drawing from anthropological work on temporality, risk and potentiality, I will consider how two mechanisms—specifically sexual norms regarding teenage sexuality (particularly among young girls) and lay challenges to scientific and expert knowledge<sup>35</sup>—may be contributing to low and stagnating vaccination rates among resource-laden populations, acting as countervailing mechanisms against (debatably) beneficial health behaviors, in this case HPV vaccination.

In my fieldwork, I found that parents challenged expert knowledge and the universalizing assertions of public health and biomedical practices, by refusing to vaccinate their children at the recommended age. Although some of the parents did report delaying

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<sup>35</sup> Several scholars have examined how non-expert or lay individuals have challenged the dominant, biomedical model in the field of breast cancer (Zavestoski, McCormick & Brown 2004; Brown et al. 2006), AIDS (Epstein 1996) and other afflictions. Drawing from this work, I argue here that these challenges are also occurring in the realm of HPV vaccination.

other vaccinations, overall, most of the parents had their children receive the other childhood vaccinations on schedule. To defend their desire to delay HPV vaccination, parents often invoked claims to experiential evidence validated by a sense of knowing their child and his or her sexual and emotional development—attempting to redraw the lines of power based on their claim to parental knowledge that no "expert" can possess (Gieryn 1983; Nader 1996). Entangled within these claims (or acts of boundary work) are temporal assessments of risk—whereby parents weighed their child's (perceived) present risk of HPV exposure against the unknown risks of the vaccine itself. In the future, however, parents anticipated that these risks would be identified—made knowable through the experiences of other children vaccinated in the present.

## **I. FUNDAMENTAL CAUSE THEORY AND COUNTERVAILING MECHANISMS**

Due to the strong link between receipt of healthcare provider recommendation and socioeconomic status, some researchers have contended that HPV vaccination is an empirical example of fundamental cause theory (FCT) (Polonijo & Carpiano 2013). Originally proposed by Link and Phelan (1995), FCT argues that due to differential access to resources, distribution of and benefit from novel medical technologies or practices often replicate extant social inequities. While inequities regarding certain technologies can be short-term or long-term, FCT predicates that, despite changes, inequities are reproduced through established, underlying mechanisms that limit access to key resources such as preventive healthcare, knowledge, or prestige. These mechanisms can be latent or explicit, and while the specific mechanisms might change over time, the inequities continue. For example, Link and Phelan (2005) examined shifts in mortality rates of diseases whereby great preventive or

technological advancements have been made in the twentieth century (heart disease, lung cancer, and colon cancer). While overall mortality rates declined following increases in prevention and treatment, race and SES gradients shifted toward relatively higher mortality rates for these groups, indicating that extant mechanisms—possibly inequities in access to treatment or preventive behaviors such as healthful diets—are replicating disparities despite technological changes.

An important, but often overlooked, component of FCT is the notion of countervailing mechanisms (Phelan, Link & Tehranifar 2010). In most cases, populations with access to resources will select health behaviors and practices documented to be linked to improved health—which most often is reflective of scientific or expert arguments that a certain behavior leads to increased likelihood of longer life expectancy or in some cases improved “quality of life”—which may infer increased physical activity, decreased pain, positive mental health, or positive impact on mood or social relationship. However, in some cases, countervailing mechanisms (such as power or social norms) may result in these populations selecting against beneficial health behaviors. For example, the historic association between masculinity and smoking promoted by popular media may have contributed to continued high rates of smoking (even after public warnings emerged of the health hazards) in the late twentieth century even among populations with access to social and material resources. Although interventions have often focused on individual behaviors, FCT argues that structural factors, similar to arguments made more recently by Metzl and Hansen (2014), need to be examined and targeted to address long standing health disparities.



## **II. POPULATION PATTERNS AND HPV VACCINATION IN THE UNITED STATES**

Despite the significant marketing and promotion of the HPV vaccine, uptake of the vaccine continues to be low across all populations in the United States, and according to some studies is disproportionately low among groups at higher risk for developing cervical cancer and high-risk HPV infection, including African Americans and populations with low socioeconomic status (Krieger 2005; Kahn, Lan, & Kahn 2007; Downs et al. 2010; Niccolai et al. 2011). Additionally, differences by socioeconomic status and race in factors associated with vaccination uptake, including HPV-related knowledge, healthcare provider recommendation, and geographic location, have been shown. For example, numerous studies have shown gaps in knowledge (which has been linked to vaccination uptake) among lower socioeconomic status and minority groups concerning what HPV is, how it is spread, and how it can be prevented (Friedman & Sheppard 2007; Olshen et al. 2005; Scarinci et al. 2007). These gaps are likely due to numerous social and structural factors, including differential access to education as well as information from both doctors and other sources (Kontos et al. 2012; Hughes et al. 2009; Viswanath 2005). As such, in the information age, narrowing gaps between "information rich and information poor" may help reduce disparities in cervical and other cancers (Viswanath et al. 2006).

In addition to patterns of uptake, the specific design of HPV vaccine may actually lead to further disparities among the most vulnerable groups. As noted, the quadrivalent HPV vaccine is argued to protect against two strains of HPV linked to cervical cancer (HPV-16 and HPV-18) and two strains linked to genital warts (HPV-6 and HPV-11). Although these strains are claimed to be the most prevalent strains in the United States, a recent study by

Vidal and colleagues<sup>36</sup> examined prevalence rates of specific HPV strains among White and Black women, and found that the quadrivalent vaccine does not include those strains most prevalent in Black women—and thus those at greatest risk may not benefit equally from vaccination. Disparities in the enrollment of minorities in clinical trials—as well as the meaning and impact of inclusion efforts by the NIH and others—highlight the multitude of levels at which health disparities and politics of difference are made and remade (Epstein 2007; Joseph & Dohan 2012; Mol & Berg 1998). However, despite evidence of health disparities in some studies, national data from the National Immunization Survey (NIS) does not fully support these patterns, and actually in some ways shows quite the opposite.

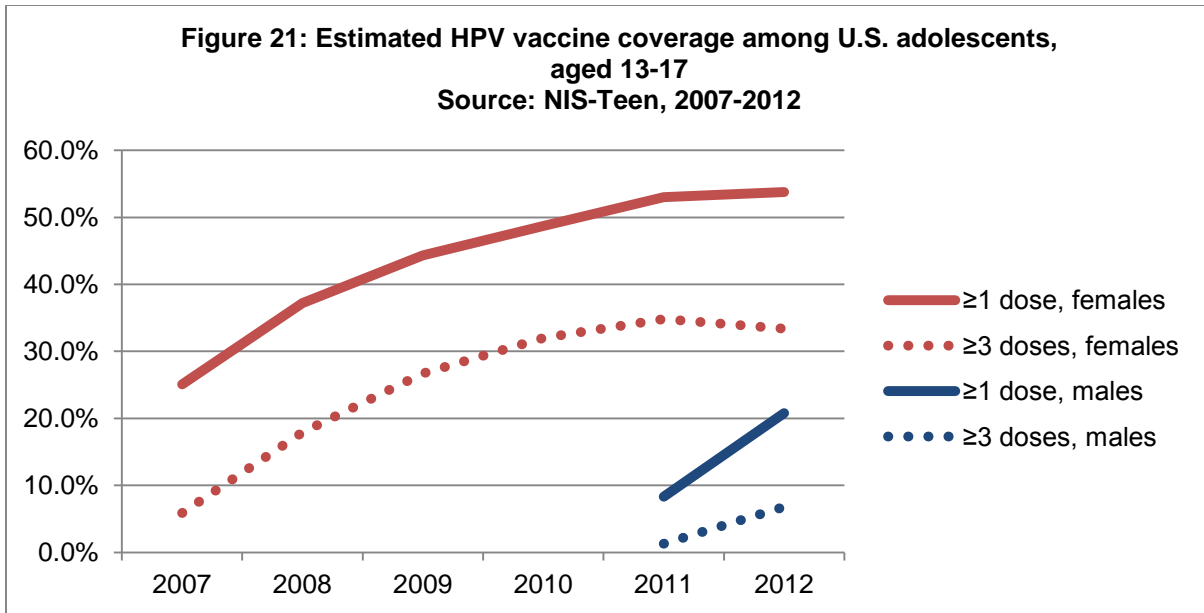
#### *NIH-Teen Survey Results*

Based on results of the 2012 NIS-Teen, only 33.4 percent of girls (aged 13-17) have completed the three-dose regimen and 53.8 percent have received at least one dose. Of boys (aged 13-17) only 6.8 percent have completed the three-dose regimen and 20.8 percent have received at least one dose (US Department of Health & Human Services 2013)<sup>37</sup>. In addition to low completion rates, the rate of vaccination completion among young girls seems to be stagnating, as coverage in 2012 (33.4 percent) actually decreased slightly from coverage in 2011 (34.8 percent). The graph below (Figure 21) depicts estimated HPV vaccination coverage among adolescents, aged 13-17, based on 2007-2012 NIS-Teen data:

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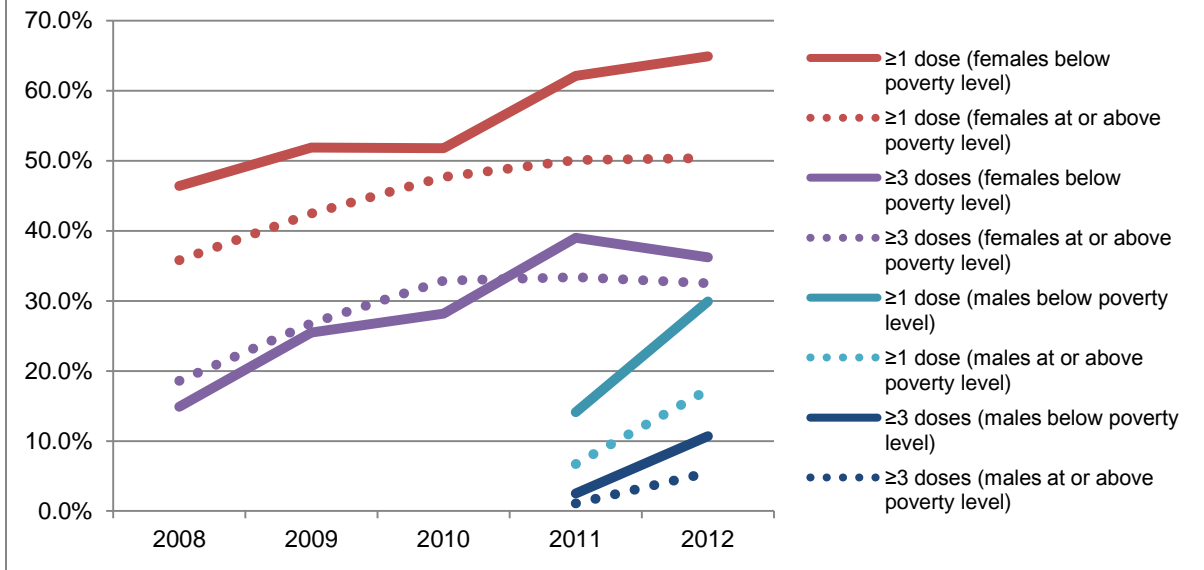
<sup>36</sup> The findings were presented on the Oct. 28, 2013 at the 12th annual International Conference on Frontiers in Cancer Prevention Research and have not yet been published ([http://www.dukehealth.org/health\\_library/news/hpv-strains-affecting-african-american-women-differ-from-vaccines](http://www.dukehealth.org/health_library/news/hpv-strains-affecting-african-american-women-differ-from-vaccines)).

<sup>37</sup> The ACIP announced its recommendation for boys to be routinely vaccinated in 2011; therefore, conclusions about gender differences in vaccine uptake should not be assessed based on these data.

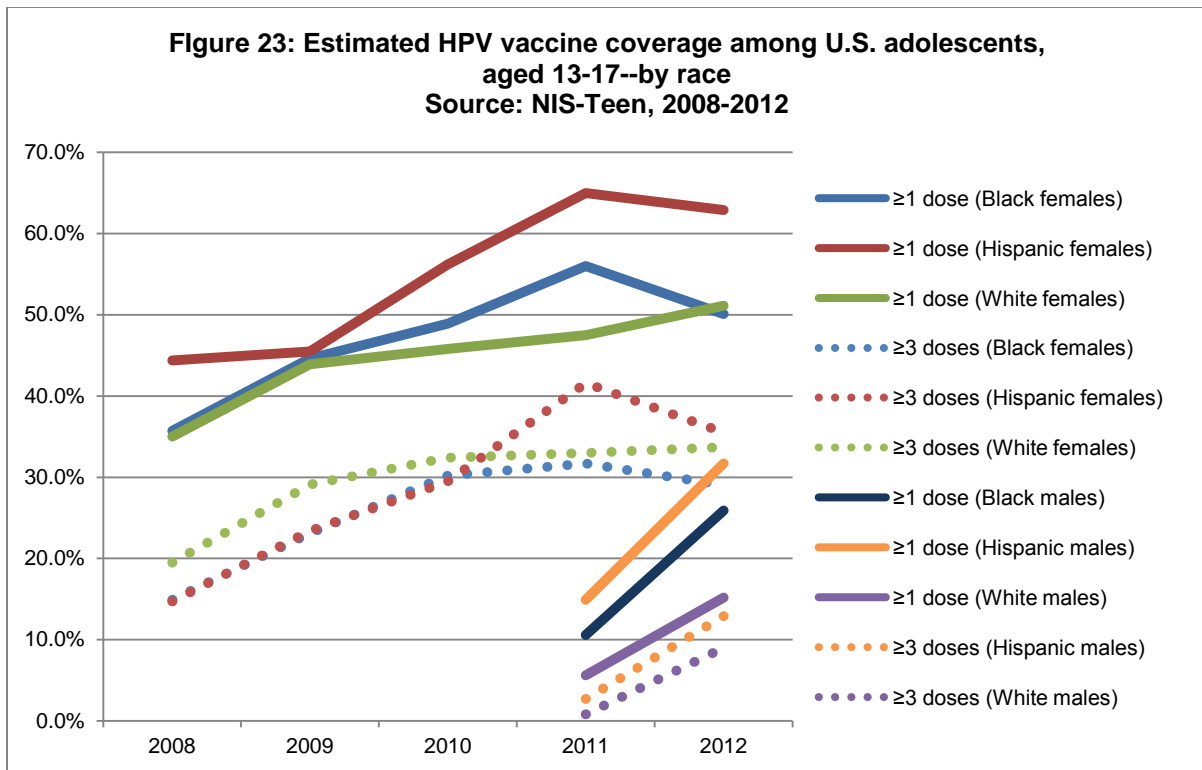


While vaccination coverage is low across the population, vaccination coverage patterns by race and socioeconomic status as estimated by the NIS-Teen data are surprising. As illustrated in Figure 22, HPV vaccine *initiation* rates among those living below the poverty level are estimated to be higher than those living above the poverty level (Stokely et al 2009). When looking at vaccination completion rates, between 2008-2010, completion rates were higher among adolescent females living at or above poverty level. In 2011, this shifted whereby those living at or above the poverty level (females and males) are less likely to have completed the series than their counterparts.

**Figure 22: Estimated HPV vaccine coverage among U.S. adolescents, aged 13-17--by poverty level**  
**Source: NIS-Teen, 2008-2012**



Similar patterns exist when looking at estimated vaccination rates by race or ethnicity. Hispanic adolescents seem to be initiating vaccination at higher rates than Black and Non-Hispanic White adolescents (Figure 23). However, before 2011, Non-Hispanic White female adolescents were completing the three-dose series at higher rates than both Hispanic and Black females. Beginning in 2011, the estimated rate of Hispanic adolescents completing the series surpassed that of Non-Hispanic White adolescents.



Through the lens of FCT or health disparities, these patterns are surprising as one would expect those groups facing structural and cultural barriers would have lower rates than those who historically do not—and based on this data, one could argue that HPV vaccination is not an example of FCT. However, based on the data and analysis discussed earlier (which often examined mediating factors), disparities have been demonstrated by race and socioeconomic status. Furthermore, based on my dissertation findings, I argue that fundamental cause theory—and its notion of countervailing mechanisms—does help explain current patterns of HPV vaccination. In the next section, I will examine how two mechanisms—norms regarding teenage sexuality, and lay challenges to expert knowledge increasingly present in risk societies—may help to explain why populations with access to resources and power are choosing not to vaccinate (at least at the recommended age).

Intertwined within each of these mechanisms are constructions and challenges to universalizing claims of biomedical practices as well as temporal assessments of risk, sexuality and science.

### III. ASSESSMENTS OF TIME, SEX, RISK, AND SCIENCE

In media coverage and scientific literature concerning HPV vaccination, parents are often placed into a binary model of those who support vaccination and those who oppose. However, surprisingly, very few parents with whom I spoke expressed strong or definitive opposition to HPV vaccination, even if they had not vaccinated their child. Rather most parents expressed uncertainty regarding HPV vaccination, in large part due to the novelty of the vaccine, and the age at which it is recommended (11-12 years of age). As noted earlier, even among parents who had not yet vaccinated their children, most parents reported that they planned to so in the future. Even among those who stated that they were unlikely to vaccinate, most conveyed the possibility of vaccinating their children, depending on if in the future the safety of the vaccine is confirmed,<sup>38</sup> but wanted time to pass to allow for more "evidence" to be gathered. As Rebecca described,

*Rebecca: The only question mark that I would have when it comes down to whatever the right time is, or the suggested time, would really be just—doing a second check. Cause childhood vaccines cause they have been utilized for so many decades, that it's, like, tested. I am kind of a fan of letting a full period of time run in the market before taking any kind of drug...I wouldn't want my kid to be the first real application of it even if it's gone through field trials (Mother of unvaccinated 11-year old daughter)*

The novelty of the vaccine gave parents pause, which as Eric explained, reflected general

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<sup>38</sup> Although post-licensure large-scale studies continue to show the safety of the vaccine (Chao et al. 2012; Klein et al. 2012), even among parents who described using academic journals (or "PubMed") to guide decision-making, most did not mention these studies.

approaches to not only health, but consumerism as well:

*Eric: It's a lot of, I guess, unknown skepticism as I would call it. That'd be a good—it would be a good defining word that I would use. It's basically, what it amounts to being, do you wanna be an early adaptor and believing the Center of Disease Control and your medical professional? Or are you a risk adverse and you want to have a little more development as far as the findings of the drug and its known side effects in individual boys? Do you want to buy that first year of that model of car or do you wanna wait for a few models to see what's gonna, what's really underneath the hood? I mean if it's gonna keep it humming. It would be a good analogy (Father of unvaccinated 9- and 12-year old sons).*

The decision to delay was also articulated through parents' assessments of present day risk—from HPV—to their child based upon assessments of their child's sexual (in)activity, and often supported by recommendation of their child's doctor. As Jeanne explained:

*Jeanne: Well, at first [the doctor] said, 'Let's just wait a few years until we see that this is a good vaccine.' Then the most recent visit, the sixteen-year visit, basically [the doctor] said that it would probably make more sense to wait until she was either ready to be sexually active or off to college. They don't know yet what the drop off is going to be in the effectiveness over time.*

*Kate: Have you talked to your daughter directly about it?*

*Jeanne: She's been in the room with me and the doctor while this conversation is going on. I have told her when you get ready to have sex you have to have these shots first (Mother of 16-yr old unvaccinated daughter).*

The decision to delay is based in part on parental assumptions that their child is being completely honest and open regarding their sexual activity, and that the parent will have preparatory time to have their child complete the three-dose series prior to onset of sexual activity<sup>39</sup>. Like Jeanne, many parents expressed that the doctor played a key role in either recommending or at least supporting their decision to delay. Beyond recommendation for

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<sup>39</sup> In the interviews, I did not explicitly explore what constituted sexual activity in the views of parents (for instance, intercourse, genital touching, or any intimate contact). In the context of HPV vaccination, this notion is important as some evidence indicates that HPV can be transmitted from hand to genital contact (Hernandez et al. 2008).

their own children, parents also often asked if doctors planned to vaccinate their own children and at what age. In these moments, the expertise of the doctor comes from not their status as a doctor, but as parent charged with the same responsibility to protect their children.

As Delia explained:

*Delia: I plan to have both children have this vaccine; however, I would like to wait another few years even though my daughter is 12. I would actually like to wait until ever there is a little more research behind it. There will be a bigger pool of people who have taken it, and I'm sure all parents say this, but I'm 100% certain she's not sexually active. I think my doctor said the same thing. She has three daughters and I think she was waiting a little bit—instead of twelve—until about 14 to 16 (Mother of unvaccinated 12-yr old daughter and 9-yr old son).*

Claims to knowing their child's sexual activities were sometimes supported by parental claims to having open conversations with their children regarding sex. As Ruth, mother of two teenage daughters, both unvaccinated, explained:

*Ruth: I have to tell you I'm one of these mothers who goes, 'You DO not have unprotected sex. You ALWAYS use a condom. You get tested beforehand.'*

*Kate: So you have pretty open conversation-*

*Ruth: Very, with both of my girls.*

*Kate: And how do they respond—do they ask questions? Do they shy away?*

*Ruth: Um, it depends on the mood they're in. They will ask me questions. They will roll their eyes and go, 'Yes, Mom. We know.' Then I say, 'Knowledge is power. You have to know. You are responsible for your own health. You're responsible for your sex life.'*

However, parents also used claims to generally knowing their children—physically and emotionally—to assess their sexual activity and readiness as well as potential physical reaction to the vaccine, rather than providing indication that they have explicitly asked their children about their sexual activity. When I asked Joyce why she had decided to have her son vaccinated at age 15, she replied:



*Joyce: I think the general consensus was [the age] is somewhat child dependent. Some kids are more socially and sexually active earlier, and so you might think about it sooner than you would with the slower child. At some point, you just kind of have to start 'cause you don't know when they're going to be sexually active. I know he's not and he hasn't been, and so there's no need to do it earlier. He's a small kid, and so to wait a little bit just to be bigger made sense. The pediatrician may have initiated that process. I think her idea was just even to bring them in together so that I had fewer appointments (Mother of unvaccinated 13-year old daughter and vaccinated 15-year old son).*

Although the pediatrician wanted to vaccinate both children at the same time to reduce the burden of multiple appointments on this mother, Joyce decided ultimately not to have her 13-year old daughter vaccinated at the same time as her son, explaining: "I think partly, when he had the appointment she wasn't available, partly because she's "not there yet" so I wasn't feeling the urgency." By 'not there yet,' she is assessing his physical and emotional readiness to engage in sex from her evaluation.

Beyond assessments of their own child's sexuality (which may or may not reflected actual behavior), numerous parents—supported by their doctor often—expressed similar notions of the "right time" or ideal age to vaccinate, often right before college. The right time to vaccinate, for many parents, is much later than the recommended age of 11-12 for boys and girls, which is founded upon expert claims that vaccine is more effective at this earlier age, and population statistics estimating the average age when young girls and boys become sexually active<sup>40</sup>. Drawing upon claims to parental and experiential knowledge, parents resisted the universalizing assertions of biomedicine that position ages 11-12 as the right time to vaccinate. Intertwined within these assertions are also normative views of when and where

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<sup>40</sup> Based on Advisory Committee on Immunization Practices (ACIP) meeting notes, three factors formed the foundation of the target age selection. 1) Population statistics estimating the average age when adolescents first have vaginal intercourse; 2) Population statistics estimating rates of sexually transmitted infections (STIs) across the different age groups; and 3) Immunogenicity data that showed that the vaccine is slightly more effective at producing an immune response in 10-15 year old boys and girls than 16-23 years. These statistics mostly came from two nationally administered surveys, the National Survey of Family Growth (NSFG) and the Youth Risk Behavior Survey (YRBS).

young girls should first become sexually active. The story of Alice, an elementary school teacher and mother of one daughter, highlights these connections and complexities well.

#### **IV. DEBATING THE ‘RIGHT TIME’ TO VACCINATE**

When I asked Alice to tell me about who makes up her family, as I often did to begin interviews, she started with the challenges—and benefits—of conceiving her daughter through a sperm donor. "So in the beginning [my female partner and I] thought we wanted all kinds of things, and then, when you look at the profiles, you realize only a few things really matter." For Alice and her partner, the things that really mattered was the ability for their daughter to be able to contact her biological father at age 18, and to "weed out for some sensitivities...cancer, alcoholism, and mental illness" in her family history. For Alice, protecting her daughter began before conception, and throughout our conversation, she continued to express a great concern for providing the best care for her daughter.

In asking her if she had heard about any negative aspects of the HPV vaccine, she explained that she had heard about general rumors that the HPV vaccine may not be effective long term and that it may have resulted in the death of a local girl. I asked if she had looked into any of these rumors, she explained when she first heard, she "had a visceral reaction and I shut down and I stopped looking at it. And I said, I'm not going to look at this for a while because it is not something [my daughter] is going to get at twelve—She is not."

When I asked her to explain further why she did not want her daughter to be vaccinated at age 12, she invoked similar concerns that other parents had mentioned regarding evidence of the vaccine effectiveness and known risks, but also normative assertions to when and where girls (should) become sexually active:

*Joyce: See, I don't think there's enough research to tell us how effective it is, and I don't think there's enough research to tell us, well here's my problem. You vaccinate a girl, and she's twelve and she's not sexually active, and then she goes off to college thinking she's ok. She has partners and then she's followed or whatever, but if you're done at twelve, the research I saw didn't even show all the way through college, so there's not enough evidence and there's not enough evidential partners to tell me jack crap. That's my problem, is that really I could traumatize my daughter for absolutely nothing, or I could traumatize her and protect her. I need to see longer-term studies...I want her to be protected and I'm not gonna give her the vaccine until—my ideal age is seventeen, so she has a year before she goes off to college.*

Her decision to delay is shaped by both a need for "evidence" of the safety and effectiveness of the vaccine as well as the desire—and obligation—to protect her daughter. As such, her decision to delay is also an act of boundary work, in which parents (lay individuals) are challenging scientific knowledge through claim to experiential expertise. These assessments are constructed through claims to knowing her daughter (and her sexual activity) and normative understandings of when the ideal time for her to be vaccinated is. Many other parents expressed this moment ("right before college) as well, which I argue reflects not only individual claims to knowing their child, but also normative assertions regarding the appropriate time for young girls to become sexually active.

In these ways, I argue that sexual norms and lay challenges to scientific knowledge may be acting as a countervailing mechanism in the context of HPV vaccination, resulting in low and stagnating vaccination rates among highly educated and resource-laden groups. In other words, parents are selecting against beneficial health behaviors for their children (HPV vaccination) due to perceived negative social consequences of vaccinating, supported by experiential assessments of when their child will become at risk for exposure. These social consequences are not in the form of behavior disinhibition (i.e. risky sexual behavior), but rather are more subtle and may be centered on concerns that vaccinating at an earlier age may give the impression that their daughter "needs" to be vaccinated because she is sexually

active. They may also reflect general societal resistance to discussing sex between parents and child, and even patients and doctors.

Moreover, doctors are supporting these decisions to delay and parental claims to knowing if their child is sexually active in many cases. Stemming from current and historic discrimination of ethnic minorities in the United States, it is reasonable to hypothesize that doctors may not *believe* parental assertions of knowing their child equally across all patient populations<sup>41</sup>, leading to disparities in not vaccination uptake, but rather disparities in who is encouraged (or allowed) to delay vaccination. While I do not have data to speak to provider's assessments, parents did convey notions that the right age to vaccinate may be different for different "types" of girls.

After describing her strong feelings regarding the age at which her daughter would be vaccinated, Alice explained that for some adolescents, it might be necessary to vaccinate earlier. As she noted:

*Alice: I don't believe that the vast majority of children twelve to sixteen are sexually active. I just don't believe that. So I don't believe it's appropriate. However, when you look at generational...when you're looking at three generations of pregnancies under age sixteen, they need to be vaccinated at twelve...The thing is, this is horrible to say, but I know several of the parents of my students, in Oakland in particular, who are not afraid of their girls having babies because then they could be the caregiver and the checks would continue. There was a cycle of poverty of depending on the checks. Part of it quite honestly, I think they were just too afraid of not being able to work or not finding work or didn't know how. But this generational poverty, it's not a shame to be a grandparent, or a great grandparent at forty.*

Although race is never explicitly mentioned, this parent's reflections, particularly the mentioning of Oakland, a predominantly Black city, and use of tropes of "welfare queens," reveals how discriminatory notions of race and poverty come to bear on assessments of not

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<sup>41</sup> In my future research, I plan to investigate these findings further to examine how social norms may be impacting patient-provider communication and vaccination practices across different racial and ethnic groups.

only when adolescents should be vaccinated, but parenting as a moral and ethical practice as well.

## **V. FUTURE DIRECTIONS AND CONCLUSIONS**

In this chapter, I have argued that social norms regarding sexuality and growing uncertainties regarding science and vaccines may help explain low and stagnating HPV vaccination rates across affluent and educated parents, particularly with regard to the age of vaccine initiation. For many of the parents I spoke with, defining the right age was not based on scientific experts or population level data on risk, benefit or behavior, but rather on experiential, parental knowledge backed by claims of knowing their child and their child's sexual behavior. In some cases, it also included a challenge to the authority of the ACIP and other experts, due to concerns regarding the long-term effectiveness of the vaccine. At the cores of these temporal debates are contested claims over when—and through what specific encounters—the individual body becomes at risk for HPV exposure. For biomedical actors, in order to create national guidelines, this individual moment was translated into a collective moment, estimated on population statistics of age of sexual debut and rates of STIs. However, for many of the parents with whom I spoke, the right time to vaccinate is perceived to be much later, often supported by recommendations from their child's doctor.

From the perspective of public health and health social work practice, these findings suggest that interventions designed to increase HPV vaccination need to identify ways to mitigate not only structural barriers such as access to care, but also parental concerns regarding the safety and efficacy of the vaccine, perceptions regarding their child's sexual activity, and the timing of vaccination. Further research is needed to understand if and how

“blind spots” among healthcare providers—and potentially latent discrimination—may be shaping how providers frame HPV vaccination to different populations. Are ethnic minorities or low-income parents given less allowance to delay? Are these allowances guided by normative assumptions regarding parenting among underserved and high-resource populations? Furthermore, if parents are making decisions regarding HPV vaccination based on perceived sexual activities of their children, interventions should help to assist providers in communicating directly to adolescents regarding their actual behavior to ensure vaccination is occurring prior to sexual debut. Social workers have a significant role to play not only in conducting this research, but also in the mediating the delivery of this information in the clinical setting, due to their training and understanding of how to communicate in comprehensive and sensitive ways.

The need to address cultural factors and health communication may become increasingly important amid the current changes in the healthcare system, stemming in large part from the passage and approaching full implementation of the Patient Protection and Affordable Care Act (ACA). Through insurance reform and expansion, the statute’s primary goal of providing all individuals with health insurance is well aligned with population health’s focus on eliminating structural barriers to health. The ACA also offers opportunities and incentives to directly incorporate population health goals into healthcare practice, including reconfiguring provider and health plan reimbursement rates to include measurements of health promotion activities and health outcomes. While the ACA offers the potential to more closely integrate population health with healthcare delivery, it is unclear how these policy-level changes will be enacted in practice, and how these policies will impact the long-term health of specific populations across the nation. Furthermore, although

the ACA aims to remove systemic barriers to health by transforming the healthcare system and providing universal health coverage, other structural and institutional mechanisms contributing to population health disparities are not as directly addressed.

My findings also raise the larger questions (to which I do not have the answers) of the ethics and implications of designing interventions that target patients with access to material, social, and structural resources, and conversely, the limits of health promotion as a moral mandate. In some ways, the parents I spoke with are informed—maybe too informed—with access to arguably some of the best healthcare in the United States and, privileged educational training enabling them to understand and critically examine health promotion materials. They face no significant structural barriers to care, and their decision not to vaccinate could be framed as merely an act of informed agency. However, in my conversations, these parents did not have complete scientific understanding of the risks and benefits of HPV vaccination, nor did they communicate that their provider had been completely open or available to answer their questions. Therefore, it would be reasonable to design educational interventions for medical care providers and health promotion materials that fill these identified needs. As Metzl and Hansen (2014) argue patients in power are also a result of the economic, political and structural conditions in the United States. However, in the context of structural competency, under what circumstances are interventions designed to translate and communicate medical information actually challenging structural inequalities (resulting from for example lack of access to education, or lack of transparency of clinical trial results) and when are these interventions merely supporting a deficit model of health promotion whereby individuals not engaging in a certain behavior are positioned as merely misinformed.

## **CHAPTER FIVE: MORAL RESPONSIBILITIES, INDIVIDUAL RIGHTS, AND COLLECTIVE GOOD**

In this chapter, stemming from public conversations regarding parental rights and mandatory HPV vaccination, I will examine how tensions between individual rights and collective good, often scripted through political and social values, emerged in my discussions with parents. Within these discussions, I will consider how notions of responsibility and obligation as both a parent and member of society guided HPV vaccination decisions, and how each parent conceptualized their relationship to not only their child, but to the nation-state and its members, through these considerations. Drawing from literature critically engaging with health promotion as a practice and mandate, I will examine how moral obligations to prevent social and corporeal risk—and desires to care—shaped these notions. In these ways, the act of vaccinating (or not vaccinating) gained meaning as an ethical act of protection guided by constructions of morality, responsibility, and risk—an act that is guided by questions of how we choose to live (Lakoff & Collier 2004). These ethical reflections also expose the processes by which health has become a new morality (Metzl 2010). In conclusion, I will consider the ways in which parents positioned HPV vaccination as distinct from other vaccinations based the manner in which it is transmitted, revealing how normative discourses that stigmatize certain behaviors—and bodies—are remade amid medical and technological change.



## **I. PARENTAL RIGHTS AND MANDATORY VACCINATION**

As previously discussed, concerns regarding parental rights erupted following initial legislative pushes to include HPV vaccination in the suite of immunizations required for public school entry. Although levels of documentation and justifications required differ, every state in the United States has some form of "opt-out" policy regarding required childhood vaccinations. All allow for exemptions based on medical reasons and most allow for exemptions based on religious or philosophical beliefs. Despite presence of opt-policies, policy groups (largely conservative) and some parents pushed back against legislative efforts to require HPV vaccination, stating that it would infringe on a parent's right to decide what is best for their child. While discourses regarding individual rights—whether it be parental, patient or otherwise—in contrast to government mandates have long been part of the economic and cultural landscape of the United States (Colgrove 2006), these debates have recently become more polarized (or at least become more visible) centered on differing views of the proper role (and size) of government and the rights of individuals. Although interwoven throughout various political parties, these sentiments have become quite visible in the emergence and actions of the Tea Party movement.

Although there is much argument on the origins of the Tea Party movement, framed by supporters as an example of a "grassroots political movement" and by opposition as a movement driven by the funds and desires of elite conservatives like the Koch Brothers, the movement and its followers have played a central role in political and cultural events in the last five years. Following 2008-2009 federal government economic stimulus plans to assist failing corporations and struggling mortgage owners, national Tea Party protests surfaced,

beginning with the actions of Rick Santelli on the floor of the Chicago Mercantile exchange in February 2009 (McGrath 2010) and spreading from there across the nation. At the core, Tea Party activists are in support of "fiscal responsibility, constitutionally limited government, and free market economic policies."<sup>42</sup> Although once at the fringe of political discussions, the values of Tea Party followers have recently become more incorporated into mainstream politics—especially the Republican Party platform—due in part to the successful election of individuals such as Congressman Paul Ryan of Wisconsin and Representative Michele Bachmann of Minnesota<sup>43</sup>.

As mentioned earlier, most of the parents with whom I spoke did not express support for statements made by Bachmann, or for conservative politics in general, which is not entirely surprising due to the general political climate of the San Francisco Bay Area. Most parents I interviewed identified as Democratic (76 percent) with some identifying as Republican (13 percent), and the rest identifying as Green, Independent, or Libertarian (11 percent). The majority also described their political values as extremely liberal or liberal (64 percent)<sup>44</sup>. Purposely employing language present in U.S. political media coverage of the Tea Party, I asked parents the following question in the written questionnaire: *If you had to choose, which would you rather have a) a smaller government that provides fewer services to citizens or b) a bigger government that provides more services to citizens?*

The majority (82.9 percent) stated that they would prefer a bigger government, which is not surprisingly given the liberal political values expressed by most parents. However, I

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<sup>42</sup> Tea Party Patriots website (<http://www.teapartypatriots.org/>).

<sup>43</sup> In 2010, Michele Bachmann launched and organized the Tea Party Caucus, comprised of 52 members, all of who identified as Republican (<http://teapartycaucus-bachmann.house.gov/about-me/history>).

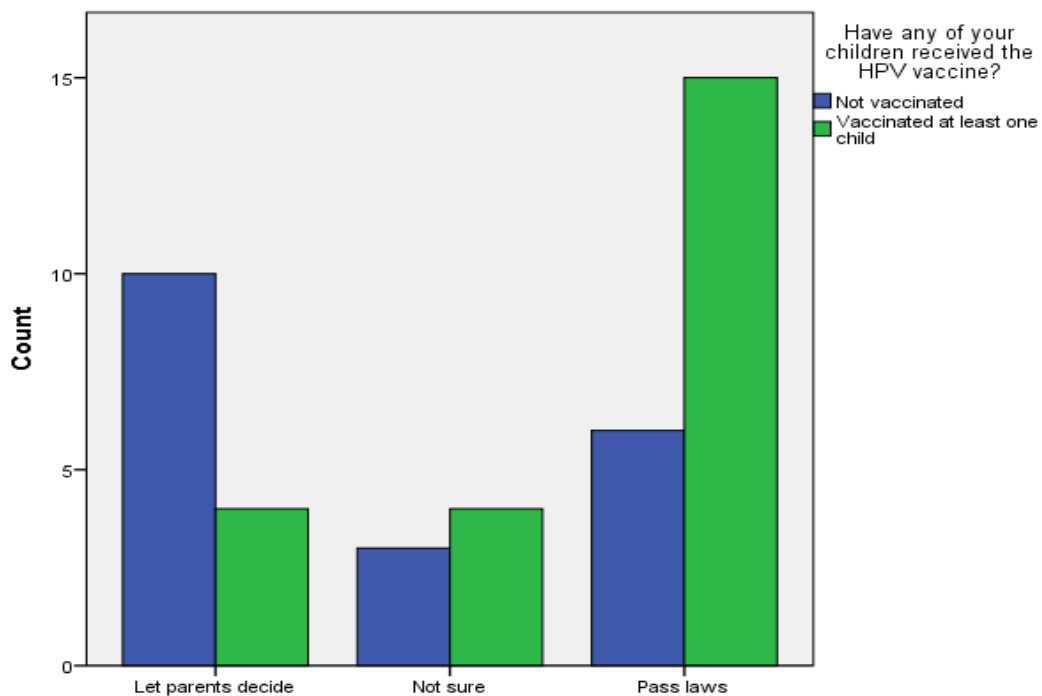
<sup>44</sup> There was no significant relationship between political party affiliation or political values and vaccination decision.

also asked parents to respond to the following question regarding parental rights and governmental involvement:

*Which of the following statements do you agree with more a) government should let parents decide for themselves how best to protect their children even if it means they don't always do the right thing; b) government should pass laws to ensure all children are protected even if it sometimes interferes with parents' rights to make their own decisions?*

Overall, more parents selected wanting more government involvement (57.5 percent), but only by a slight margin, with 42.5 percent stating that they would prefer to let parents decide

**Figure 24: Parental responses to “Which of the following statements do you agree with more a) government should let parents decide for themselves how best to protect their children even if it means they don't always do the right thing; b) government should pass laws to ensure all children are protected even if it sometimes interferes with parents' rights to make their own decisions?” by vaccination status**



(Figure 24). Also, based on the results of an independent t-test, there was a significant relation between responses to this question and vaccination status,  $X^2(2, n=42) = 6.247$ ,  $p=.044$ . When I excluded those parents who answered not sure, I found an even stronger

relation between two variables,  $X^2(1, n=35) = 6.217, p=.013$ , indicating that those parents who valued parental rights over government laws were less likely to have vaccinated.

Parental rights have been at the center of public debates regarding HPV vaccination since licensure (as described in a previous chapter). As evidenced by questionnaire data as well as interview data, opinions regarding parental rights seemed to play a clear role in vaccination decisions and deliberations among parents with whom I spoke. For example, Lillian, mother of one unvaccinated 16-year old daughter, stated it most plainly when she said: "I'm the type person—like, I don't let government rule over what I'm gonna do to my child. And [HPV vaccination] is one of them that I'm not gonna let them rule."

However, views on parental rights did not always fall in line with general political values expressed by parents. As Valerie explained:

*Valerie: I certainly think that it's the government's responsibility to help promote health. I mean, I identify as a Democrat, and I generally believe that the government should be here to help people. It's kind of like saying pharmaceutical company when you say government. There's all this implied negativity. But I think at its best that the government should be involved, you know, in the public school system, in the counties, in advertising—and they do. You know the five a day, trying to get people to eat healthier, exercise more, and I think that's great (Mother of a 5-year old son and 7-year old daughter, both unvaccinated).*

However, when I asked Valerie her opinion on childhood immunizations, she surprisingly stated she did not think they should be required:

*Valerie: But I think generally, you know for things like mumps, measles – things that are serious illnesses that people should vaccinate their children. However, I do not think that the government should mandate that people's children be vaccinated. I really believe truly that it's a parent's decision even if—yes even if there's parents out there that don't vaccinate and there is potential to put people at risk. That's the way life is. It's random. You know what I mean?*

*Kate: So you're willing to take the risk that there may be people that decide not to vaccinate because you strongly believe in parents' rights to decide what's best for them?*

Valerie: *Yes.*

Although a supporter of governmental policies promoting public health in general, she placed higher value on parental rights so much that she was willing to accept potential individual and collective risk to maintain these rights. Sarah, on the other hand, a libertarian in support of small government, strongly supported mandatory vaccinations. As she explained:

*Sarah: I had trouble answering the question...I kinda lean libertarian or more moderate. And so, therefore, I'm kinda in favor of a smaller government. But on the other hand, there's a few, like the topic of vaccines, I feel like vaccines should be mandatory for everyone that can get them. So in that area, I'm more in favor of a large government. So I really—I have an internal conflict there (Mother of vaccinated 14-year old son and 17-year old daughter).*

Although the questionnaire forced parents to choose one versus the other, many parents expressed an uncertainty and tension regarding the role of government in relationship to their vaccination decision during interviews. Within these tensions, questions of freedom and ethical responsibility as parents and members of society—specifically in relation to health—are invoked and articulated to help negotiate uncertainties of risk and desires to care for their children.

### *Notions of Freedom*

Across our conversation, David, a city planner and father of one daughter, expressed his opinions in a way that allowed for complexity, controversy, and care to emerge. Born in China, he moved with his family to San Francisco at a young age, and never left. When I asked him about his views on what role the government should play in his parenting decisions, using Christian Scientists as an example, he explained:

*David: It's tough. It's hard for me to say. I don't want a child to die un-needed for something I consider so little, but [Christian Scientists] whole-heartedly believe in their religion. And I can't step on their religion and say no, what you believe in is*

*completely ridiculous; your God would never want a child to die. Whatever their belief is, that's a tenet of American society—religious freedom. It's what our country was founded on; that's why we came here. It's not like I was on the Mayflower or something, but you're asking such a very, very difficult decision, that question. Because I don't want the government to one day—it is a slippery slope to demand this, this and this. You know, they won't sell soda over a certain ounce because it's going to cause obesity, which is going to cause your kid to have diabetes, which is going to cause them to have all these diseases. That right there is over-governing, you know? I don't want the government telling me what I can and cannot eat. That goes back to my eating ice cream for breakfast. If that's gonna be illegal, if I do that, the government is going to come down to my house and take my daughter because I fed her ice cream for breakfast. These are extremes, where the government forces that they think is best for you, versus what a parent is free to do; eat ice cream, or not take asthma medication.*

Earlier in our conversation, in the context of his view of health, David had disclosed that he sometimes likes to eat ice cream for breakfast, and for him, this behavior, while he recognizes may not be the most healthful, should be a choice allotted to him as an individual and parent, not governed by the external policies. He further explained:

*David: It's hard. I want something in the middle where it's—if I had to choose, you're asking for me to choose, and this is partly political, partly, I'm going to edge towards the side of a parent's freedom. I think it is human nature to protect your child, and I will believe in the goodness of a parent's heart that they want the best for their child. Yeah, there are extreme cases. You see tiger's eating their babies. You see parent's selling their babies on E-Bay, pimping out their kid for crack. So there are abnormalities. There are outliers, but I still believe the vast majority of parent's believe what's best for their kids. They want what's best for their kids.*

In these deliberations, David and other parents invoked more than personal political values, but situated parental decision-making (including vaccination decisions) as representative of a core American value—freedom. These notions of freedom are also shaped—and reassured—by a general hope that parents will do what is best for their children. Jessica, a mother of five children who identified strongly with the Mormon religion, also invoked the importance and existence of freedom, even if she felt her own values were not always supported by larger public health promotion.

Jessica: *I think [public health] is limited sometimes because of just different viewpoints, say on things like sexual health. Certainly public views on that, in my opinion, don't always correspond with mine, and I believe mine actually promote more health. But I feel like we can't talk about it 'cause it's feels like you're saying you have to live a certain way, and we want freedom of how we live.*

Kate: *And do you feel that what's out there and what you hear allows you to have the freedom to live your life?*

Jessica: *Yeah, I feel like we do have freedom in this country, though there are a lot of things you know talked about at schools that if you are in the minority opinion, um, you can feel silenced about your opinions. It's just easier not to say anything, and to promote something that you really do think is healthy... But I do feel free to live how I want to and have a difference of opinion on things and do what's best for my family. I do feel the freedom to do that.*

Sharon Kaufman (2010) in her work on vaccination and autism discussed how notions of freedom and doubt are shaping rising uncertainty regarding vaccines in the United States. Beyond vaccines, these notions underlie much of what constitutes broader political discussions regarding healthcare—and scientific knowledge—amid increased risk management and assessment as a way to organize life (Lupton 1995) and growing vaccine anxieties (Leach & Fairhead 2007). These values—and uncertainties—shape not only healthcare decisions, but are embedded in the way in which we—as a nation and collective—parent and care. Although there are great differences between individuals, these values and practices are also culturally shared. To those outside of the United States, the commonalities and differences are made clearer. As one parent born and raised in Northern Ireland noted:

Natalie: *Why are people, why are families not getting [the HPV vaccine]? Well, it's, interesting. It's—we're all so towed to our kids. I have a kid who really, the eldest one tried to rule our home and kind of did. It was kind of like constant battle to try and take control. So it's interesting you know, culturally, why we're not obedient to our doctors. That's not how I grew up in Northern Ireland...for vaccines we were lined up at school and had them. And there was just no, no fuss about it. Nobody wanted it, but you just got on and had it...That whole, that's sort of a movement that we're in charge of our health destiny, not the recipients of medical care. So it's that whole self-care movement is therefore questioned. The whole, you know, you're going*

*in and you're telling your doctor what new drug you should, you know, it's ridiculous* (Mother of vaccinated 16- and 20-year old daughters).

Whether or not these values are unique to the United States is unclear, as there has been much discussion of the broader patient empowerment movement across (at least) Europe, Australia and other more westernized countries. However, as Natalie suggested vaccination decisions are more than questions of safety and risk, more than questions of biomedicine, but rather are entangled in questions of—and given meaning through—our cultural, political, and moral values.

In the next section, I will further examine the notion of responsibility and how this came to bear on vaccination decisions. Considerations of responsibility and parenting are also imbued with moral assessments—an *othering* of sorts—whereby individual parents construct lines between themselves as responsible parents who should be free to parent as they deem, and other (often unnamed) irresponsible parents who should not be given the same freedom they expect for themselves. Through these lines, moralizing discourses construct clear demarcations between the right and wrong way to parent.

## II. MORAL ASSESSMENTS

*Pearl: So I'd like to say [government policies] shouldn't impact mine at all cause I'm a responsible parent. But I think for things like this that can have a big impact on other people that it makes a lot of sense for the government to have required vaccines or treatments or whatever. But I tend to see it more a recommendation kind of thing, but I know there are people out there that aren't going to pay attention to that or are not even educated enough to see the benefit of doing things like that* (Mother of unvaccinated 3-year old son, and 5- and 8-year old daughters).

Pearl, a biomedical researcher and mother of three children, supports mandatory vaccination as a safeguard against the harms that other (uneducated) parents' actions may have on society. However, for her, she does not "need" these policies, as she is "a responsible parent."



For many parents, similar to Pearl, their support for government intervention regarding parenting choices came from a benevolent desire to protect children, and a realistic (or pessimistic) understanding that not all parents placed children first. As Sadie explained:

*Sadie: My response in the questionnaire was that I would rather have a large government and more services for everybody, and that government should be involved in making regulations for parenting. And my thinking is just because the person could live through a lot of abuse, and you know in my case I likely don't need regulations, but I may not be the common. There are many, many children who suffer because their parents are not doing the right things. So for those who are not protected by the parents, the government should intervene. That's why we remove children from the abusive parents, and that's very unfortunate. But otherwise, they would just continue to be abused. Yeah, I think they should intervene, it's unfortunate but I can't think of just me and not think of everybody who will treat their children well. That doesn't guarantee anything. People can still be abused at any level of society (Mother of vaccinated 17-year old daughter and unvaccinated 19-year old son).*

Although often unnamed or invisible, many parents invoked these "other" parents as evidence of the need for governmental policies to protect all children. However, for some, these parents are known intimately, as in the case of Marlene. In our conversation, Marlene discussed her niece, a mother who did not vaccinate and homeschooled her children, to situate her own beliefs. For example, when I asked if she believed parents should be in charge of whether or not their children are vaccinated, she explained:

*Marlene: Yes, I think parents should have the right not to vaccinate their children, but I think there should be pretty aggressive education campaigns for parents. I know my particular pediatrician's office, if you do not believe in childhood vaccines you cannot be their patient. They'll talk to you about it, and they'll probably maybe do a modified schedule or something. But they feel very strongly that it's a public health issue and it's not a for your individual child's issue. I mean they're still your kids, and it's not like you should have no rights, but I think it should be very carefully researched. Unfortunately not all parents do that. I know it's colored by my particular niece, but you know you get into these communities that are all very like-minded, and they all home school so they're not getting any information from the public schools or private schools. And they're not taking their kids to regular doctors. They're going to these alternative doctors... So there are, I think, an awful lot of people that it's hard to reach them with information, particularly because there's a whole, kind of, God defense that even if you did reach them with the information they*

*would refuse it. Which then if they're refusing it, as opposed to not knowing it (Mother of unvaccinated 7-year old son and 12-year old daughter, and vaccinated 14-year old daughter).*

Although education is an important step in ensuring the safety of children, as Marlene and others explained, it may not resonate with parents who refuse to vaccinate based on intersecting moral, religious or social practices. For these parents, not vaccinating is constructed as *not* protecting or caring for children. However, what constitutes care is clearly not uniform across parents with regard to vaccination, as the meaning attributed to the act (vaccinating or not vaccinating) differed depending on constructions of risk. Regardless of views on HPV vaccination, many parents stressed the government had a responsibility to protect children when parents were not fulfilling their moral obligation to care. In these ways, responsibility—in the shape of caring for children—becomes central to the construction and subjectivity of what it means to be a parent.

### **III. RESPONSIBILITY TO PROTECT**

*Nowhere does it seem that kinship, as a system of subjectivation, has assumed the exclusive character of a system of subjection. Perhaps it has come close, and in its various interfusions with class or race or gender, closer still. Yet it seems always to have stopped short of sheer imprisonment, sheer slavery. It thus seems always to have left a bit of room--if greater room for some (usually adult heteronormative male) beings-in-relation than for others--for what Foucault would have us understand as ethics (Faubion 2011:18).*

Foucault and those who speak through or against his work have discussed the ways in which individuals become subjects of certain moral and ethical orders. As noted in earlier chapters, I originally used these theories as the primary focus of my dissertation project. However, as noted by Faubion, in terms of kinship or parenting, there has always been room for individuals to resist and rework "systems of subjectivation" through practices. In my

conversations with parents, responsibility to care—or protect—emerged as key to how parents understand and construct what it means to be a parent. As Annie, mother of 16- and 18-year old daughters, both vaccinated, explained:

*Annie: I'm not inclined to be a permissive parent and I'm not inclined to see parenting as a partnership with a child, the fact that I'm going to make this decision. I know parents that, particularly with this [HPV] vaccine, have left it up to the daughter to decide. And to me that's up to the parent. If you want it fine, if you don't want it fine, but I think it's your job to make these decisions. I think it's my role to make these decisions and to provide the best protection and to give them the best chance to have a healthy adult life, and, relieving them of a certain amount of worry if I possibly can.*

Annie stresses that although parents can decide what they want with regard to vaccination, it is their job—and their job alone—to decide. Other parents invoked this notion of protection as part of a parent's obligation as a parent, yet, as Ruth noted, parental power to protect becomes increasingly difficult as children age:

*Ruth: I think as a parent I would like to keep her safe from as many things as I can, but I'm very aware that you know she's gonna be an adult soon and she's gonna be separate from me. And quite frankly, um, even though she may not be ready to be an adult at eighteen, she will be. And at that point in time, there are fewer things that I can compel her to do. I can ask her, I can cajole and beg, but I can't make her. But I can right now and um, I suppose if she said to me, 'Mom, I'm absolutely against this. I don't want to do this,' that I would strongly consider her opinion. But she doesn't have that opinion formed yet and if I, if I can protect her from something, I think it's my job (Mother of unvaccinated 12- and 16-year old daughters).*

In these ways, parents are choosing to vaccinate in the present to help extend protection over their children in the future. As Rebecca explained: “Where vaccinations come into play, if I feel I'm not aware of tremendous down sides and high risks, taking preventative action—It's just kind of my personality, and planning for the best outcome in the future” (Mother of unvaccinated 11-year old daughter).

For many parents with whom I spoke, the driving reason to vaccinate their child reflected a larger obligation and desire to care for their child. As Delia simply stated, “I think

[HPV vaccination] is part of me taking good care of my child." Beyond caring for their children, for many, vaccination also represented a moral obligation to help protect other children and society in general. As Joyce explained:

*Joyce: I don't really see [vaccination] as a parenting issue except that parents typically make the decision for their kids and are the ones to get their kids to the vaccination channel, wherever that is. But I see it much more as a social obligation than a parenting obligation...I just think that some of the diseases that have come back, because parents or whomever has opted not to vaccinate their families, I think is socially irresponsible and unfair to everybody else. I don't see it as a political issue and I don't see it as a religious issue. To me it's like stopping at a red light (Mother of unvaccinated 13-year old daughter and vaccinated 15-year old son).*

When I asked Pearl how she sees her decision to vaccinate fitting in with overall parenting values, she responded:

*Pearl: I think it promotes healthy lifestyle, and I also think it's the responsible thing to do.*

*Kate: Responsible in what way?*

*Pearl: Society. So it protects them, but it also protects other people from potentially getting whatever they could carry.*

Some parents viewed the act of vaccinating their child as primarily a way to protect their child, and only secondarily a way to protect society. As Ruth described: "I think with [HPV vaccination,] in particular, it's a very personal, you know, that's *my* child. And I guess that you can extrapolate out that I'm protecting other peoples' children, but in the process I'm not really thinking about them." While others, like Emily, acknowledged that they were willing to take the minor potential for risk to their child to protect others.

*Emily: I can make decisions for my own children, but many of those decisions and the things that happen to them might affect the other people, either in their own generation or broadly. So, for example, with vaccinations I know that even though, the more people get a particular virus or disease, the more likely it is to spread, so in the interest of public, the general health of the public—of the society—sometimes we need to take more care to those things. So I'm very concerned about contagion and spreading issues. So, for example, when I talk to my children about sexuality I talked*

*a lot about [that] it might not be that it's a problem for you, but there's a problem for the society doing such and such. So I keep that in mind in making the decisions— meningitis and HPV. At this point, I can see socially, and if I think my son is going to be of risk to society in not having [the HPV vaccine], then I would probably urge it— despite any risk to him (Mother of unvaccinated 16-year old son).*

For these parents, they viewed vaccinating their child as part of their subjectivity and responsibility as parents to protect. For some protection extended only to their child, while for other protection extended to broader society. As detailed in an earlier chapter, other parents viewed not vaccinating as the best way to protect their child as they viewed the HPV vaccine as a source of risk, not protection. Beyond protecting their children, whether they vaccinated or did not plan to vaccinate, many parents invoked other ways to protect children against HPV that reflected not only the nature of transmission, but moral assessments of certain behaviors and constructions of vulnerability (Nichter 2003).

#### **IV. VULNERABILITY, RISK, AND NEW MORALITIES**

Although often conspicuously absent from the marketing of the HPV vaccine, a early concern from the perspective of health advocates regarding uptake of HPV vaccines was the nature in which the virus is spread: through intimate, sexual contact. Although Hepatitis B is also primarily spread through sexually contact, very little public resistance occurred when this vaccine became part of the suite of recommended childhood vaccines<sup>45</sup>. This may be partly due to the differences in the recommended timing of the vaccine, which for Hepatitis B begins at infancy (six months old), while for HPV vaccination it is recommended at 11— closer to an age when a child *might* become (or be perceived to be) sexually active.

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<sup>45</sup> More recently, more parental resistance has been noted, which may be reflective of larger societal resistance to vaccinations in the United States (See Comis 2011 for further discussion).

In the context of HPV vaccination, for many parents, particularly those who supported other childhood vaccinations, but not necessarily the HPV vaccine, the transmission of HPV situated the vaccine and vulnerability to the virus as different. Lorraine, who I introduced in an earlier chapter, stated it simply that "the HPV one is different in character." When I asked her why she explained:

*Lorraine: Cause you're talking about a behavior that leads to some diseases, and the case of chickenpox or polio, you're talking about exposure. You can't avoid the diseases by avoiding behaviors.*

*Kate: In the case of HPV, what are the behaviors?*

*Lorraine: I mean if you can practice safe sex, and of course, my kids aren't having sex yet and I'm sure at some point I'll need to know more about it when they do, but I'm not an expert at it at all. Having PAP smears regularly, of course, to look for cervical cancer, and again, I don't really know what the incidence rates are. I'm sure they're big enough numbers to want people to want to do this... You're not going to sit next to somebody on a bus and get it. You could sit next to someone with whooping cough.*

Pearl also used the notion of riding the bus to explain differences between HPV vaccination and other required immunizations:

*Pearl: Whooping cough doesn't require sexual interaction with another person, which is more intimate than sitting next to someone. Hopefully that's a decision that you make as opposed to—with whooping cough you could be sitting next to somebody on a bus or something like that.*

Beyond the intimacy and perceived control, vulnerability to the disease is constructed through notions of ethics—whether it ethical reflections in the form of personal convictions or parental obedience. As Mona explained in the context of her opinions on requiring HPV vaccination for school children:

*Mona: I don't think this country is in a position for that right now. I think that people—for right or wrong—people are, a lot of people, like to bury their head in the sand about what their kids sexual activity is anyway. But because of that, and you've got parents who believe that their kids are not sexually active or are expecting that their kids won't be until they're married, it's asking them to do something that is*

*gonna prevent something that they shouldn't be getting because they're following their parents rules. That's intruding in a way every family—it's not your convictions that stop you from getting whooping cough. It's a different thing. You get these things from very specific activity; it's not from being in the wrong place at the wrong time on a bus (Mother of 9-year old unvaccinated daughter).*

In these reflections, developing and transmitting communicable diseases—such as pertussis—are constructed through innocence—a shared vulnerability that even moral individuals have from "being in the wrong place at the wrong time"—innocent bystanders vulnerable to the randomness of life. However, even among this randomness, there is meaning and power. Let us take, for instance, the act of riding the bus used by many parents. This is an act that is purposive in some cases—particularly in a geographic region that prides itself as “green” or environmentally conscious—I choose to ride the bus because I care about the environment. However, riding the bus may also be a forced choice—due to economic status, structural inequalities, or lack of other alternatives. In this case, this act can be stigmatizing. While this single act carries many meanings, parents used this as an example of innocence and susceptibility beyond the control of the individual to be exposed to disease, and thus reason for why one would be vaccinated. HPV transmission, on the other hand, requires intimate contact. While sexual behavior is a practice that has been in existence arguably as long as humans themselves have, it carries distinct meaning and judgment, even among liberal communities.

For other diseases, blame is removed from the individual through perceived lack of control. In the case of HPV, parents constructed the ability to prevent the spread of this communicable disease through "convictions" and other morally just behaviors. Despite its near ubiquity across the population, HPV is entangled with moral assessments of behavior and values, reflecting historic and current norms regarding sex. Even for parents who may

not view the act as distinct for themselves, they recognized that, for others, this might be a reason for resisting vaccination. As Ruth explained:

*Ruth: There are certain vaccines that should just be required. Um, hepatitis, you know all of those, why you would want to be at risk for that. I just can't imagine. And HPV, well you know, that's, that's a harder one for me to require. You know people can be weird about sex...I kinda look at it as it's where you get babies from, you know, I mean let's be real here...I don't think of it in terms of public health but it is actually a public health issue 'cause I think at first you think of sex as being a one-on-one. But then when you think about if you have sex—If you've had sex with how many other people than it becomes a public health issue. Which is why I go back to my kids and say, 'Always use barrier method'...I'm the crazy lady who says when my kid goes to piano lessons she comes home and I say, 'Wash your hands.' She's like, 'Why?' 'Cause you been playing piano with sixty-seven other people'...You know, well it goes for sex too. [laughing].*

*Kate: That might actually be an effective public health slogan—Playing piano with sixty-seven others [laughing].*

Although joking, in thinking through the public health implications of my findings, I do think beyond identifying ways to ensure parents of different classes, races, and ethnicities have equitable access to comprehensive information regarding potential risks and benefits of HPV vaccination, public health promotion and physicians may need to directly address the parents' concerns—embedded in normative concerns of parenting rights, sexuality, and prevention—to increase vaccination uptake. Training programs for health educators should aim to open communication pathways between parents, healthcare providers, and children regarding not only HPV vaccination, but also sexual health in general. Additionally, I believe public health campaigns should directly address parents' concerns regarding the sexual health—not only cancer prevention—implication of HPV vaccination, as well as clearly explain what evidence exists (or does not) regarding the safety and potential risk of HPV vaccination.



## CHAPTER SIX: FUTURE DIRECTIONS

*How can we facilitate a more informed debate about the uncertainties of the science, effectiveness, and true costs of therapeutic advancements? (Biehl 2011:281).*

Increasingly, in the field of anthropology, scholars have called for action-oriented ethnography in which we use the richness of our methods and closeness to those with whom we study to challenge the networks and practices of power that result in unequal conditions. While not a mandate, I have struggled to place action and implication as driving forces behind the research questions I find most relevant and meaningful, even when working with those communities who have access to power. In the field of social work, action has always been at the core of the discipline. However, amid limited resources and devaluation of the practice, the need to act may not leave much room for critical engagement or reflection, opening up the potential for action to be misplaced or misguided.

As an interdisciplinary scholar, I have experienced these tensions, feeling the pressure to conduct quickly translatable research without losing the value and detail that (by nature time-consuming) ethnography offers. How does one translate the richness of ethnographic findings into action without succumbing to such levels of reduction that the value is lost? On the contrary, rapid intervention that focuses on only one predictive factor, while missing the

complexity of lived experience, does not necessarily mean one is chipping away at the underlying causes, but rather through reduction, the value once identified may be lost completely.

In this dissertation, I have not come close to achieving balance—between the hope and harm—of illuminating complexity while identifying clear, actionable ways to improve health and reduce inequitable conditions. It may stem from my own uncertainty of what “improvement” or “action” means in the context of HPV vaccination or health promotion in general. I have reviewed the scientific evidence, and I understand why parents are uncertain regarding both the potential benefit and risk regarding HPV vaccination. However, I also understand the potential benefit of a vaccine that possibly prevents cancer, and the history of initial, public resistance to a new vaccine that several years later, hardly anyone questions. Additionally, I am critical of the influence and power of the pharmaceutical industry, but also critical of those outright against vaccination as they also have an agenda, and use information in strategic ways to achieve their own motives. Furthermore, the people with whom I studied are largely privileged with access to material and social resources beyond what most of the world can imagine. So, what, then, are the implications of my research? When those in the position of power reject, resist, or avoid what biomedical experts’ position as ‘health’, what if anything is there to be done?

In nearly each interview, parents concluded by asking me questions, not about my project or my thoughts as an anthropologist or social worker, but as a person—an expert—with access to (and time to reflect upon) information. Is the HPV vaccine safe? Is the HPV vaccine harmful? Will the vaccine protect my child from cancer? What would I do if I had to decide for my daughter now? Careful to first convey that I am not a medical doctor (covering

my own liability as *just* a researcher), I would turn off the recorder and give my honest answer—I do not know. I would follow up stating that based on scientific evidence, it seems the HPV vaccine is as safe as any other vaccine, and that it has been shown to reduce precursors to cervical cancer, but more time is needed to evaluate its impact on cancer incidence. However, in the end, I could never with certainty answer the questions parents asked me. Uncertainty prompted this project, and at its end, the uncertainty remains.

However, much to my surprise, when I answered parents, they did not seem disappointed, or entirely surprised by my answers. My acknowledgment that I—an expert of sorts that has spent the better part of a decade trying to understand the topic—am also uncertain made sense, and usually did not sway their intentions or decisions regarding vaccination in the slightest. It did, however, open up the potential for informed debate and acknowledgement of the uncertainties of not only science, but the ethical challenges of deciding how best to care and live amid technological change.

In the end, where I see the most clarity regarding the implications of my research, is to help promote and encourage open conversations about the uncertainties of the HPV vaccination in the United States as well as the structural factors associated with HPV vaccination. Medical information and care is not being shared equally, and those engaging in critical examination of health promotion may be as much to blame as any others. From my observations, I do not believe an informed debate is occurring, between scientists and parents, between parents and providers, between parents and adolescents, and between those in staunch support of HPV vaccination and those strongly against. This is not to say that informed debate will lead to uptake of certain behaviors (or should it), but I do believe access to knowledge should be shared equally. Amid a flurry of information, many parents felt that

healthcare providers, public health pamphlets, and pharmaceutical industry are not answering the questions they have. For example, many parents asked *Why age 11? Is it because the vaccine is more effective, or is merely a matter of making sure to vaccinate before children are sexually active?* After searching clinical trial data, I did find scientific data supporting the potential increased immunogenicity of the vaccine at earlier ages, but even if parents can find it, the information does not *mean* anything necessarily either because they may not understand the highly specialized jargon or because it is based on a small sample of *other* people's children. Even among my highly educated sample, medical knowledge is not easily communicated or understood, but without attempts to open up the conversation, we are not acting to help improve conditions. While the parents with whom I spoke are in a position of power in comparison to some, there are those in much higher positions—namely, pharmaceutical industry and even physicians—who are access to more power and are making decisions that shape health outcomes across the population.

Beyond the need for researchers and providers to more fully communicate, many parents, as patients and caretakers, may not be even attempting to ask these questions. This may be due to inherent power relations between providers and parents, more pressing concerns due to structural inequalities, or general lack of awareness (or desire) regarding how to evaluate and decide on medical care. Furthermore, parents may not be communicating to their own child regarding sexual activity and why vaccination should or should not be delayed. Each of these communication breakdowns offers an opportunity for action.

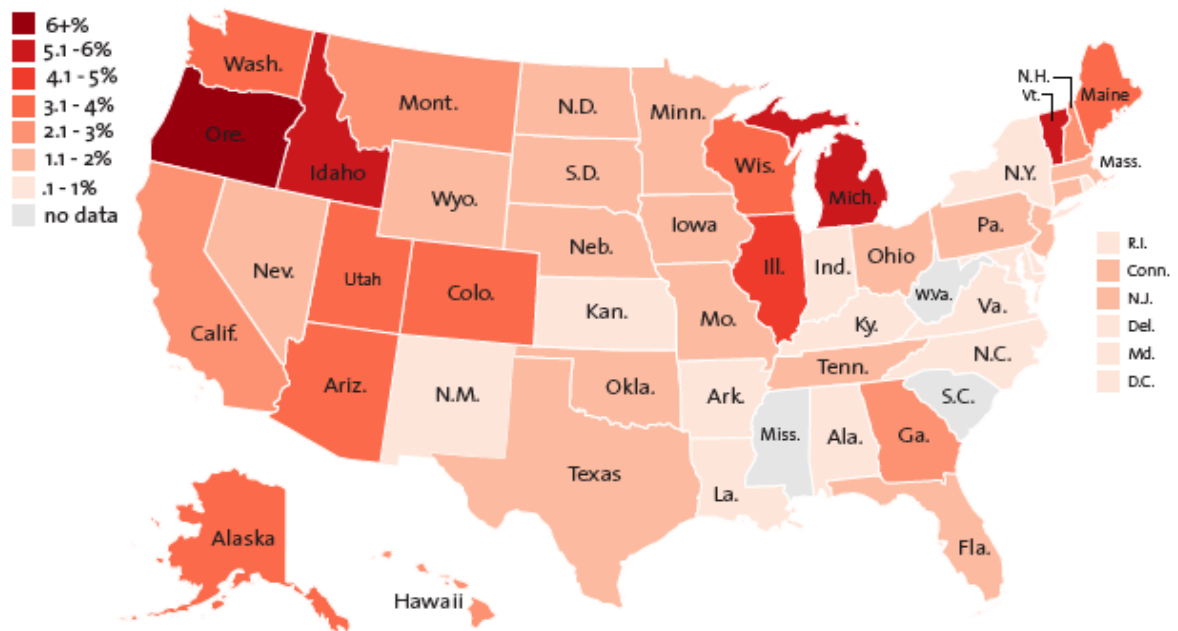
As such, my findings suggest that interventions—whether they are at the level of mass media or clinical encounters—need to address how *we* can help communicate not only the uncertainty of science, but also the true costs—and potential benefits—of medical care.

This is not to devalue or dissuade or even persuade individuals from engaging in preventive health behaviors, but rather by opening up communication, make space for informed debate to occur. Social workers have a key role to play in these discussions as they have unique training in communicating—and listening—to individuals to not only elicit their preferences for care, but also ensure information is presented in a manner that is both comprehensive and comprehensible for all individuals. Anthropologists, whether in the form of direct practice or research methodology—can also provide invaluable insight into the complexities—and inherent uncertainties—in deciding how and what it means to care.

In addition to communication interventions, structural inequities that not only prevent access to healthcare, but restrict access to education, employment, and safe environments need to be reduced to allow parents the opportunity to think through the costs and benefits of medical care. Additionally, it should not be assumed by researchers, providers, or others that parents of low levels of education, lower income status, or different cultural or ethnic background all desire (or do not desire) to learn more about the uncertainties of medical care or engage in open communication. Although most of the parents with whom I spoke came from privileged backgrounds, those who did not, expressed great interest, reflection, and thought into why and how they decided to vaccinate or not vaccinate their child against HPV. I would agree that without access to basic needs and healthcare, these considerations may seem secondary, but to make presumptions either way serves to perpetuate, rather than eliminate, health and resource inequities. In many ways, those most vulnerable have suffered the greatest costs with regard to therapeutic advancement, and thus potentially stand to benefit the most from open, informed conversation.

APPENDIX A: VACCINE EXEMPTIONS BY STATE

**Rate of Nonmedical Vaccine Exemptions By State**  
 Percentage of kindergartners with nonmedical exemptions, 2012-13 school year



Note: Children with exemptions may still be vaccinated.  
 Source: Centers for Disease Control

Mother Jones

Source: Raja & Mooney (2014)

## APPENDIX B: INTERVIEW GUIDE

### Introduction

1. Please tell me a little about yourself and your family
2. Please imagine your child as an adult and describe what kind of person you would like your child to be (emphasizing the three most relevant characteristics).
3. Please imagine your child as an adult and describe to state what kind of person you would not like the child to be (emphasizing the three most relevant characteristics).
4. Lastly, please describe which of your main values (emphasizing top three) that you would like to pass onto your child.

### Theme I: Health Care

1. How many times in the last year did your child visit a doctor of any kind in the last year?
2. Who took the child to these visits (e.g. yourself, child's other parent, other)?
3. How many of these visits were for preventive reasons (e.g. shots, physicals, check-ups)?
4. What kind of health care provider does your child usually see (e.g. primary care, emergency care)?
5. How would you describe the care your relationship with your child's doctor?
6. Has your child received any childhood vaccines? If so, did you follow a standard schedule or different?

### Theme II: Learning about the HPV Vaccine

1. When did you first become aware of the availability of the human papillomavirus (HPV) vaccine?
2. Were you aware of HPV before learning about the vaccine? If so, how did you learn about it?
3. With whom in your life (e.g. friends, family members, health professionals) have you discussed HPV vaccination?
4. What public sources (e.g. newspapers, internet) have you used to learn about HPV and HPV vaccination?
5. Are you aware of the public debates surrounding HPV vaccination? If so, what is your opinion on this issue?
6. Have you seen any media advertisements or commercials for the HPV vaccine?
7. Have you seen any public health outreach on the HPV vaccine?
8. What sources do you most trust in learning about HPV vaccination?

Theme III: Personal Constructions of Risks, Benefits, & Facts

1. From your understanding, what does the HPV vaccine claim to protect against?
2. Who can be vaccinated against HPV?
3. What evidence are you aware of concerning the efficacy of HPV?
4. What are the risks of HPV?
5. What are the risks and/or benefits of HPV vaccination?
6. What sources did you use to learn about the risks and benefits?
7. When someone says something is a fact, what does that mean to you?

Theme IV: Salient Factors in Decision-Making

1. Have you vaccinated your son(s) or daughter(s) against HPV?
  - a. If so, has your child completed all three doses? Which type (Cervarix or Gardasil) did he or she receive? Where did you child receive the vaccine (location)? Did your child have a reaction to the vaccine?
  - b. If not, are you planning on vaccinating your child in the future?
2. Have you been vaccinated yourself?
3. What factors influenced your decision to vaccinate or not to vaccinate your child (e.g. information, other parents, doctor, or personal experience)?
4. Who made the decision to vaccinate or not to vaccinate your child (e.g. you, other parent, doctor, or child)? How involved were you in the decision to vaccinate or not to vaccinate your child?
5. How, if at all, has the media and marketing campaign affected your decision?
6. Did you find the decision difficult? Why or why not?
7. How long it take you to decision?
8. Did you feel confident about your decision? Why or why not?
9. How often do you worry about your child contracting HPV? Developing cervical or other HPV-related cancers?
10. What do you think is the chance of your child developing a HPV-related cancer (cervical, anal, or head & neck) in his or her lifetime?
11. What do you think is the chance of your child contracting HPV in his or her lifetime?

Theme V: Influential Values and Norms

1. Please describe your overall parenting style (e.g. values, approaches).
2. What factors have contributed to your parenting style (e.g. family, classes, religion)?
3. How do you see your decision to vaccinate or not to vaccinate fitting in with your parenting values?
4. Do you think both boys and girls should be vaccinated? Why or why not?
5. Would you support the HPV vaccine if it only prevented genital warts?
6. What is your opinion of the role of pharmaceutical companies in public health policies?
7. What is your opinion of childhood immunizations in general?

Theme VI: Role and Responsibility of Parents to Protect Children and Nation

1. Is vaccination the best way to protect against HPV?



2. Do you feel parents should be in charge of deciding whether children should be vaccinated against HPV?
3. Who should be responsible for ensuring the safety of vaccines?
4. What role do you believe you play in ensuring your child's overall health? Sexual health?
8. In general, do you support mandatory vaccines for children? Why or why not?
9. In your opinion, what role should public health or government policies play in your parenting decisions?
10. What does public health mean to you?

Closing

1. Do you have any additional comments or feelings you would like to express?

### APPENDIX C: CODING DICTIONARY

<b>ATLAS CODE</b>	<b>DEFINITION</b>
AUTISM	Any text referencing autism or the autism spectrum.
AWARE_AGE_WHO	Any text indicating parent's awareness of who is recommended to receive the vaccine.
AWARE_AGE_WHY	Any text indicating parent's awareness of why 11-12 are target age (or of target age).
AWARE_GWARTS	Any text indicating parent's awareness that HPV is linked to genital warts.
AWARE_HPВ_BEFORE	Any text indicating parent's awareness of HPV prior to the vaccine.
AWARE_HPВ_RISK	Any text indicating parent's awareness of the risks associated with HPV.
AWARE_PROTECT	Any text indicating parent's awareness of what the HPV vaccine claims to protect against or prevent.
AWARE_SPREAD	Any text indicating parent's awareness of how HPV is commonly spread.
BACHMANN	Any text referencing explicitly Michele Bachmann or indication of her.
BACKGROUND	Any text referencing the upbringing or background of parent (e.g. education, childhood).
BELIEF_ADULTS_VAC	Any text referencing parental views on adults (over age 18) receiving HPV vaccine.
BELIEF_ANTIVAC	Any text describing parent's general view of people who do not vaccinate their children in general.
BELIEF_BIOMEDICAL	Any text describing the parent's perception of biomedical practices.
BELIEF_BOTH_SEXES	Any text describing parent's view on whether boys and girls should be vaccinated.
BELIEF_EVIDENCE	Any text describing evidence (scientific or experiential) regarding vaccination (for or against).
BELIEF_IMMUNITY	Any text describing parent's construction of immunity or immune system.

BELIEF_MAND_VAC	Any text describing parent's perception of mandatory vaccines.
BELIEF_PHARMA	Any text describing thoughts or perceptions of pharmaceutical companies.
BELIEF_STI_ONLY	Any text referencing parent's view of HPV vaccination for prevention of sexually transmitted infection (beyond cancer).
BELIEF_VACCINES	Any text describing parent's general view of childhood vaccines.
CDC	Any text referencing explicitly the CDC.
CDC_FACTSHEET	Any text describing the CDC factsheet about the HPV vaccine.
CHILD_DESCRIBE	Any text describing parent's children in general.
CHILD_EMOT_SELF	Any text referencing parent's perception of child's emotional self.
CHILD_MED_HIST	Any text referencing child's medical history (e.g. serious illness).
CHILD_PHYS_SELF	Any text referencing parent's perception of child's physical self.
CHILD_SEX_ACTV	Any text referencing parent's perception of child's sexual activity.
CHILD_VAC_PERC	Any text referencing child's view or awareness of the HPV vaccine.
COMM_CHILD_MD	Any text describing communication between doctor and child.
COMM_PARENT_CHILD	Any text describing communication between parent and child.
COMM_PARENT_FRIEND	Any text describing communication between parent and friend, acquaintance, or coworker.
COMM_PARENT_GYN	Any text describing communication between parent and own doctor.
COMM_PARENT_KIN	Any text describing communication between parent and other family members.
COMM_PARENT_MD	Any text describing communication between doctor and parent.
COMM_PARENT_SPOUSE	Any text describing communication between parent and spouse/partner.
CONTRACT_HPV	Any text describing parent's perception of likelihood of child contracting HPV.
DELAY_MD_SUGGEST	Any text indicating that doctor suggested delaying to parent.
DELAY_MD_SUPPORT	Any text indicating that doctor supported parents' decision to delay.
DEVELOP_CANCER	Any text describing parent's perception of likelihood of child developing cancer.

DM_CHILD_SEX_ACT	Any text referencing perceived sexual activity (or inactivity) as a decision-making factor.
DM_CORP_RISK	Any text referencing potential corporeal risk of the vaccine (e.g. death, fainting) as a decision-making factor.
DM_COST	Any text referencing the cost of the vaccine as a decision-making factor.
DM_EVIDENCE	Any text referencing general evidence or information (either limited or substantial) about the vaccine as a decision-making factor.
DM_FUTURE_PRTNR	Any text referencing the desire to protect future partners (girls or boys) as a decision-making factor.
DM_INSURANCE	Any text referencing insurance status as a decision-making factor.
DM_MD_REC	Any text referencing provider recommendation as a decision-making factor.
DM_OTHER	Any text explicitly referencing factor contributing vaccination decision not already a code.
DM_PREV_CANCER	Any text referencing cancer prevention (other than cervical cancer) as a decision-making factor.
DM_PREV_CANCER_CV	Any text referencing cervical cancer prevention as a decision-making factor. Do not use for general cancer prevention.
DM_PREV_SPREAD	Any text referencing the desire to prevent the spread of the virus as a decision-making factor.
DM_PROTECT_GEN	Any text referencing prevention of genital warts as a decision-making factor.
DM_VAC_EFFECT	Any text referencing effectiveness of the vaccine as a decision-making factor.
ETHNICITY	Any text referencing cultural, ethnic or racial identify.
FACT_CONSTRUCT	Any text referencing how parents construct facts.
FDA	Any text referencing explicitly the FDA.
FIRST_HEARD_HPV	Any text describing when first heard about the HPV vaccine and from what source.
FLU	Any text referencing explicitly the flu or flu vaccine.
FORMAL_ED	Any text referencing the public education their child received.
FREEDOM	Any text indicating freedom (as an American ideal).
GENDER	Any text indicating normative gender roles or behaviors.
HEPATITIS	Any text referencing explicitly hepatitis or hepatitis vaccine (A, B, or C).
HERD_IMMUNITY	Any text discussing the concept of herd immunity.
HERPES	Any text referencing explicitly genital herpes. Do not use for genital warts.

HPV_DIFF_TRANS	Any text indicating transmission of HPV as different from other communicable diseases.
HPV_OTHER_HAS	Any text indicating parent has personal experience with HPV (not self).
HPV_SELF_HAS	Any text indicating parent has personal experience with HPV (self).
HPV_VAC_AGE	Any text referencing the age that child received the first dose of HPV vaccine.
HPV_VAC_BENEFIT	Any text describing general perceived benefits of vaccination
HPV_VAC_DEC_QUAL	Any text describing decision quality including decision confidence, regret, or satisfaction.
HPV_VAC_DECISION	Any text referencing vaccination decision explicitly (including past or future decision).
HPV_VAC_DELAY	Any text referencing delaying vaccination for specific age, moment, or situation (including past or present considerations).
HPV_VAC_DM_PROCESS	Any text describing the general decision making process (e.g. weighing pros and cons) for HPV vaccination.
HPV_VAC_DM_ROLE	Any text describing past or future decision-making role or role preference.
HPV_VAC_EFFECT	Any text describing parent's perception regarding the effectiveness of the HPV vaccine.
HPV_VAC_EVIDENCE	Any text describing parent's perception of the evidence regarding the efficacy, safety, or risk of HPV vaccination..
HPV_VAC_LOCATION	Any text describing the location where child received the HPV vaccine.
HPV_VAC_NOVELTY	Any text referencing the amount of time since licensure (novelty) of the HPV vaccine.
HPV_VAC_REACTION	Any text description vaccine reaction experienced by child (HPV specific).
HPV_VAC_RISK	Any text describing general perceived corporeal or social risks of vaccination.
HPV_VAC_SAFETY	Any text describing safety of HPV vaccine.
HPV_VAC_SCHEDULE	Any text describing scheduling the vaccine series or efforts provided by doctor to assist in scheduling (e.g. reminder cards/calls).
HPV_VAC_TYPE	Any text referencing the type of HPV vaccine child received.
ILLNESS_EXP	Any text indicating personal experience with serious illness (self or other people in his/her life).
ILLNESS_EXP_CVCAN	Any text indicating personal experience with cervical cancer (self or other people in his/her life).
IND_COLLECT	Any text highlighting tensions between or constructions of individual and collective.

INFO_SEEKING	Any text describing information seeking behaviors for general medical or HPV specific information.
INFO_SOURCE_GEN	Any text describing information sources usually sought out by parent about any medical information.
INFO_SOURCE_HPV	Any text describing information sources sought out by parent about HPV or HPV vaccine.
INSURANCE_STATUS	Any text referencing the insurance status of the parent or child.
KNOW_CHALLENGE	Any text references challenges to expert knowledge (scientific or otherwise).
KNOW_EXPERIENCE	Any text describing knowledge produced from experience—either from own experience or others. Do not use to indicate professional experience.
KNOW_EXPERT	Any text describing expert knowledge that is not explicitly scientific or biomedical but references experts (e.g. trained professional, policy)
KNOW_SCIENCE	Any text describing scientific or biomedical knowledge.
LAW_PUB_HEALTH	Any text referencing public health or health policy laws (other than vaccines).
MCCARTHY	Any text referencing Jenny McCarthy.
MD_CARE	Any text indicating larger quality of healthcare received (including access to care).
MD_RECOMMEND	Any text regarding doctor's recommendation for HPV vaccination.
MD_REGULAR	Any text referencing if the child has a regular doctor he or she sees.
MD_RELATIONSHIP	Any text describing the quality of relationship with doctor.
MD_TYPE	Any text referencing the type of doctor the child sees (e.g. pediatrician).
MD_VISITS	Any text referencing how many times the child went to the doctor in the last year.
MD_VISITS_TAKES	Any text referencing who usually takes the child to the doctor.
MEDIA	Any text referencing media coverage of HPV vaccination in general.
MEDIA_DEBATES	Any text describing thoughts or reactions to public controversies regarding the HPV vaccine or vaccines in general.
MEDIA_DTC	Any text describing pharmaceutical marketing for HPV vaccination or in general.
MEDIA_HEALTH	Any text describing the public health promotion of the HPV vaccine.
MEDIA_POLITICS	Any text explicitly describing the political debates regarding HPV vaccination.

MERCOLA	Any text referencing Dr. Mercola or his website/literature.
MMR	Any text referencing explicitly the MMR vaccine or MMR.
MORAL_OBGAT	Any text framing medical or parenting practices as a moral obligation.
NEW_CAR	Any explicit use of new car/technology as metaphor for HPV vaccination.
PARENTING_CHI_HL	Any text referencing parent's perception or belief of their role in their child's health (including sexual health).
PARENTING_CHI_RESP	Any text describing how parent believes child responds to his/her parenting.
PARENTING_FACTOR	Any text describing factors contributing to parenting style (e.g. books, upbringing, experience).
PARENTING_INDV_CHOICE	Any text referencing individual rights to decide what is best for their child (often in contrast to what is best for society).
PARENTING_SEX_ED	Any text referencing parent's approach or practices to talking with kids about sex.
PARENTING_SPOUSE	Any text referencing partner's approach to parenting.
PARENTING_STATE	Any text referencing parents' view on the role of the state, government, or public health in parenting decisions.
PARENTING_STYLE	Any text describing general approach to parenting (e.g. parenting style, type).
PARENTING_VAC	Any text referencing how vaccination decision fits into parenting values.
PARENTING_VALUE	Any text explicitly referencing values of parent as they relate to parenting practice.
PATIENT_RIGHTS	Any text describing healthcare in terms of patient rights.
PERRY	Any text referencing explicitly Rick Perry or indication of him (e.g. Governor of Texas).
PERTUSSIS	Any text referencing explicitly pertussis/whooping cough or TDAP vaccine.
PH_PERCEPTION	Any text referencing parents' perception of what public health is.
PH_SOCIAL_DUTY	Any text referencing public health as a social duty or responsibility that all individuals should support.
POLITICS	Any text referencing personal political beliefs or practices.
POX	Any text referencing explicitly chicken pox (varicella) or chicken pox vaccine.
PROACTIVE_PREV	Any text referencing the desire to vaccinate as a representative of a proactive behavior.
RELIGIOUSITY	Any text referencing personal religious or spiritual beliefs.
RESP_VACC_SAFETY	Any text describing who the parents thinks should be responsible for vaccine safety

RIGHT_TIME	Any text indicating constructions of the right time to vaccinate (HPV only).
RISK_PERCEPTION	Any text referencing personal perceptions or constructions of risk.
ROLE_PREF	Any text describing role preference of parent.
SEX_ED	Any text referencing the formal sexual education their child received.
SEXUALITY	Any text describing sexuality in a general or conceptual manner.
SOCIAL_RISK	Any text describing risk as socially shared or practiced.
SPOUSE	Any text referencing parent's description of spouse (e.g. traits, beliefs)
SUBJECTIFY	Any text indicating parents as subjects, or young children as subjects.
TEMPORALITY	Any text indicating time (future, past, or present).
TETLOCK	Any text referencing explicitly her, her parents, or indication of her.
TRAIT_SELF	Any text referencing what trait parent has that he or she hopes to pass onto their children.
TRAITS_NOT_WANT	Any text referencing what three traits parent hopes child/children will not have as an adult.
TRAITS_WANT	Any text referencing what three traits parent hopes child/children will have as an adult.
TRUST	Any text describing trust as a concept or practice.
UNCERTAINTY	Any text indicating uncertainty or doubt.
UNDERSERVED	Any text referencing public health in connection to underserved populations.
VACCINATE_SELF	Any text referencing parents who considered HPV vaccination for themselves.
VACCINATE_BEST_WAY	Any text describing parents view on HPV vaccination as the "best way" to prevent transmission.
VACCINE_CARD	Any text referencing the immunization card that parents and providers use to track immunization record.
VACCINE_RECEIVED	Any text explicitly referencing what childhood vaccine their child has received (or not received).
VACCINE_SAFETY_RESP	Any text referencing who parents believe should be responsible for ensuring vaccine safety.
VACCINE_SCHEDULE	Any text referencing vaccine schedule for vaccines other than HPV vaccine.
VULNERABILITY	Any text indicating vulnerability of self or others.



## APPENDIX D: QUESTIONNAIRE

B1. How many children do you have?

B2. What are the ages and genders of your children?

B3. What is your gender?

- Female
- Male
- Transgender
- Other

B4. In what year were you born?

B5. What language do you primarily speak at home?

- English
- Spanish
- Other

B6. What other languages do you speak?

B7. Which racial categories do you identify with? (*Check all that apply*)

- White
- Black or African American
- Asian or Asian American
- Pacific Islander or Native Hawaiian
- American Indian or Alaskan Native
- Other Race
- Decline to answer

B8. Do you consider yourself Latino/a or Hispanic?

- Yes
- No (**Skip to B10**)

- B9. If so, which group(s) do you identify with? (*Check all that apply*)
- Mexican, Mexican American, or Chicano/Chicana
  - Puerto Rican
  - Cuban
  - Other
  - Decline to answer
- B10. Of the following statements, which best describes your current relationship status?
- I am married and living in the same household as my partner.
  - I am living as married and my partner and I live in the same household.
  - I have a steady partner, but we don't live in same household.
  - I do not have a steady partner.
- B11. Have you ever been married, divorced or widowed? (*Check all that apply*)
- Married
  - Widowed
  - Divorced
  - None of the above
- B12. What social class do you most identify with?
- Lower class
  - Working class
  - Middle class
  - Upper class
- B13. Approximately, what was your household income in 2011?
- Under \$5,000
  - \$5,000-\$9,999
  - \$10,000-\$19,999
  - \$20,000-\$34,999
  - \$35,000-\$49,999
  - \$50,000-\$64,999
  - \$65,000-\$79,999
  - \$80,000-\$99,999
  - \$100,000-\$119,999
  - \$120,000-\$149,999
  - \$150,000 or above
  - I don't know
  - Decline to answer
- B14. What is your current employment status?
- Working full-time
  - Working part-time
  - Unemployed or laid off
  - Retired
  - Homemaker

- Student
- Other
- Decline to answer

B15. Were you born outside of the United States?

- Yes
- No (**Skip to B17**)
- Decline to Answer

B16. If not born in the United States, in what country were you born?

B17. Were any of your children born outside of the United States?

- Yes
- No (**Skip to B19**)
- Decline to Answer

B18. If not born in the United States, in what country(s) were your children born?

B19. Were your parents born outside of the United States?

- Yes
- No (**Skip to B21**)
- Decline to Answer

B20. If not born in the United States, in what country(s) were your parents born?

B21. What is the highest level of education you have completed?

- 8th grade or lower
- High School Diploma or equivalent
- Technical/Vocational Certificate
- Associate's Degree
- Bachelor's Degree
- Master's Degree
- Doctorate
- Other

B22. In what field or area is your highest degree or certificate?

B23. What type of health insurance do you have for yourself?

- None/Uninsured
- Private or Employer Plan
- Medi-Cal or Medicare
- Other

B24. What type of health insurance do you have for your children?

- None/Uninsured
- Private or Employer Plan
- Healthy Families or Medi-Cal
- Other

B25. Which political party do you most identify with?

- Democratic
- Independent
- Libertarian
- Republican
- Tea Party
- Other
- Do not identify with any political party

B26. With respect to your political values, which of the following do you consider yourself?

- Extremely liberal
- Liberal
- Moderate or Middle of the Road
- Conservative
- Extremely Conservative
- Not sure

B27. If you had to choose, which would you rather have? (*Choose one*)

- A smaller government that provides fewer services to citizens
- A bigger government that provides more services to citizens
- Not sure

B28. Which of the following statements do you agree with more? (*Choose one*)

- Government should let parents decide for themselves how best to protect their children even if it means they don't always do the right thing.
- Government should pass laws to ensure all children are protected even if it sometimes interferes with parents' rights to make their own decisions.
- Not sure

B29. Do you consider yourself a member of any of the following religious traditions?

- Evangelical Protestant
- Mainline Protestant
- Historically Black Protestant
- Catholic
- Mormon
- Jewish
- Other Christian
- Muslim
- Hindu
- Buddhist

- None
- Other
- Decline to Answer

B30. How often do you attend religious services?

- Never
- About once a year
- A few times a year
- Once or twice a month
- At least once a week
- Every day
- Decline to Answer

B31. Which of the following statements comes closest to what you believe about the existence of God or a Universal Spirit?

- I don't believe God exists.
- I am unsure if God exists.
- I am fairly certain that God exists.
- I am absolutely certain God exists.
- Decline to answer

B32. In your opinion, who should determine what medical care you receive?

- Doctor alone
- Mostly doctor
- You and the doctor equally
- Mostly you
- You alone

B33. In your opinion, who should determine what medical care your child receives?

- Doctor alone
- Mostly doctor
- You and the doctor equally
- Mostly you
- You alone

B34. In your opinion, how much should a child be involved in deciding what medical care he or she receives?

- Very involved
- Involved
- Somewhat Involved
- Involved very little
- Not involved at all

M1. Do you own any of the following items? (*Check all that apply*)

- Personal computer
- Mobile phone
- Smartphone
- Tablet (e.g. iPad)
- Television

M2. How often do you go online or use the internet?

- Every day
- A few times a week
- Once a week
- Less than once a week
- Never

M3. What device do you use most often to access the internet?

- Home computer
- Work computer
- Public computer (e.g. at library or school)
- Smartphone
- Tablet (e.g. iPad)
- Other: \_\_\_\_\_

		<b>Few times a day</b>	<b>Once a day</b>	<b>Once or twice a week</b>	<b>Once a month</b>	<b>Once a year</b>	<b>Never</b>
M4.	How often do you read news stories online?						
M5.	How often do you visit social media sites (e.g. Facebook, Twitter) online?						
M6.	How often do you visit health-related websites (e.g. WebMD)?						

M7. Thinking about the past 12 months, did you actively look for information about the HPV vaccine from doctors, other people, or from the media?

- Yes
- No
- I don't remember

M8. In the past 12 months, did you actively look for information about the HPV vaccine from any of the following sources (*Check all apply*)?

- Doctors or other health professionals
- Family, friends, or coworkers
- Television or radio
- Newspapers, magazines, or newsletters
- The Internet
- Other sources: \_\_\_\_\_

M9. Thinking about the past 12 months, did you hear or come across information about the HPV vaccine from doctors, from other people, or from the media even when you were not actively looking for it?

- Yes
- No
- I don't remember

M10. Thinking about the past 12 months, how many times did you hear or come across information about the HPV vaccine from each of the following sources?

	<b>Not at all</b>	<b>One or two times</b>	<b>Three times or more</b>	<b>I don't remember</b>
Doctors or other health professionals				
Family, friends, or coworkers				
Television or Radio				
Newspapers, magazines, or newsletters				
The Internet				

M11. In general, have you heard positive, negative, or neutral stories about the HPV vaccine in the media?

- Generally Positive
- Generally Negative
- Neutral
- I don't remember

M12. If you needed more information on the HPV vaccine, where would you go first?

- Doctors or other health professionals
- Family, friends, or coworkers
- Television or radio
- Newspapers/magazines
- The Internet
- Other Sources: \_\_\_\_\_

## Section II: General Opinions

In this section, you will read a list of statements describing different opinions on a variety of current topics in the United States. Please mark how much you agree or disagree with each of the statements. 5-point Likert Scale, 1=Strongly Agree, 5=Strongly Disagree.

O1	Whenever religion and science conflict, religion is always right.
O2	On the whole, technology is making our lives easier.
O3	On the whole, science is making our lives healthier.
O4	Technology is decreasing our ability to connect with other people in meaningful ways.
O5	It is not important for me to know about science in my everyday life.
O6	Most men are better suited emotionally for politics than are most women.
O7	If my party nominated a woman for President, I would vote for her if she were qualified for the job.
O8	A working mother can establish just as warm and secure a relationship with her children as a mother who does not work.
O9	A preschool child is likely to suffer if his or her mother works.
O10	It is much better for the family if the father works outside the home and the mother takes care of the home and children.
O11	Family life often suffers when men concentrate too much on their work.
O12	Men are better at making rational decisions than women.
O13	On a whole, men make better business executives than women do.
O14	Women are natural caretakers.
O15	Men should openly express their emotions.
O16	Women make better nurses than men do.
O17	Women make better scientists than men do.
O18	Women should wait to have sex until marriage.
O19	Men should wait to have sex until marriage.
O20	Same-sex couples should have the right to marry one another.
O21	It is wrong for an adult man and an adult woman to have sexual relations before marriage.
O22	It is wrong for a 16-year boy and a 16-year old girl to have sexual relations before marriage.
O23	It is wrong for a married person to have sexual relations with someone other than their marriage partner.
O24	It is wrong for two adults of the same sex to have sexual relations with each other at any time.
O25	Birth control should be available to teenagers between the ages of 14 and 16 even if their parents do not approve.
O26	Sex education should be taught in public schools.
O27	Sometimes it is necessary to discipline a child with a spanking.
O28	Abortion should be legal in all cases.
T1	All patients receive high quality medical care from the health care system in the United States.



T2	The health care system in the United States puts making money above patients' needs.
T3	Patients get the same medical treatment from the health care system in the United States—no matter what the patient's race or ethnicity.
T4	Patients get the same medical treatment from the health care system in the United States—no matter what the patient's income status.
T5	I trust doctors' decisions about which medical treatments are best.
T6	I trust doctors to tell me all the risks and benefits of medical treatments.
T7	I trust doctors to put the needs of patients before what is most convenient or best for them.
T8	I trust doctors to tell me if they are not certain about the risks and benefits of a certain medical treatment.
T9	All in all, I trust doctors completely.

### Section III: Opinions about Vaccines

In this section, you will read a list of statements describing different opinions about vaccines in the United States. Please mark how much you agree or disagree with each of the statements. Five-point Likert Scale, 1=Strongly Agree, 5=Strongly Disagree.

I1	Vaccines are more harmful than helpful
I2	The government should not have the right to force children to be vaccinated.
I3	Vaccines should be mandatory for all children.
I4	Tax dollars should be used to pay for vaccines for children who cannot afford the cost.
I5	Vaccines are pushed mostly to make money for drug companies.
I6	Vaccines have greatly improved the health of American citizens.
I7	We no longer need vaccines to protect us from diseases like polio because no one gets this disease anymore.
I8	Childhood vaccines are safe.
I9	Parents who decide not to vaccinate their children are putting other people's children at risk.
H1	I am concerned that the HPV vaccine costs more than I can pay.
H2	Both girls and boys should be vaccinated against HPV.
H3	Only girls should be vaccinated against HPV.
H4	Adults should also be vaccinated against HPV
H5	The HPV vaccine is safe.
H6	There is not enough scientific evidence that the HPV vaccine is safe.
H7	The HPV vaccine is being pushed to make money for drug companies.
H8	I think laws to require children to be vaccinated against HPV are a good idea.
H9	HPV vaccine should be available to teenagers between the ages of 14 and 17 even if their parents do not approve.

#### Section IV: Claims of the HPV vaccine

In this section, you will read statements describing claims made by different people about the HPV vaccine. Please mark **how much you believe** each of these statements to be true or false. Five-point likert scale from 1=Absolutely True to 5=Absolutely False

F1	The HPV vaccine protects against cervical cancer.
F2	The HPV vaccine protects against genital warts.
F3	Being infected with HPV may lead to cervical cancer.
F5	Being infected with HPV may lead to anal cancer.
F6	Being infecting with HPV may lead to neck and head cancer.
F7	The HPV vaccine, Cervarix, protects against only cervical cancer.
F8	The HPV vaccine, Gardasil, protects against both cervical cancer and genital warts.
F9	HPV is a sexually transmitted virus.
F10	The HPV vaccine may cause mental retardation.
F11	The HPV vaccine may cause children to have sex at an earlier age.
F12	Men who have sex with men are at higher risk of contracting HPV.
F13	HPV is only associated with cancers that affect women.
F14	There is only one type of HPV.
F15	Condoms are very good at preventing the spread of HPV.
F16	Girls who are vaccinated against HPV do not need to have regular pap smears as adult women.
F17	The HPV vaccines may cause autism.

#### Section V: Perceptions of Risk

R1. How informed do you consider yourself about the risks and benefits of childhood vaccines?

- Very informed
- Somewhat informed
- Neither informed nor uninformed
- Somewhat uninformed
- Very uninformed
- Not sure

R2. How informed do you consider yourself about the risks and benefits of HPV vaccination?

- Very informed
- Somewhat informed
- Neither informed nor uninformed
- Somewhat uninformed
- Very uninformed
- Not sure

R3. How effective do you think the HPV vaccine is in preventing genital warts?

- Not at all
- Slightly effective
- Moderately effective
- Very effective
- Extremely effective
- I don't know

R4. How effective do you think the HPV vaccine is in preventing cervical cancer?

- Not at all
- Slightly effective
- Moderately effective
- Very effective
- Extremely effective
- I don't know

*These questions are about your thoughts on developing cancer. If you have already had cancer in your lifetime, please answer the questions in relation to your perceived chance of developing cancer again.*

R5. What do you think your chance is of developing cancer in your lifetime (Between 0% = no chance of cancer and 100% = will definitely get cancer)?

R6. How would you rate your chance of developing cancer?

- Very Low
- Low
- Moderate
- High
- Very High

R7. Overall, how do you think your chance of developing cancer compares to the average woman or man your age?

- Much lower
- Lower
- About the Same
- Higher
- Much Higher

R8. How often do you worry about developing cancer?

- Not at all
- Rarely
- Sometimes
- Often
- All the time

R9. How much does worrying about developing cancer interfere with your everyday life?

- Not at all
- Rarely
- Sometimes
- Often
- All the time

**APPENDIX E: CNN REPUBLICAN PRESIDENTIAL DEBATE TRANSCRIPT<sup>46</sup>**

*BLITZER: Governor Perry, as you well know, you signed an executive order requiring little girls 11 and 12-year-old girls to get a vaccine to deal with a sexually transmitted disease that could lead to cervical cancer. Was that a mistake?*

*PERRY: It was. And indeed, if I had it to do over again, I would have done it differently. I would have gone to the legislature, worked with them. But what was driving me was, obviously, making a difference about young people's lives. Cervical cancer is a horrible way to die. And I happen to think that what we were trying to do was to clearly send a message that we're going to give moms and dads the opportunity to make that decision with parental opt-out. Parental rights are very important in state of Texas. We do it on a long list of vaccines that are made, but on that particular issue, I will tell you that I made a mistake by not going to the legislature first. Let me address Ron Paul just a minute by saying I will use an executive order to get rid of as much of Obamacare as I can on day one.*

*(APPLAUSE)*

*BLITZER: Congresswoman Bachmann, do you have anything to say about what Governor Perry just said. You're a mom.*

*BACHMANN: I'm a mom. And I'm a mom of three children. And to have innocent little 12-year-old girls be forced to have a government injection through an executive order is just flat out wrong. That should never be done. It's a violation of a liberty interest.*

*That's -- little girls who have a negative reaction to this potentially dangerous drug don't get a mulligan. They don't get a do-over. The parents don't get a do-over. That's why I fought so hard in Washington, D.C., against President Obama and Obamacare.*

*President Obama in a stunning, shocking level of power now just recently told all private insurance companies, you must offer the morning-after abortion pill, because I said so. And it must be free of charge. That same level coming through executive orders and through government dictates is wrong. And that's why again we have to have someone who is absolutely committed to the repeal of Obamacare and I am. I won't rest until it's appealed.*

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<sup>46</sup> Source: <http://archives.cnn.com/TRANSCRIPTS/1109/12/se.06.html>

*BLITZER: Let's let Governor Perry respond. Was what you signed into law, that vaccine for 11 and 12-year-old girls, was that, as some of your critics have suggested, a mandate?*

*PERRY: No, sir it wasn't. It was very clear. It had an opt- out. And at the end of the day, this was about trying to stop a cancer and giving the parental option to opt out of that. And at the end of the day, you may criticize me about the way that I went about it, but at the end of the day, I am always going to err on the side of life. And that's what this was really all about for me.*

*BLITZER: Senator Santorum -- go ahead.*

*BACHMANN: Can I add to that, Wolf? Can I add to that?*

*(CROSSTALK)*

*BLITZER: Hold on a second. First Congresswoman Bachmann, then Senator Santorum.*

*BACHMANN: I just wanted to add that we cannot forget that in the midst of this executive order there is a big drug company that made millions of dollars because of this mandate. We can't deny that...*

*(APPLAUSE)*

*BLITZER: What are you suggesting?*

*BACHMANN: What I'm saying is that it's wrong for a drug company, because the governor's former chief of staff was the chief lobbyist for this drug company. The drug company gave thousands of dollars in political donations to the governor, and this is just flat-out wrong. The question is, is it about life, or was it about millions of dollars and potentially billions for a drug company?*

*BLITZER: All right. I'll let Senator Santorum hold off for a second.*

*You've got to response to that.*

*PERRY: Yes, sir. The company was Merck, and it was a \$5,000 contribution that I had received from them. I raise about \$30 million. And if you're saying that I can be bought for \$5,000, I'm offended.*

*(APPLAUSE)*

*BACHMANN: Well, I'm offended for all the little girls and the parents that didn't have a choice. That's what I'm offended for.*

**APPENDIX F: HPV-RELATED ARTICLES PUBLISHED ON DR. MERCOLA WEBSITE  
2006-2013**

Article Title <sup>47</sup>	Publication Date
Feds approve unnecessary cervical cancer vaccine that will make drug company billions	15-Jul-06
More U.S. states considering HPV vaccine requirement	27-Jan-07
Will the HPV vaccine soon be mandatory for schoolgirls?	17-Feb-07
Opponents rally against Texas forcing sixth grade girls to receive unnecessary HPV vaccine	20-Feb-07
Growing controversy over new Merck vaccines	10-Mar-07
Gardasil reactions and deaths on the rise	24-Jun-07
Absurd vaccine marketing -- cervical cancer vaccinations for boys	18-Sep-07
Doctors in denial about vaccine reactions?	6-Oct-07
Thousands have gotten sick from Gardasil HPV vaccine	22-Dec-07
Is the rise in male oral cancer related to HPV?	8-May-08
The HPV vaccine: Preventive care or human sacrifice?	10-May-08
HPV vaccine blamed for teen's paralysis	2-Aug-08
Drug company marketing leads to HPV vaccine rise	9-Sep-08
Gardasil is dangerous as well as unproven	7-Oct-08
Prominent scientist warns of HPV vaccine dangers	25-Oct-08
How the U.S. government is covering up HPV vaccine side effects	15-Nov-08
Katie Couric reports on serious vaccine safety issues	19-Feb-09
Spain withdraws Gardasil after illnesses	24-Feb-09
Hundreds of thousands of reactions to Gardasil...Is your child next?	8-Aug-09
Inconvenient truths about Gardasil and swine flu vaccines	19-Sep-09
Grieving mother blames Gardasil	28-Jan-10
Time for the truth about Gardasil	17-Apr-10
Does Gardasil actually increase your risk of cervical cancer?	20-Jun-10
Don't give this to your daughter - despite what your doctor says	5-Nov-10

<sup>47</sup> Most of the articles (24/38) did not list an author. Of the 14 that list an author, Dr. Mercola is listed on 12 and Barbara Loe Fisher (president of National Vaccine Information Center) is listed on two articles.

The lethal medical failure that's still recommended by your doctor	29-Dec-10
60 lab studies now confirm cancer link to a vaccine you probably had as a child	18-Feb-11
Don't let your child be the next victim of this deadly vaccine	5-Apr-11
A parent's horrid nightmare: coming soon to YOUR state?	16-Sep-11
How vaccine policy & law threatens parental rights in America	26-Oct-11
49 sudden deaths, 213 permanent disabilities - And the silent plan to poison your child	29-Nov-11
213 women who took this suffered permanent disability	24-Jan-12
The worthless way to prevent cancer	29-Jan-12
This foolish cancer "prevention" may only extend your life by 2.8 days	13-Mar-12
This could give women deadly blood clots - US health officials admit	27-Mar-12
New evidence demolishes claims of safety and effectiveness of HPV vaccine	16-Oct-12
UBC researchers advocate HPV vaccine scrutiny	13-Nov-12
Avoidance of HPV vaccine may contribute to increase of some cancers?	24-Jan-13
US cancer death rates on the decline, but cancer incidence is still rising. Here's why...	26-Jan-13



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