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# “This Isn’t Like Diphtheria, You Know?”: The Sociocultural Context of Human Papillomavirus Immunization, Potential Mandates, and Narratives of Risk Among

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“This Isn’t Like Diphtheria, You Know?”: The Sociocultural Context of Human  
Papillomavirus Immunization, Potential Mandates, and Narratives of Risk Among  
Mothers

by

Hannah Louise Helmy

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Master of Arts  
Department of Anthropology  
College of Arts and Sciences  
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**“This isn’t like diphtheria, you know?”: The Sociocultural Context of Human Papillomavirus Immunization, Potential Mandates, and Narratives of Risk among Mothers**

Hannah Louise Helmy

**ABSTRACT**

Many in the biomedical community have praised the recently released Human Papillomavirus (HPV) vaccine, Gardasil, for having the potential to significantly reduce the disease burden of cervical cancer and genital warts. However, complex intersections of ideology, morality, and politics have made this new vaccine considerably contested, particularly as public debate has turned to the ethics of state-mandated HPV vaccination for 11-12 year old girls. Subsequently, the extent to which mandatory vaccinations are accepted by parents and implications regarding the infringement of these coercive measures on their rights to make health care decisions for their children has become powerfully positioned in public discourse. This research seeks to examine how mothers of girls conceptualize Gardasil and the potential mandates in order to illuminate the multi-faceted socio-cultural context of risk embedded within this immunization. Major themes that emerged from in-depth interviews include diverse perceptions of the risk of HPV for their daughter(s) specifically, children as actual or potential sexual beings, concerns about vaccine safety, mistrust of pharmaceutical companies and government collusion, and conceiving of vaccination against HPV as imbued with a either a moral or cancer prevention subtext. The need for collaboration and communication between the medical and governmental institutions who promote vaccines such as Gardasil and the public who politically and socially consumes them has been apparent throughout my research. Applied anthropologists have a unique role to play by situating diverse stakeholder perspectives across interdisciplinary fields in order to develop more appropriate and informed policies.

## **Chapter One: Introduction**

According to the Centers for Disease Control and Prevention, genital human papillomavirus, of which over 40 strains exist, is the most prevalent sexually transmitted infection (CDC 2008). Globally, genital HPV is estimated at approximately 440 million (World Health Organization 2008). In the United States, recent prevalence and incidence statistics indicate that about 20 million people currently have HPV infections, with 6.2 million people acquiring an HPV infection each year. The CDC estimates that approximately half of sexually active men and women will become infected with HPV at some point during their lives (2008). A recent study by Dunne and colleagues conducted with women and girls between ages of 14 and 59 (n=1921) found that the overall prevalence of HPV in their sample was 26.8 percent. Significantly, about 25 percent of females between the ages of 14 and 19 were currently infected with HPV (Dunne et al. 2007).

Genital HPV infections are often asymptomatic; however, certain strains of HPV have been causally linked with genital warts (Kahn 2005:S11). Additionally, epidemiological studies have established that certain strains of HPV are the necessary cause for the development of cervical cancer, with “high-risk” strains present in over 99 percent of these cases (Kahn 2005:S10). Cervical cancer incidence, prevalence and mortality rates have taken very different trajectories when comparing the United States and other developed nations with developing nations. This is largely due to the

effectiveness, availability, and usage of the Papanicolau, or Pap screening test. The World Health Organization estimates that the worldwide prevalence of cervical cancer is about 500,000, resulting in 250,000 deaths each year, “over 80 percent of which occur in developing countries, where neither population-based routine screening nor optimal treatment is available” (WHO 2008).

According to the American Cancer Society, the cervical cancer death rate in the United States declined by almost 75 percent between 1955 and 1992, during which time the Pap test was more widely used (ACS 2008). However, geographic and socioeconomic disparities still exist with regard to cervical cancer treatment and mortality in the United States (National Cancer Institute 2008). In 2008, The American Cancer Society estimates that 11,070 women will be diagnosed with invasive cervical cancer; of these women, they estimate that 3870 will die (2008). The most recent epidemiological data available for cervical cancer incidence in Florida indicated that in 2005, 910 women were diagnosed with cervical cancer; in 2007, 262 women in Florida died from cervical cancer (Florida Department of Health 2007a; Florida Department of Health 2007b).

In June of 2006, after years of research developing a vaccine that would protect against some strains of HPV, Merck Pharmaceuticals' Gardasil was approved by the Food and Drug Administration. The Gardasil vaccine protects against the two high-risk strains of HPV that lead to almost 70 percent of cervical cancers, and two low-risk strains that cause 90 percent of genital warts (HPV 16, 18, 6, and 11 respectively) (Kahn 2007:101). After the FDA approved Gardasil, it was presented to the CDC's Advisory Committee on Immunization Practices (ACIP). Subsequently, it was universally recommended for use in 11 to 12-year-old-girls (Kahn 2007:101). This range of ages

was chosen because Gardasil is most effective when administered before the onset of sexual activity (Constantine and Jerman 2007:2).

### **Anthropological Issues**

The research conducted for this thesis attempts to address several overarching anthropological issues within the sociocultural context of childhood immunization, and particularly the HPV vaccine Gardasil, from the perspectives of mothers of girls. Perhaps one of the most salient and relevant concepts relating to immunization is how risk is perceived and understood by the public who socially and politically consumes these biotechnologies. Anthropological research on risk in diverse areas of study has examined the ways in which it is differentially represented and contextualized by various stakeholders (Douglas and Wildavsky 1982; Pool and Geissler 2005; Leach and Fairhead 2007). Another issue of importance to this research is an exploration of the ways in which mothers conceive of and negotiate biomedicine as a cultural system. More specifically, examining the values motivating this particular kind of ethnomedicine regarding vaccines and disease prevention is of relevance for the research questions investigated in this thesis. A related theme in this research involves assessing the ways in which the biomedical community and parental perspectives on the purposes of immunization and the dissemination of vaccines are sometimes conflicting; an argument made in this paper is that an understanding of the ways in which parents interpret and negotiate vaccination is of significance to the biomedical community, even if they are not in agreement, because this discord has implications for health policy and public health education messages geared towards parents. Finally, the research conducted for this

thesis problematizes a prevalent but shifting perspective among public health professionals involved in vaccine acceptance research and vaccine delivery that simply providing parents with “correct” biomedical information regarding vaccines and thus “improving” their knowledge will increase vaccine acceptance and coverage rates.

## **Background**

The Gardasil vaccine was, for the most part, heralded by the scientific community as an important medical breakthrough. However, complex intersections of ideology, morality, and politics have made this new vaccine considerably contested, particularly as public debate has turned to the ethics of state-mandated HPV vaccination for 11 to 12-year-old girls. At the point of this writing, 43 states and the District of Columbia had introduced legislation that would either: 1) fund the HPV vaccine; 2) mandate the HPV vaccine for school entry; or 3) inform the public in some capacity about HPV (National Conference of State Legislatures 2008). Texas was the first state to mandate the vaccine for all sixth grade girls. There was such widespread public outcry over this decision that when the Texas legislature passed a bill to overrule the executive order, governor Rick Perry acquiesced to public opinion and did not utilize his power to veto the bill (National Conference of State Legislatures 2008). Virginia has also passed an HPV vaccine mandate, but it is unclear whether a new bill would push back the start date of that legislation (National Conference of State Legislatures 2008). Florida was one of the 24 states that introduced legislation mandating the HPV vaccine for 11 to 12-year-old girls. The bill (SB660), brought to the Florida state legislature in early 2007, would have made HPV vaccines a requirement for girls entering the 6<sup>th</sup> grade beginning in September of

2009. Amendments continued to be made on this bill throughout the spring of 2007, and it has since stalled in committee (The Florida Senate 2007). The ingenuity of this new vaccine, the first of its kind to protect against some strains of a sexually transmitted infection, combined with the introduction of a slew of mandatory HPV vaccination bills that followed have contributed to the widespread attention Gardasil has received in the media. Subsequently, the extent to which mandatory vaccinations are accepted by parents and the implications regarding the infringement of these coercive measures on their rights to make health care decisions for their children have become powerfully positioned in public discourse.

I came to the topic of HPV in general as a graduate research assistant in the College of Public Health at the University of South Florida. Several studies on which I worked while I was there examined various psychosocial aspects of HPV transmission and the impact an HPV vaccine would (or would not) have on reducing cervical cancer incidence and mortality. In the fall of 2006, I paid close attention to the extensive media coverage swirling around the release of the Gardasil vaccine. In particular, I was interested in the ways in which various “interest” groups such as parents, legislators, school officials, and spokespersons for conservative organizations framed their opinions about such a vaccine and the potential of it being made mandatory for all girls. For the purposes of the thesis research, I decided to narrow my focus to include parents, and specifically mothers, of girls, in order to explore their attitudes and beliefs regarding vaccination within the context of the HPV vaccine Gardasil.

The research conducted for this thesis examines how public health initiatives such as mandatory vaccines are conceptualized and negotiated by mothers of girls,

illuminating the socio-cultural context of immunizations and risk for children. While my focus lies with the HPV vaccine and potential mandates, I was also interested in exploring mothers' beliefs about other childhood vaccines and the ways in which the HPV vaccine is similar to and different from them. Additionally, I wanted to ascertain what mothers currently knew about the HPV vaccine and the mandates specifically to explore if knowledge had an effect on their attitudes about it. Finally, as the issues surrounding the HPV vaccine have been publicly conceptualized as largely a division between religion and science, I was interested in eliciting if, how, and to what extent mothers felt that their religious and/or political beliefs shaped their opinions and attitudes about the HPV vaccine and the possibility of it being made mandatory for their daughters.

### **Research Questions**

- 1) How are public health measures such as vaccine mandates understood and negotiated by mothers of girls?
- 2) What do mothers think about other vaccines that are mandatory and in what ways is the HPV vaccine similar to or different from them?
- 3) What do mothers know about the HPV vaccine in general and the mandates specifically, and what impact, if any, does this have on their attitudes about it?
- 4) To what extent do mothers feel their attitudes and beliefs about the HPV vaccine and its potential mandate are influenced by their political and/or religious beliefs? How?

In order to develop appropriate research questions and methodology and fill in relevant gaps in the literature, background research on what has currently been studied with regard to this new vaccine was conducted. In that vein, various public health reports



(Adams et al. 2007; Constantine and Jerman 2007; Dempsey et al. 2006; Gonik 2006; Kahn 2007; Lenselink et al. 2008; Mays et al. 2004; Ogilvie et al. 2007; Sturm et al. 2005; Waller et al. 2006; Zimet 2006) have assessed parental “acceptability” of the vaccine, as well as identifying obstacles to implementation. These studies have largely been based on responses to surveys (Constantine and Jerman 2007; Ogilvie et al. 2007; Lenselink et al. 2008). None of the studies I came across contained research on parental attitudes about a potential HPV vaccine mandate or mandatory immunizations in general. Also, much of the literature that touched upon the more “controversial” aspects of an HPV vaccine with regard to the sexual nature of HPV transmission and the ethics of state-mandated vaccination was speculative and not based on original research (Colgrove 2006a; Charo 2007; Dailard 2006; de Melo-Martin 2006; Monk and Wiley 2006). Finally, anthropology as a discipline has not contributed to the literature on HPV, HPV vaccines, or vaccine mandates, with the exception of a recent book by Leach and Fairhead (2007) on parental fears and concerns about vaccines in general.

The exploratory research conducted for this thesis attempts to bridge some of the gaps in the literature in several ways. First, rather than gathering quantitatively analyzed data, qualitative approaches, including semi-structured interviews and participant observation, have been employed. Also, research questions used to frame this study include exploring mothers’ attitudes about mandatory immunizations in general and a potential future HPV mandate specifically, both of which were absent from the literature. Finally, the study presented in this thesis incorporates methods commonly employed in anthropology such as participant observation and in-depth interviewing, as well as

theories and related research from the discipline in order to situate the multifaceted components of the topic more comprehensively.

### **Research Setting**

Participant observation conducted for this research occurred only once, at one day of a statewide immunization conference. Several sessions were attended and topics ranged from immunization and adolescents to challenges in immunization among rural populations. The majority of participants interviewed were from the general geographic locales of Plant City and south Tampa; the rest were from other more centrally located neighborhoods in Tampa, Lakeland, or St. Petersburg. Notably, then, the women interviewed for this study do not comprise a cohesive community, although smaller groups within them contain dense social networks. Several of the participants were interviewed in their homes, while others opted for a less intrusive interaction and met me at restaurants or coffee shops.

Plant City is a largely rural community located about 30 minutes outside of Tampa, while south Tampa, just south of downtown, is, comparatively, more urban and developed. My drives to both south Tampa and Plant City to meet participants in their homes or at restaurants were illuminating in terms of contextualizing the experiences shared with me within participants' geographic locales. The scenery changed significantly as I exited I-4 towards Plant City; farms and farm-related businesses and warehouses, local stores, and homogenous looking housing communities dotted the landscape. Conversely, an abundance of chain restaurants and shops, ranging from average to upscale, and older homes, many of which looked quite expensive, comprised

the surroundings in the areas in which I interviewed participants in south Tampa. Lack of a consistent research site created some difficult analytical and interpretive decisions; however, a standard research setting or cohesive community did not necessarily lend itself well to the topics I chose to investigate, so it was both a limitation and a practical reality of the study.

### **Outline of the Thesis**

Chapter two will present relevant literature in the fields of anthropology, public health, and bioethics regarding several large areas of interest relating to the context of vaccination. The first section will provide a historical background of immunization and vaccine mandates in the United States, which will be followed by a brief introduction to the “anti-vaccine” movement in the United States. A discussion of public health law and bioethics will follow in order to contextualize vaccine mandates and differing interpretations of the ethical implications of such requirements. The next two sections will describe perspectives of American biomedicine and socio-cultural vaccine and pharmaceutical research from the anthropological literature. The last section will briefly provide an epidemiological background on what is currently known about the Human papillomavirus and its connection to cervical cancer, as well as the political and social trajectory of the HPV vaccine Gardasil. Finally, this chapter will outline how the research conducted for this thesis fits into and expands upon recent research on HPV and Gardasil.

Chapter three will describe the methods employed in this study. Because of the newness of the HPV vaccine Gardasil and the lack of anthropological research conducted

on this topic, exploratory research was necessary. Semi-structured interviews with mothers of girls are the primary methodology utilized. Participant observation and a media analysis are also employed, the process of which will be discussed here. Additionally, the context of the research setting, sampling, recruitment, and a plan for analysis of the data will be included in this chapter.

Chapter four will describe the results of the three types of research methodologies utilized. First, an explanation of the findings from the media analysis will be offered. Next, impressions from the participant observation conducted at the statewide immunization conference will be discussed. Finally, the results from the semi-structured interviews with 25 mothers of girls will be presented.

Finally, chapter five will summarize and draw conclusions from the results presented in the previous chapter. In addition, findings from the study will be related to the disciplines of anthropology, applied anthropology, and public health. Limitations of this research project will also be described and recommendations to the issues outlined will then be offered.

## **Summary**

This thesis chapter introduced the overarching issues and topics that will be addressed in this research. These included epidemiological information on HPV and cervical cancer; an exploration of the sociocultural context of risk in childhood immunizations, particularly with regard to the HPV vaccine Gardasil and potential vaccine mandates; an examination of the ways in which mothers interpret and negotiate biomedicine as a cultural system with regard to vaccination; the ways in which

differential understandings of the values inherent in and importance of vaccination can produce tension between public health goals and parental desires regarding their children's health; and finally, the implications these topics have for health education strategies regarding vaccine acceptance. These topics were addressed in this study through participant observation at a statewide immunization conference; a media analysis of representations of the HPV vaccine Gardasil; and interviews with mothers in the Tampa Bay area about their perceptions of the HPV vaccine Gardasil and the potential for it to be made mandatory in the future for their daughters. Research was primarily conducted in the fall of 2007 and early spring of 2008. The remainder of this chapter presented a brief overview of topics to be covered in each subsequent chapter of this thesis.

## **Chapter Two: Literature Review**

### **Introduction**

This chapter will describe pertinent literature in the fields of anthropology, public health, and bioethics regarding several large areas of interest, which converge within the context of vaccination and are integral to a discussion of the thesis research. The first section will provide a historical background of immunization and vaccine mandates in the United States. This will be followed by a brief section on the anti-vaccine movement in the United States. Then, a discussion of public health law and bioethics will ensue to contextualize vaccine mandates and differing interpretations of the ethical implications of such requirements, including perspectives from anthropology. The next two sections will describe perspectives of American biomedicine and socio-cultural vaccine and pharmaceutical research from the anthropological literature. The last section will briefly explain what is currently known about the Human Papillomavirus and its connection to cervical cancer, as well as the political and social trajectory of the HPV vaccine Gardasil, which was FDA-approved in July of 2006. Finally, this chapter will explore how the study conducted for this thesis fits into and expands upon recent research on HPV and the HPV vaccine Gardasil.

### **History of Mandatory Vaccination in the United States**

To use Lawrence Gostin's modern definitions,

...Vaccination is the administration of a vaccine or toxoid used to prevent, ameliorate, or treat infectious disease. A vaccine is a suspension of attenuated or noninfectious microorganisms (bacteria, viruses, or rickettsiae) or derivative antigenic proteins. (2000:180)

Edward Jenner developed the first vaccine, for smallpox, in 1796, which was subsequently brought to the United States in 1801 (Colgrove 2006b:6). Despite the risks involved in small pox immunization, the effectiveness of the vaccine encouraged lawmakers in America to make it mandatory. In 1809, Massachusetts was the first state to require small pox inoculation. By the early 1900s, many states had compulsory small pox vaccination laws (Gostin 2000:181).

Historically, the use of vaccines in the field of medicine was controversial and contentious to some factions. However, vaccinations have and continue to be a widely used preventative public health approach due to their efficacy at reducing disease burden and their relatively inexpensive implementation (as compared with secondary and tertiary prevention strategies) (Gostin 2000:180). Criticism about vaccination has continued to the present day. Opponents of vaccines have cited several concerns about this public health measure, which include vaccine efficacy, harm caused by the vaccination (including the spread of diseases), and religious or philosophical opposition. Some have also seen mandatory vaccination as an imposition of the State on people's autonomy and freedom (Gostin 2000:180). To illustrate the persistent popular concern over immunization that continues in our current society, a recent cover of TIME magazine from May of 2008 asked the question, "How Safe are Vaccines?" Inside, the article (Park

2008) delved into many of the same issues raised historically about the safety of vaccines, in addition to addressing the widespread public perception that autism and vaccines are related. These issues will be explored further in a subsequent section of this chapter on the anti-vaccine movement in the U.S.

Immunization standards of more recent times were developed to address measles transmission in schools during the 1960's, which was largely influenced by lower incidence rates of measles in states with immunization laws (Gostin 2000:181). Thus, instead of requiring immunizations in emergency situations such as disease outbreaks, as many states had previously done, legislatures turned to state health departments to require mandatory immunization of certain diseases for attendance in school and licensed day care centers (Gostin 2000:181). James Colgrove, a research scientist at Columbia University who studies vaccine politics and public health ethics writes,

These laws have been challenged both on their foundations and in their particulars, but for the most part have been remarkably well accepted by the public and successful and increasing coverage rates among school-aged youth. The use of persuasion remained a cornerstone of vaccination programs, with school laws serving in the eyes of health officials as a kind of societal safety net to catch the children of the 'hard to reach.' (2006b:12)

In the last two decades, the National Childhood Vaccine Injury Act (1986), the Comprehensive Childhood Immunization Act (1993), and the creation of State Immunization Registries have been introduced to support the infrastructure and provision of vaccines and vaccination policy, which many public health professionals widely consider to be the most cost-effective preventive infectious and communicable disease



strategy (Gostin 2000:184-5). Currently, recommendations are made from the CDC-based Advisory Committee on Immunization Practices (ACIP), which puts forth a list of recommended vaccinations that are then adopted by medical associations such as the American Academy of Pediatrics and the American Medical Association. Notably, all states have required immunization laws for school entry for certain diseases: diphtheria, measles, polio and rubella (Gostin 2000:181; Isaacs et al. 2003:392). In Florida and many other states, new vaccines have been added as requirements for school entry (as of 2001), including one for chicken pox (Varicella) and another for Hepatitis B (Florida Department of Health 2007c). As of 2006, more than 24 vaccines were in use; of those, 14 have been universally recommended by ACIP for children (Colgrove 2006b:2).

Virtually all states (48) have included exemptions (sometimes called “opt-outs”) to their immunization laws whereupon children can be excused from mandatory vaccinations, including if their physician feels they will experience an adverse reaction to the vaccine or if parents have a religious belief against vaccination (Gostin 2000:181; Isaacs et al. 2003:392). Fewer states (approximately 20) also have exemptions for parents who are opposed to vaccination for philosophical reasons, which can include moral, personal, or other beliefs (Isaacs et al. 2003:392). Each state decides individually how to handle these exemptions to mandatory vaccination, and the rigor of each state’s process to obtain it is variable (Gostin 2000:181-2). In Florida, religious and medical exemptions are allowed (forms must be filled out and returned to county health departments), but exemptions on philosophical or moral grounds are not permitted

(Florida Department of Health 2007c).

The extent to which parents' decisions on this issue are respected and supported by their child's physician, the state of residency, and/or the school district is variable. In some states, parents who continually decline required vaccinations could be threatened with childcare proceedings (Isaacs et al. 2003:392). In November of 2007, hundreds of parents in Prince George County, Maryland, were sent letters from the county threatening their children's removal from the school system, potential jail time, and fines unless the children were immunized or they indicated proof of immunization as required by state law. Parents were strongly encouraged to bring their children to the courthouse to provide immunization documentation or receive the state's mandatory vaccinations. There appeared to be little public awareness that opting out was possible, nor of the process involved to do so (Abruzzese 2007:1).

As mentioned previously in this chapter, one of the reasons parents may oppose mandatory vaccination is infringement upon religious beliefs; however, Gostin argues that the Supreme Court has previously ruled that, in fact, religious beliefs can and ought to be superceded when a community or child has the potential to be exposed or to expose others to a communicable disease (2000:182). He clarifies, "States are not constitutionally obligated to grant religious exemptions, but are permitted to do so" (Gostin 2000:183). Additionally, states have different ways of determining "legitimate" religious exemptions, including only accepting them from particular "recognized" denominations or churches and "insisting that the belief against compulsory

vaccination...be ‘genuine,’ ‘sincere,’ and an integral part of the religious doctrine” (Gostin 2000:183). A recent USA Today article (LeBlanc 2007:1) describes the increase in the number of American parents opting out of mandatory vaccines on religious grounds, despite not actually having religious objections to immunization. Rather, the parents’ objections to vaccines centered on fears that they would produce negative side effects. The justification utilized by several parents featured in the article was that vaccination laws make it difficult to opt out for other reasons besides medical adverse reactions and religious exemption.

### **The Anti-Vaccine Movement**

James Colgrove (2006b) recently wrote a book on the history of immunization politics in America through the 20<sup>th</sup> century. State of Immunity chronicles the use of vaccines, their opponents and advocates, strategies implemented to increase vaccine acceptance, and the ethical issues surrounding legally mandating certain vaccines. He argues that one of the major differences between vaccines and other medical interventions that may contribute to controversy about their use is that vaccines are given to healthy people (Colgrove 2006b:2). Additionally, “Because the benefit vaccination offers—the absence of disease—is a “negative” or unapparent one, its risks, though rare, seem more salient” (Colgrove 2006b:8). In his book, Colgrove cites a nationwide survey conducted in 1999 which indicated that while the majority of those surveyed expressed positive attitudes towards immunization and the utility of vaccines for their children,

about 25 percent felt that too many vaccines would undermine a child's immune system and that children received more vaccinations than they should (Gellin et al. 2000). Public anxiety about vaccines is certainly not new, but different concerns have entered the debate that center on not only the safety of vaccines, but also the integrity of the medical profession. Colgrove writes,

Reminiscent of the diversity of vaccination dissidents during the Progressive Era, the modern generation of activists [at the turn of the twenty-first century] encompassed a range of political and philosophical views but was united in its antagonism to compulsion. The most vocal segment was made up of parent groups who rejected the risk-benefit calculations that had long been used to justify routine immunization. (2006b:219)

According to Colgrove, by 2000, the typical two-year-old American child had received 11 vaccines in potentially 20 injections (2006b:227). Numerous health concerns, from allergies to juvenile diabetes, began to be blamed directly or indirectly on the increase of childhood vaccinations. Autism, however, has received the most widespread attention in its supposed link to vaccines (Colgrove 2006b). In 1998, the *Lancet* journal published what is now a largely debunked report (Wakefield et al. 1998), the results of which indicated a relationship between autism and the MMR (measles-mumps-rubella) vaccine (Colgrove 2006b:229). This report and others in its wake spurred parent activists to demand that the link be investigated further (Colgrove 2006b:230). These claims contributed to the increasing numbers of individuals and groups who were growing wary of the safety of vaccines and questioned pharmaceutical companies' and health officials' motives in promoting them (Colgrove 2006b:219).

Additionally, a common preservative containing mercury used in many vaccines, Thimerosal, was criticized during this time and subsequently removed from childhood vaccines due to concerns about mercury exposure in children (Colgrove 2006b:231-2). Because of these various concerns with vaccination and several others not delved into here, committee hearings held by the U.S. House of Representatives began in 1999 regarding vaccine safety (Colgrove 2006b:3). Various reports have been written since that time, which investigated the relationship between vaccines and a number of diseases, including autism (Colgrove 2006b:234). The evidence has consistently tended to support the idea that vaccines are “safe.” This information has not, however, had much of an impact on the small but growing anti-vaccine movement in the U.S. (Colgrove 2006b). The following section will address the larger ethical conflict inherent in mandatory vaccinations – the public’s health, parental rights and autonomy, as well as describe anthropology’s contribution to this discussion.

### **The Ethics of Mandatory Vaccination**

On “American character,” Bulger and colleagues write,

Our nation was born in rebellion against tyranny to preserve individual liberty; tension between the powers of the state and the rights of the individual has persisted, and it colors the public debate and resolution of major moral issues. Ambivalence about the proper role of government, together with a fervent belief in the power and ultimate triumph of individual efforts, is manifested in a pluralistic approach to political, social and ethical issues... (1995:43)

The ethical context surrounding mandatory vaccination in America is one such example of the ways in which state control and civil liberties have clashed and created frequently intense periods of public debate. The Supreme Court and other judiciary committees have historically supported mandatory vaccination for certain diseases on the grounds of “communal well-being,” arguing that it is within state’s rights to mandate it, in addition to upholding laws that require vaccination for school entry (Gostin 2000:182). As a discipline, public health credits compulsory vaccination laws with high rates of complete immunizations for children – roughly 95 percent in the United States. Morbidity and mortality for what were once considered debilitating and life threatening childhood illnesses, such as polio, have been reduced drastically (Gostin 2000:183). Gostin writes,

Perceptions differ sharply depending on whether the risk of vaccination is viewed from an individualistic or societal perspective...The state is explicitly asking parents to forgo their right to decide the welfare of their children not necessarily for the child’s benefit, but for the wider public good. (2000:183)

If enough people in a community are vaccinated, herd immunity can occur against communicable diseases that are transmitted only through human-to-human contact. When parents are given the choice to not vaccinate their children, this phenomenon loses its efficacy (Gostin 2000:184). What is essentially at stake here, Gostin articulates, are “the trade-offs between public goods and private rights, and the dilemma of whether to use coercive or voluntary public health measures” (2000:xix). Autonomy and individualism, highly valued attributes in American society, “...holds [sic] that people who are able to make decisions for themselves have the right to determine their own course of action,

even when they refuse medical treatment, and that others have the obligation to respect their decisions” (Muller 1992:451). Furthermore, Colgrove writes,

Other regulations that limited individual liberty in order to protect the common good generally required that people refrain from an action or behavior. Vaccination, in contrast, required people to submit to a procedure, one that involved discomfort and whose safety and efficacy remained uncertain in the minds of many. (Colgrove 2006b:10)

In recent years, anthropologists have contributed their perspectives to the discipline of bioethics (Marshall 1992; Muller 1994). Historically, bioethics in the United States has been rooted in and valued individualism, autonomy, and a “common morality” (Marshall 1992; Muller 1994; Turner 2003). As subjective as “morality” may be, for the purposes of its use in bioethics, it can be conceived of as encompassing secular, religious, and professional values and traditions, which cannot be neatly separated from each other (Campbell 1990:9). Leigh Turner, a bioethicist, criticizes his discipline’s frequently one-sided assessment of ethics in biomedicine, arguing that in multi-ethnic and faith societies such as the United States, “it is unsurprising that biomedicine and the body become sites for profound, far-reaching disputes about morality and the boundaries of acceptable behavior” (2003:114).

In conjunction with a paradigm shift in bioethics that problematizes “the priority given to autonomy and individualism,” anthropologists have more recently contributed a unique perspective by bringing cultural relativity, cultural context, and an absence of so-called (and some would argue non-existent) common morality to current bioethical debates about health and illness (Marshall 1992:52-4). Marshall sees the importance of

anthropology in bioethics “through the comparative study of the moral aspects of medical standards and the cultural construction of health and illness beliefs” (1992:57).

Additionally, by situating ethics within a cultural, historical, and social framework “that regulate[s] both the definition and resolution of moral quandaries,” the debate can perhaps shift from one intrinsic value versus another, into a more reflexive and productive discourse that more accurately describes the complexity of these issues (Marshall 1992:62; see also Muller 1992).

### **Risk and Anthropology**

Mary Douglas’ contributions to anthropological theory on risk are also of relevance to the topics of immunization and vaccine mandates. Her work with Aaron Wildavsky, *Risk and Culture: An Essay on the Selection of Technical and Environmental Dangers* (1982) examines how some dangers are selected and others ignored by society. While much of the book focuses this discussion on pollution and other environmental issues, as the title suggests, introductory information about risk and risk perception is very applicable to the literature on vaccines as well. Douglas and Wildavsky write,

The current consideration of risk has three peculiarities. The first is that disagreement about the problem is deep and widespread in the Western world. The second is that different people worry about different risks – war, pollution, employment, inflation. The third is that knowledge and action are out of sync: whatever programs are enacted to reduce risks, they conspicuously fail to follow the principle of doing the most to prevent the worst damage. In sum, substantial disagreement remains over what is risky, how risky it is, and what to do about it. (1982:1)



Importantly then, as Douglas and Wildavsky succinctly state, “Since there is no single correct conception of risk, there is no way to get everyone else to accept ‘it’” (1982:5). Because vaccines both protect against a disease which the medical community has defined to be dangerous and entail a certain amount of risk in their implementation, critiquing the notion of risk itself is necessary.

In their discussion of situated risk, medical anthropology, and HIV/AIDS, anthropologists Pool and Geissler (2005) write,

Anthropological research on HIV/AIDS has moved from a narrow focus on individual behavior to a broader consideration of the cultural setting in which this behavior takes place. It has also made it clear that many of the theoretical models of behavior, taken uncritically from social psychology, which focus on the individual and assume a rational basis for decision making, are inadequate. (2005:65)

Similarly and with respect to vaccines and risk, anthropologists Leach and Fairhead contend that the technical, objective approach to risk which assumes that people are aware of and are motivated by probabilities of real events, is a central theme in debates about vaccination and policy (2007:26). They argue,

This approach often presumes a conflict of interest between rather singular visions of the individual and public good; between being selfish and public-spirited. Yet people belong to many social worlds. Important as the ongoing debate about individual versus social risks and benefits is, it overlooks the variety of collectivities and forms of common good that people may already be part of, and that shape their thinking and practice around engaging with technologies. (Leach and Fairhead 2007:26)

## **American Biomedicine**

In examining biomedicine, anthropologists have attempted to define and characterize it not only as one particular kind of ethnomedicine, but also one in which “...like all ethnomedicines...is rooted in cultural presuppositions and values, associated with rules of conduct, and embedded in larger societal and historical context” (Hahn 1996:132). While medicine is obviously influenced by science, and indeed most would argue is its primary foundation, culture dictates much of its manifestations as well (Payer 1988; see also Casper and Koenig 1996).

In the 1980’s, Lynn Payer contrasted the American medical system with other biomedical systems in Western Europe (France and England) and the ways in which similarities and differences occur due to, what she believes, is culture. The utility of this exercise demonstrates that biomedical approaches are not consistent across the board, nor are they informed entirely by empirical and objective science; “...our [American] medicine is not the inevitable result of medical progress but of choices—conscious or not—that arise from our own cultural biases” (Payer 1988:152). These choices, including the ways in which American biomedicine has come to identify and characterize disease, prevention, and health have important implications for a study about perceptions of vaccines, particularly one which aims to prevent some strains of a sexually transmitted infection.

Paraphrasing Howard Stein’s work, *American Medicine as Culture* (1990), Baer and colleagues write,

Within the U.S. context, biomedicine incorporates certain core values, metaphors, beliefs, and attitudes that it communicates to patients, such as self-reliance, rugged individualism, independence, pragmatism, empiricism, atomism, militarism, profit-making, emotional minimalism, and a mechanistic concept of the body and its repair. (Baer et al. 2003:12)

Payer relates an assessment of aggressiveness seen in our American brand of biomedicine to “an aggressiveness of the American character” (1988:127). One result of the frontier lifestyle and overcoming various elements in nature during our country’s founding, she argues, was the way in which medicine was approached and diseases treated. She writes, “Disease could also be conquered, but only by aggressively ferreting it out diagnostically and just as aggressively treating it, preferably by taking out rather than adding something to increase the resistance” (1988:127).

Relating to this notion of aggression in the treatment of illness, Payer argues that American medicine frequently conceptualizes the body as a machine (1988:32).

From birth—which is more likely to be by cesarean than anywhere in Europe—to death in hospital, from invasive examination to prophylactic surgery, American doctors want to *do* something, preferably as much as possible. (Payer 1988:124)

Hahn’s perspectives on biomedicine as a cultural system also reflect this observed aggressive “can do” notion of action above knowledge and doing *something* rather than not doing anything (1996:152). In relation to immunization practices in particular, Payer argues that American medicine’s goal is eradication of the disease, not the protection of individuals (1988:126). Finally, the concept of paternalism is evident in biomedicine, particularly, as Hahn argues, within the doctor-patient relationship. He writes,

That...patients are “entrusted to” the care of physicians and that physicians may abrogate confidentiality to protect the patient indicates a paternalism in which the

physician, better than the patient, may be thought to know and judge what is best for the patient. (Hahn 1996:143)

Paternalism in biomedicine also has relevance for immunization practices, as individuals' risks and perceptions of risk for certain diseases are determined for them, and, in many American instances, require parents to legally submit to federal and state public health laws for their children's health.

### **Anthropological Research on Medications and Vaccines**

Anthropologists Whyte, Van der Geest, and Hardon have conducted extensive research on the "study of medicines," and particularly, on their socio-cultural implications in various far-reaching contexts. While not focused on vaccines specifically, their research on consumers of pharmaceuticals in Western contexts has significant parallels to many of the social issues confronting vaccines. According to Whyte and colleagues, consumers of Western medications have become increasingly more skeptical of their use due to perceptions of them as toxic or unnatural, among other justifications (2002:63).

They further explain that, "Scepticism [sic] towards medicines in industrialized countries gained momentum in the 1970s when criticism of biomedicine in general grew under the influence of publications about doubtful medical practices..." (Whyte et al. 2002:67). In addition, there was an increasing criticism of pharmaceutical products due to their commercial manufacture (Whyte et al. 2002:67). As a result,

Pharmaceutical companies – and in their wake, medical doctors – were accused of putting profits before health. Thus, the critical attitude towards medicines as potentially dangerous substances was reinforced by the argument that pharmaceuticals were made for profit as much as for therapy. (Whyte et al. 2002:67-8)

Perhaps not too surprisingly, American parents and activist groups who have voiced concerns about vaccines (Colgrove 2006b) have used similar justifications as those explained by Whyte et al. (2002).

Historically, the discipline of anthropology has not contributed much to the literature on vaccination; however, in 2007, Melissa Leach and James Fairhead wrote a book entitled, Vaccine Anxieties: Global Science, Child Health and Policy, which described the complex constellation of factors, both global and local, impacting fears and concerns about vaccines in England and the Gambia, specifically. Through years of work in European and African contexts, the authors' research on vaccination aims to explore:

How parents understand and experience...bodily, social and wider political dimensions of vaccinations...not least because parents' own views and experiences have so often been submerged and obscured by dominant biomedical and policy framings of vaccination issues. (Leach and Fairhead 2007:10)

The authors argue that several key concepts or arguments emerged in the studies conducted intending to examine parents' conceptions of vaccines. These are ignorance and misunderstanding of science, risk, trust, rumor, and resistance (Leach and Fairhead 2007). A perception that parents wary of or opposed to vaccines are simply lacking the information they need to make logical, scientific decisions is a theme of the first key concept, mistrust and misunderstanding of science (Leach and Fairhead 2007). The authors also challenge the "narrow, technical approach to risk" that, taken uncritically, renders invisible the ways in which parents frame and estimate risk for their children

(Leach and Fairhead 2007). According to the authors, the key concept of trust assesses the perception that societies are, in fact, experiencing more suspicion and doubt and that this lack of trust in medical establishments is at least somewhat responsible for vaccine “anxieties” (Leach and Fairhead 2007). The concepts of rumor and resistance question the ways in which parental concerns become represented as “unsubstantiated gossip” in vaccination discourse. Additionally, these concepts examine how parents may choose to defy vaccines themselves and/or the politico-medical ideologies vaccines may represent (Leach and Fairhead 2007). Unlike numerous public health studies on parental “acceptance” of vaccination, which typically address knowledge deficits and “misinformation,” Leach and Fairchild’s work situates parents’ concerns within their social worlds and serves to powerfully elucidate why it is critically important to understand how vaccines are framed and conceptualized by the various groups who socially and politically consume this bio-technology (2007).

### **HPV and Gardasil**

The current controversy surrounding the recently FDA approved Human Papillomavirus (HPV) vaccine (Merck and Co.’s Gardasil) serves to underscore aspects of and issues contained in the preceding literature review on values of compulsory vaccination, ethical debates surrounding autonomy and the public’s health, and critical perspectives of American biomedicine. Additionally, it raises both significant and

sensitive issues regarding adolescents and sexuality, which further obfuscates how the HPV vaccine is conceptualized and received.

The HPV vaccine Gardasil was approved in June of 2006 after years of research on the link between HPV and cervical cancer (Kahn 2005:S15). Epidemiological studies have established that certain strains of HPV are implicated in virtually all cases of cervical cancer, with high-risk strains present in over 99 percent of these cases (Kahn 2005:S10). Additionally, certain strains of HPV have been causally linked with genital warts (Kahn 2005:S11). The Gardasil vaccine produced by Merck Pharmaceuticals protects against the two high-risk strains of HPV that lead to almost 70 percent of cervical cancers, and two low-risk strains that cause 90 percent of genital warts (HPV strains 16, 18, 6, and 11 respectively) (Kahn 2007:101). After its FDA approval, Gardasil was taken up by the CDC's Advisory Committee on Immunization Practices, and universally recommended for use in 11 to 12-year-old-girls, though the vaccine was clinically tested and licensed for females ages 9 to 26 (Kahn 2007:101). This age cohort was chosen because the vaccine is most effective when it is administered before sexual activity is initiated (Constantine and Jerman 2007:2).

While the vaccine was, for the most part, well received by the medical community and heralded as an important scientific breakthrough, it was clear that an assessment of parents, adolescents, and other groups who would have a vested interest in the vaccine needed to be conducted. Various public health reports (Adams et al. 2007; Constantine and Jerman 2007; Dempsey et al. 2006; Gonik 2006; Kahn 2007; Lenselink et al. 2008;

Mays et al. 2004; Ogilvie et al. 2007; Sturm et al. 2005; Waller et al. 2006; Zimet 2006) have assessed parents' "acceptability" of the vaccine (both hypothetically before FDA approval and afterwards), as well as identifying obstacles to implementation. Some of these articles shared original research, while others conducted literature reviews, approaching the topic from a more theoretical standpoint. These articles also offered points to consider and recommendations for increasing the acceptability of HPV vaccines.

Results of the studies have been mixed. Most have indicated that the majority of parents (sometimes only mothers were sampled) would vaccinate their daughters against HPV, but the rates at which vaccination would occur and the ways in which investigators obtained and reported this data varied from study to study. One study said that participants "broadly" favored HPV vaccination with some reservations (Waller et al. 2006). Other studies expressed these data in terms of percentages, which ranged from 70 percent to 88 percent (Constantine and Jerman, 2007; Ogilvie et al. 2007; Lenselink et al. 2008). Additionally, of the five original research studies described in this thesis, three were conducted outside of the United States, in the United Kingdom, Canada, and the Netherlands (Waller et al. 2006; Ogilvie et al. 2007; Lenselink et al. 2008). A continual theme among all of the reports was a concern, either expressed by parents themselves or presented in the literature reviews, about whether this vaccine would promote or encourage increased teenage sexual activity (Adams et al. 2007; Constantine and Jerman 2007; Dempsey et al. 2006; Gonik 2006; Kahn 2007; Lenselink et al. 2008; Mays et al.



2004; Ogilvie et al. 2007; Sturm et al. 2005; Waller et al. 2006; Zimet 2006). Other concerns were presented regarding the safety and/or newness of the vaccine, perceptions that an HPV vaccine was not relevant to their daughter, and parental attitudes towards vaccination in general (Kahn 2007; Waller et al. 2006; Dempsey et al. 2006; Ogilvie et al. 2007; Adams et al. 2007; Lenselink et al. 2008; Sturm et al. 2005; Zimet 2006).

As briefly discussed above, one of the reasons why the HPV vaccine, mandatory or not, is particularly contentious is because it offers protection against some strains of a sexually transmitted infection. As a result, there has been massive media coverage about the “wrong” messages it may send to young girls (see Chapter 4 for results of a media analysis). Researchers Monk and Wiley (2006) address this concern in their commentary, “Will Widespread Human Papillomavirus Prophylactic Vaccination Change Sexual Practices of Adolescent and Young Adult Women in America?” The authors argue that other preventive health measures such as increased access to emergency contraception (EC) over-the-counter and vaccinating the entire population against Hepatitis B have not resulted in an increase of “risky” behaviors (Monk and Wiley 2006). Therefore, to assume that HPV vaccination will promote sexual promiscuity among women and girls is unrealistic (Monk and Wiley 2006). Requiring an HPV vaccine for school entry only serves to exacerbate the issues. In a recent report by the Guttmacher Institute, Cynthia Dailard explains,

...the cervical cancer vaccine could become the next battlefield in the social conservatives’ crusade to advance an abstinence-only-unless-married agenda, and...leading activists would be working to ensure that it would meet the same

regulatory fate as efforts to bring emergency contraception over the counter. (2006:8-9)

Perhaps not too surprisingly, when legislators and officials at the CDC attempted to make the Hepatitis B vaccine mandatory in the late 1990's, similar debates involving which populations should receive it and the ethics of mandating a vaccine against a sexually transmitted infection were promulgated (Sharfstein 2000:768; Colgrove 2006b:2390). During the Committee meetings held by the U.S. House of Representatives on vaccine safety, the Hepatitis B vaccine was one of the first to come under attack because of a purported link between the vaccine and sudden infant death syndrome (SIDS) and multiple sclerosis (MS) (Colgrove 2006b:231). The additional association of Hepatitis B with sexual contact and injection drug use created further contempt for such a vaccine to be mandatory (Colgrove 2006b:231). One activist at the hearing was quoted as saying,

Almost every newborn baby is now greeted on its entry into the world by a vaccine injection against a sexually transmitted disease because they couldn't get the junkies, prostitutes, homosexuals, and promiscuous heterosexuals to take the vaccine. (Colgrove 2006b:231)

Several articles on the ethics of mandatory HPV vaccination have also been published since Gardasil received FDA approval in 2006 (Colgrove 2006a; Charo 2007; de Melo-Martin 2006). All of these articles delve into the concerns raised by the popular news media and parental acceptability studies. In particular, the authors discuss the fact that the solely sexual transmission of HPV differentiates this vaccine mandate from other mandates in the past to many in the public (Colgrove 2006a; Charo 2007; de Melo-Martin

2006). Additionally, however, Colgrove (2006a) argues that it would be a mistake to view HPV vaccine mandates “as solely, or even primarily, evidence of a conflict between science and religion” (Colgrove 2006a:2389). Critical considerations include some parents (and influential activist groups representing them) wishing to make the circumstances for opting out of mandatory vaccines more liberal for various reasons not necessarily related to religious or conservative agendas, including:

...Devotion to “natural” or alternative healing, libertarian opposition to state power, mistrust of pharmaceutical companies, belief that vaccines are not as safe as experts claim, and conviction that children receive more shots than are good for them. (Colgrove 2006a:2390)

By the end of 2006, despite persistent concerns as to its controversial implications, it was apparent that some type of legislation regarding the HPV vaccine Gardasil was going to be initiated in some states. At the point of this writing, 43 states and the District of Columbia had introduced legislation that would either: 1) fund the HPV vaccine; 2) mandate the HPV vaccine for school entry; or 3) inform the public in some capacity about HPV (National Conference of State Legislatures 2008). At least 17 states have passed some form of legislation that addresses one of these policies. Of the initial 43 states and D.C., 24 of them and D.C. introduced bills to expressly *require* the HPV vaccine for school entry (National Conference of State Legislatures 2008). Texas was the first state to mandate the vaccine for all sixth grade girls, through an executive order by governor Rick Perry. This decision received such widespread public outcry that when the Texas legislature passed a bill to overrule the executive order, the governor acquiesced to public opinion and did not utilize his power to veto the bill (National

Conference of State Legislatures 2008). Virginia has also passed an HPV vaccine mandate, but it is unclear whether a new bill would push back the start date of the legislation (National Conference of State Legislatures 2008). Florida was one of the 24 states that introduced legislation mandating the HPV vaccine for 11 to 12-year-old girls. The bill (SB660), brought to the Florida state legislature by Senator Fasano early in 2007, would have made HPV vaccines a requirement for girls entering the 6<sup>th</sup> grade beginning in September of 2009. Amendments continued to be made on this bill throughout the spring of 2007, and it has since stalled in committee (The Florida Senate 2007).

In conclusion, recent studies on parental acceptability of the HPV vaccine Gardasil cited in this chapter have been largely based on responses to surveys, administered either by telephone or in person (Constantine and Jerman, 2007; Ogilvie et al. 2007; Lenselink et al. 2008). Additionally, none of the studies mentioned in this chapter contains research on parental attitudes about a potential HPV vaccine mandate or mandatory immunizations in general. Also, much of the literature that touched upon “controversial” aspects of an HPV vaccine presented in this chapter from the disciplines of public health and bioethics was speculative. In other words, many of these academic articles were commentaries or opinion pieces regarding public perceptions about the HPV vaccine and/or potential mandates that were not based on original research (Colgrove 2006a; Charo 2007; Dailard 2006; de Melo-Martin 2006; Monk and Wiley 2006). Finally, Anthropology as a discipline has not contributed to the literature on HPV, the vaccine, or vaccine mandates, with the exception of Leach and Fairhead’s research (2007) on parental fears and concerns about vaccines in general.

The exploratory research conducted for this thesis attempts to bridge some of

these gaps in the literature in several ways. First, rather than gathering data to be quantitatively analyzed, qualitative approaches, including semi-structured interviews and participant observation, have been employed. This approach produces a deeper context in which to analyze the overarching research questions. Also, research questions used to frame this study include exploring mothers' attitudes about mandatory immunizations in general and a potential future HPV mandate specifically. Additionally, a media analysis was conducted in order to assess popular messages presented to the public regarding HPV and Gardasil. This information was then used to develop interview questions to examine mothers' attitudes and beliefs regarding these major themes found in the mainstream news media. Finally, the study presented in this thesis incorporates methods commonly employed in Anthropology such as participant observation and in-depth interviewing, as well as theories and related research from the discipline in order to situate the multifaceted components of the topic more comprehensively.

## **Conclusion**

Diverse perspectives, belief systems, and worldviews regarding the socio-cultural context of vaccines lend themselves to socially and politically contentious terrain. This chapter outlined pertinent background material on vaccine policy, ethical implications of vaccine mandates, the culture of biomedicine in America, constructions of risk in anthropology, and socio-cultural research on medications and vaccines. Also, public perceptions of and academic contributions about HPV and the HPV vaccine Gardasil were explored. The next chapter will explain the research questions underlying the study, as well as describe the methodologies used for the research presented in this thesis

and plans for analysis.

## **Chapter Three: Methodology**

### **Introduction**

There are a multitude of vantage points from which one can begin to dissect the interconnecting topics of ethics, risk, and public health policy with regard to vaccinations, and HPV immunization in particular. Because of the newness of the HPV vaccine, exploratory research is necessary. Eliciting perspectives from mothers of girls in the form of in-depth semi-structured interviews is the primary methodology utilized in this study. Participant observation and a media analysis are also employed, the process of which will be discussed here. This chapter will describe the research study and means used to carry it out, including an outline of the overarching research questions, as well as describing in detail the methods utilized and the context of the research setting. Sampling, recruitment, and a plan for analysis of the data will also be included in this chapter.

### **Research Questions**

Four main questions guided the research process:

- 1) How are public health measures such as vaccine mandates understood and negotiated by mothers of girls?
- 2) What do mothers think about other vaccines that are mandatory and in what ways is the HPV vaccine similar to or different from them?
- 3) What do mothers know about the HPV vaccine in general and the mandates specifically, and what impact, if any, does this have on their attitudes about it?

- 4) To what extent do mothers feel their attitudes and beliefs about the HPV vaccine and its potential mandate are influenced by their political and/or religious beliefs? How?

### **Institutional Review Board**

The study was approved by the University of South Florida's IRB in August of 2007. An approved informed consent form was signed after participants were given the opportunity to thoroughly read the document and ask any remaining questions they had. After two pilot interviews, a modification was submitted reflecting minor changes to the interview guide (deletions only), in addition to requesting approval for a flier about the study to be disseminated through personal contacts and in public settings. Also, as many of the questions in the interview guide related to knowledge about HPV and sexual activity, I requested IRB approval to provide participants with several fact sheets created by the CDC on HPV and cervical cancer, HPV Vaccine Questions and Answers, and results from the latest Youth Risk Behavior Survey (YRBS) pertaining to sexual activity upon completion of the interview. Modifications to the study were approved in October of 2007.

### **Media Analysis**

In "Writing a Media Analysis," by Douglas Gould and Company (2004), the authors outline the steps necessary to conduct media analyses and evaluations. According to Gould and Company, a media analysis attempts to answer several pertinent questions, including how the media frames a particular issue, messages utilized when



discussing the issue, who acts as spokespersons for or advocates of an issue, and which topics are being ignored and which are chosen as the focus (2004). Because of the widespread media coverage about the HPV vaccine Gardasil, potential policy discourses surrounding it, and tangentially, HPV itself, I was interested in uncovering prevalent themes that would emerge from a media analysis.

First, I identified the search terms to be used in the analysis. Because of the sheer amount of media coverage, I decided to narrow my focus to only include the terms “HPV vaccine” and “Gardasil.” Next, I chose the media sources with which I would conduct the analysis. Again, in order to limit the amount of articles included in the media analysis, I chose six popular news sources identified in the article by Douglas Gould and Company (2004). These comprised one of the top daily newspapers in the country, The New York Times, one of the top nationally circulating newspapers, USA Today, one local newspaper, the St. Petersburg Times, two top news magazines, Time and Newsweek, and a popular Internet source, Salon.com. Salon.com is an online news magazine, updated daily, which covers a range of topics. In particular, American politics, presented from a predominantly “liberal” perspective, are discussed. I used the Lexis Nexis search engine to search for news articles from the aforementioned sources during the time period between January 1, 2007 and June 1, 2007. I chose this time frame because governor Rick Perry of Texas passed an executive order making the HPV vaccine mandatory in the state of Texas during the first week of February. The height of the media exposure around Gardasil was during the months following this decision, as 24 other states and the District of Columbia also introduced some form of HPV vaccine mandate legislation during this time. Using the search term and news source criteria, 29

articles were found for the specified time frame. All of them were included in the media analysis. Specifically, five articles from the New York Times were included; four from USA Today; three from the St. Pete Times; four from Time magazine; one from Newsweek; and 12 from Salon.com.

### **Participant Observation**

Through my employment as a research assistant in the University of South Florida College of Public Health, I was given the opportunity to attend the second day of the 2007 Florida Statewide Immunization Summit. The event was hosted by the Florida Department of Health's Bureau of Immunization and the Central Florida Area Health Education Center, Inc (AHEC). The purpose of the conference was to inform practitioners and health care workers in the state about current and new immunizations, as well as support practitioners in attaining the state's goal of immunizing 90 percent of Florida's two-year olds by July 2007 (Florida Department of Health 2007d).

While my research questions revolve around parental perceptions of vaccines in general and the HPV vaccine, Gardasil, specifically, I also wanted to situate the information I was receiving from parents in the context of the state's immunization climate, so the immunization summit provided a useful opportunity to observe the similarities and differences in how parents and health care workers and practitioners conceive of vaccines, risk, and preventing disease.

While I was at the conference for only about eight hours, I attended four presentations relating to different aspects of immunization and/or populations of interest with which to make some observations. I took detailed notes on the messages that were

being presented to the audience, as well as how audience members appeared to respond – whether in the form of personal anecdote, laughter, or questions. The first two were presentations on current vaccines and recommendations for young children and adolescents; the latter specifically discussed Gardasil. The third session was about immunization disparities and ways to reduce gaps in coverage, and the fourth session described the unique challenges facing rural communities with respect to immunization.

### **In-Depth Interviews**

In a recent National Association for the Practice of Anthropology bulletin, Inez Adams wrote about conducting an evaluation of a “high-risk” Hepatitis B vaccination program, utilizing ethnographic methods such as participant observation and interviews with informants. She found that the results gleaned from this portion of the data collection “proved to be of inestimable value” (Adams 2007:81). According to Bernard, semi-structured interviews are useful when each informant only gets interviewed once, and when the researcher wants a particular set of topics and questions to be covered in a systematic, but flexible and open-ended way (2002:205). For these reasons, semi-structured interviews seemed to best fit my population of interest: mothers of girls, not belonging to one particular community, neighborhood, or demographic group.

Between September of 2007 and January of 2008, I conducted 25 in-depth semi-structured interviews with mothers of girls between the ages of eight and 17. The length of interviews varied; the majority were approximately one hour each, with a range of 30 minutes to two hours and 30 minutes. The goal of these interviews was to elicit from mothers their approach to the health and well-being of their daughters, conversations

about sex and reproduction with daughters, their beliefs about vaccines in general, the HPV vaccine Gardasil, attitudes about vaccine requirements, and perceptions about a potential Gardasil vaccine mandate in the future. These topics were addressed through the use of open-ended questioning and appropriate probing for further information, as outlined in an interview guide. Three committee members and two other graduate students reviewed the guide. It was then pilot tested with two mothers of girls before minor revisions were submitted to the IRB. The interview guide was comprised of approximately 30 questions, in addition to probes and a brief demographics section, a copy of which can be found in Appendix A.

### **Sampling and Recruitment for Semi-Structured Interviews**

Because little anthropological data has been collected on parents' beliefs, attitudes, and values about vaccines, the risk parents may perceive they pose to their children, and mandates, I utilized a respondent-driven snowball sampling design. The goal of convenience sampling is not to ascertain population parameters, but rather to elicit ranges of options within topics of inquiry. Also, because network snowball sampling is considered an appropriate design in exploratory research, I feel that it was suitable for my research questions (Bernard 2002:184).

Inclusion criteria were that participants had daughters who were between the ages of eight and 17 years old. Mothers could not be older than 65. Additionally, they had to have at least heard of the HPV vaccine, which was ascertained by a screening question. Any type of household structure was included in recruitment. I chose to focus on mothers and not fathers for two reasons. In order to reduce confounding variables, I

decided to focus on one parental role for greater ease of analysis and interpretation. Secondly, as several of my introductory questions address conversations with their daughters regarding sex and reproduction, I felt that perhaps mothers would be better suited to respond. While this is certainly a generalization, it did appear, from my sample, that if possible, mothers are primarily having these discussions with their daughters, not fathers.

My original intention was to have two groups of mothers: those with daughters age eight through 12 only, and those with daughters age 13 through 17 only. The justification was that using age as a variable of contrast would allow for comparisons to be drawn between the two groups of mothers, as it is possible that mothers feel differently about the topics covered in the interviews based upon their daughter's perceived proximity to sexual debut. I interviewed 1) 12 mothers whose daughters were in the eight through 12 age range; 2) nine mothers whose daughters were in the 13 through 17 age range; and 3) four mothers who had daughters in both age ranges. In addition, about half way through the study, I gained access from a colleague to a network of Christian women who home schooled their children (currently or at one time). I was able to conduct eight interviews with this network of mothers, which adds an additional dimension of analysis and a new subgroup with which to draw comparisons.

Initial contacts were made through thesis committee members and personal contacts of the Principal Investigator. If two or three phone calls to a potential participant did not produce a response, I did not pursue additional contact. Also, informational flyers about the study were disseminated to colleagues and posted on email list serves. Interviews were conducted at times and places of convenience to the participant, which

was usually her home or at a lunch/coffee shop, depending on her preference. Reminder calls or emails were given a day or two prior to the interview. Upon completion of an interview, mothers were then asked if they would be willing to give my contact information for another woman they knew who fit the study criteria and/or were given the flyer and asked to pass the information on to any mothers they knew who fit the criteria for eligibility. At this time, they also received the IRB-approved informational handouts from the CDC, if they so chose.

### **Research Setting of the Interviews**

As mentioned earlier, the participants interviewed for this study do not comprise a cohesive community, although smaller groups within them contain dense social networks. I interviewed women from Dade City, south Tampa, Plant City, Temple Terrace, Lakewood, and St. Petersburg. These interviews were frequently conducted in the participants' homes, giving me an opportunity to contextualize some of the information they shared. Others opted for less personal settings and met me during breakfast or lunch at a busy chain restaurant. These interviews were typically shorter and perhaps a bit less candid, as other patrons were within earshot if they wanted to listen in on the conversation. The downside of this type of multi-sited research is clear: these interviews existed in a vacuum, which clearly does not accurately reflect the multitude of ways in which these women interact with friends, family, and other community members. However, a standard research setting or cohesive community did not necessarily lend itself well to the topics I chose to investigate, so it is both a limitation and a practical reality of the study.

## **Analysis Plan**

### **Media Analysis**

Each of the 29 articles was read twice, relevant passages highlighted, and notes were written in the margins and typed into a Microsoft Word document. These notes included information regarding the general topics covered (i.e., HPV epidemiology, vaccine mandates, HPV and men), the frequency with which these topics were discussed, interpretation regarding for whom the article was written, the use/absence of quotes by public health professionals to legitimize information presented, and in which section it was located in the news source. Because of the controversial ways in which the HPV vaccine has been positioned in the public discourse, I also wanted to examine the language with which Gardasil was presented in order to discern whether the article adopted a pro-, neutral, or negative stance towards the HPV vaccine. After reading through these notes several times, I created an additional Word document that tallied the information obtained during the analysis. This information was utilized to develop a set of specific codes, which were eventually grouped together into more general subtopics. These subtopics were then used to examine trends and observations in the data.

### **Participant Observation**

Because of the limited amount of time I was able to engage in participant observation at the Immunization Summit, the analysis plan was quite simple. Notes were taken at the conference, and when I returned home, they were typed in Microsoft Word. These notes included information shared during the conference presentations, in addition

to my impressions of the Summit. After reading through the notes several times and highlighting important points discussed in the sessions I attended, some key themes became evident. The most prevalent points were coded accordingly and developed into themes.

### **Semi-Structured Interviews**

All interviews were tape-recorded and I additionally took notes during the interview. These notes included not only responses from participants, but also body language, facial expressions, and general demeanor and attitudes towards the subject about which I was inquiring. All notes were subsequently typed in Microsoft Word, in addition to impressions noted in a field log document. Tapes were each listened to at least once and then transcribed. These transcriptions and the field impressions log comprised the data to analyze.

Because my sample size is relatively small ( $n=25$ ), my research does not lend itself well to quantitative analysis. Therefore, an analysis process that fleshed out themes and trends from exploratory, qualitative data was necessary. An inductive, grounded-theory approach was utilized to create categories of codes. According to Bernard, this approach is useful when the goal is to identify concepts that surface from the data and then connect those concepts and themes to formal theories. Inductive approaches work particularly well when conducting exploratory research (Bernard 2002:462-3). After reading through each transcribed interview several times, writing notes in the margins, and highlighting relevant passages, I began to develop a sense of the codes I would use in an analysis of the interview data. These codes started out fairly specific and were



continually refined, including combining codes that touched upon similar sentiments. A Microsoft Excel spreadsheet was created to categorize responses to questions that involved more discrete variables, such as Demographic information. Microsoft Word documents were created for each of the 15 codes and quotes from the participants were then included in each applicable code. These codes were further sorted and grouped together until I was able to elicit themes from the data.

### **Summary**

This chapter presented the methods utilized in this research study, which were a media analysis of representations of the HPV vaccine Gardasil, participant observation at a statewide immunization conference, and semi-structured interviews with mothers of girls. An outline of the study's research questions, sampling and recruitment procedures for the interviews, a description of the research setting, and analysis plan for the three methods used were also explained. The results of the qualitative analysis of the media analysis, participant observation and interviews are the subject of the following chapter.

## **Chapter Four: Results**

### **Introduction**

As outlined in the previous chapter, three qualitative methods were utilized to address my thesis project's research questions pertaining to an examination of the socio-cultural context of immunizations, Gardasil, and potential HPV vaccine mandates. This chapter will describe the results from the analysis of the data collected through these methods. Results will be presented by methodology and theme.

### **Media Analysis**

The articles selected for the media analysis could be broadly placed into three main categories: whether they were pro-, anti-, or neutral about the HPV vaccine Gardasil. These labels were attributed to an article based on the kinds of data presented and the language used. Of the 29 articles, ten could be considered neutral; two were explicitly against the vaccine and/or vaccine mandate legislation, and 17 presented the vaccine in a more positive light. In general, the Salon.com articles (nine out of 17 "pro-vaccine" articles) expressed more favorable views of the vaccine and the necessity of utilizing Gardasil as a primary prevention tool against cervical cancer and other cancers associated with HPV than did the other media sources (Clark-Flory 2007a; Clark-Flory 2007f; Maher 2007). Pro-vaccine articles, many of which would be considered opinion pieces, were labeled as such because of the ways in which these authors attempted to

address or refute the controversies surrounding Gardasil. For example, a New York Times article entitled, “A Vital Discussion Clouded” by Denise Grady presented grim HPV statistics and problematized concerns about promiscuity taking a feature role in the controversy (2007).

For the most part, the authors were journalists working at that particular news source (n=26); the remaining three were from a comedian, the governor of Texas, and a mother who had her daughter vaccinated and was reporting her positive attitudes towards Gardasil. I inferred from these articles that the predominant intended audience was parents of girls. Another intended audience was males in general, as several articles discussed the implications of HPV in men. Some articles also seemed to target older teen and adult women with regard to the utility of the HPV vaccine in their lives. Finally, when epidemiological data about HPV and cervical/other types of HPV-related cancers were used at all, most of the authors cited medical professionals, researchers, the American Cancer Society and/or the Centers for Disease Control and Prevention.

The media analysis of these articles revealed a number of striking observations. First, the majority (n=18) most frequently discussed potential HPV vaccine mandates in the context of controversy, mainly citing what was specifically occurring in Texas during this time (Barry 2007; Belluck 2007; Brody 2007; Clark-Flory 2007a; Clark-Flory 2007f; Clark-Flory 2007d; Fry-Revere 2007; Grady 2007; Harris 2007a; Lindenberger 2007; Lloyd 2007a; Lloyd 2007b; USA Today Editorial 2007; Masters 2007; Wallis 2007; Ramirez 2007; Rubin 2007a; Rubin 2007b; Sayre 2007). The language in which this discourse was occasionally couched included the use of sensational phrasing such as “the new HPV battlefield” and “vaccinating young virgins” (Sayre 2007; Lloyd 2007b).

Some of the articles sampled (n=7) included the viewpoints of those who considered the vaccine mandates to be premature and/or too intrusive on parents' rights (Fry-Revere 2007; Lindenberger 2007; Lloyd 2007a; Sayre 2007; Ramirez 2007; Rubin 2007a; USA Today Editorial 2007). These views sometimes came from public health researchers and bioethicists who worried that rushing into mandating an HPV vaccine would create a backlash without buy-in or understanding from parents. For example, Renee Jenkins, president of the American Academy of Pediatricians, was quoted as saying, "It might work out fine...But we don't need to walk down this road until we understand what the fallout might be" (Ramirez 2007). Public health education was mentioned in three articles as an important first step in order to increase awareness about HPV and Gardasil before vaccine mandates were established (Ramirez 2007, Rubin 2007a; USA Today Editorial 2007).

An additional reason for the controversy over the vaccine mandates articulated in the articles analyzed was the perceived collusion of government and Merck Pharmaceuticals (Clark-Flory 2007d; Clark-Flory 2007f; Fry-Revere 2007; Harris 2007a; Lloyd 2007a; Lloyd 2007b; Sayre 2007; Rubin 2007a; USA Today Editorial 2007). The money that Merck stood to gain by the vaccine mandates was occasionally alluded to in these articles and the tone with which these aspects of the piece were written was typically cynical. For example, Sigrid Frye-Revere, director of bioethics studies at the Cato Institute, wrote, "With a price tag of \$360 for three shots, mandatory vaccination would be a boon for Merck. If all sixth-grade girls were vaccinated, the company could reap about \$9 million a year in Connecticut alone" (Fry-Revere 2007).

The articles sampled frequently discussed the public perception among some groups (usually depicted as parent organizations or Christian activist groups) that the vaccine may promote promiscuity or encourage teenage sexual activity. The “nature” of the disease, or its mode of transmission, was often brought up at the same time (Barry 2007; Belluck 2007; Brody 2007; Clark-Flory 2007d; Clark-Flory 2007e; Clark-Flory 2007f; Dyer 2007; Grady 2007; Lindenberger 2007; Lloyd 2007a; Lloyd 2007b; Maher 2007; Ramirez 2007; Rubin 2007a; USA Today Editorial). For example, in a TIME magazine piece called, “An STD Vaccine For all Girls?,” quotes Christopher Klicka, an attorney working with the Home School Legal Defense Association that stands in opposition to mandatory HPV vaccination bills:

It’s very offensive to parents...They have to have their young daughters, as young as 10, immunized against a sexually transmitted disease. The home-schoolers, some of them have religious objections. But others just think it is misguided. There may be a real problem out there, but they should deal with the kids that have the problem, and not all the innocent children who wouldn’t even think about anything close to sexual contact. It simply oversteps a line. (Lindenberger 2007)

Whether these arguments were given any credence in the article depended on the particular slant of the writer or political orientation of the media source.

In general, the articles on Salon.com, the media outlet that reached audiences over the Internet only, more frequently used colloquialisms and interjected the authors’ bias, which was quite liberal (Clark-Flory 2007c; Clark-Flory 2007d; Clark-Flory 2007e; Clark-Flory 2007f; Lloyd 2007a, Lloyd 2007b, Maher 2007). For example, Salon.com’s articles had a pejorative mocking tone when discussing parents’ and religious groups’ concerns, dismissing their fears as illogical and backwards (Clark-Flory 2007d; Clark-Flory 2007e; Clark-Flory 2007f; Lloyd 2007a, Lloyd 2007b; Maher 2007). For example,

Clark-Flory writes, “Sex-fearing conservatives will not take a mandated cancer vaccine lying down!” (2007d). In another article on the HPV vaccine mandate controversy in Texas, she writes:

...many conservatives are up in arms over the implications of inoculating young girls against a sexually transmitted disease. To do so would undercut messages about safe sex, possibly encouraging sexual activity, they argue. This line of reasoning is so loony, so unabashedly callous, it’s amazing to hear it so widely parroted. It essentially deems naughty girls who do not heed parental warnings about the dangers of unsafe sex as expendable – either to HPV, a disease we can prevent, or, in the worst cases, cervical cancer. (Clark-Flory 2007f)

Approximately one-third of the articles sampled offered a brief snippet of background information on HPV infection, its sequelae, the prevalence of the disease and/or Gardasil’s high success rates in preventing the four strains of the virus against which it protects. As mentioned earlier in this section, this information was commonly disseminated through quotes from the CDC and other public health researchers (Barry 2007; Brody 2007; Dyer 2007; Fry-Revere 2007; Grady 2007; Masters 2007; Lindenberger 2007; Rubin 2007b; Tuller 2007; Wallis 2007). Interestingly, in articles from Salon.com, this information, if presented at all, was mentioned only briefly.

Another common theme presented in several of the articles was the public’s concern with the newness of the vaccine. Perceptions that it was unclear what side effects and unintended consequences may be down the road, and/or the ambiguity regarding the length of time for which the vaccine would protect against those four strains of HPV were mentioned in almost all of the media outlets sampled (excluding Newsweek magazine) (Brody 2007; Fry-Revere 2007; Lindenberger 2007; Belluck 2007; Dyer 2007, Lloyd 2007b; USA Today Editorial, 2007). The relatively high cost of the vaccine (\$360 for the series), as compared with other vaccines, was occasionally cited as

another reason the HPV vaccine was contentious to some (Brody 2007; Clark-Flory 2007a; Clark-Flory 2007b; Dyer 2007; Fry-Revere 2007; Wallis 2007).

Also of note, the role of men in HPV and the impact of HPV on “male” cancers (penile, anal, and oral-pharyngeal) and/or the potential of an HPV vaccine for boys to be released in the near future were mentioned relatively frequently in the articles sampled (Barry 2007; Clark-Flory 2007a; Clark-Flory 2007e; Grady 2007; Harris 2007b; Masters 2007; Tuller 2007). In the St. Pete Times, a human-interest story about a middle-aged Florida man diagnosed with oral-pharyngeal cancer (which was determined to be caused by HPV) was featured and many of the issues regarding men and HPV were discussed at length (Barry 2007).

Not surprisingly, the articles from the St. Pete Times had a much more local context in the scope of their content. All of the articles talked about the vaccine mandates nationally and the current mandate bill that had not yet died in the Florida House (Barry 2007; Dyer, 2007; Colavecchio-Van Sickler 2007.) Another presented information to parents regarding the Pros and Cons of getting your daughter vaccinated against HPV (Dyer 2007).

Much less cited was the concern that an HPV vaccine would give women and girls a “false sense of security” regarding taking care of their bodies. Pap smears and the necessity to continue annual exam visits even if Gardasil has been administered were emphasized in this context (Fry-Revere 2007; Rockwell 2007; Rubin 2007a).

Additionally, several studies about the high prevalence of HPV in women and/or the lack of effectiveness of Gardasil in women already infected with HPV (i.e., already sexually active) were published during this time in the New England Journal of Medicine and the

Journal of the American Medical Association. A summary of the results of these studies was presented in four articles sampled (Fry-Revere 2007; Grady 2007; Harris 2007a; Rubin 2007b). Finally, some of the articles could be described as explicitly defending the HPV vaccine – those with the intention of addressing the myriad of controversies lined up against it, such as an opinion piece in Time magazine by the mother of a 13 year old girl who had her daughter vaccinated against HPV (Wallis 2007; see also Brody 2007; Clark-Flory 2007f; Maher 2007; Perry 2007).

### **Participant Observation**

As part of my job duties as a research assistant in the College of Public Health working on a grant examining barriers to cervical cancer prevention in Florida, I was asked to attend one day of Florida's Statewide Immunization Summit. The intended audience included public health professionals, nurses, physicians, and social workers interested in learning more about immunizations. The conference, which the Florida Department of Health website boasts had more than 300 in attendance, took place at a hotel in Orlando in the spring of 2007. The theme of the conference was "Complete the Coverage: 90 percent by 2007," with the catch phrase, "We measure success in doses" covering their promotional materials (Florida Department of Health 2007d). As there was a lecture on current vaccines and recommendations for adolescents that would share information on the new HPV vaccine, I felt that my attendance would also provide an unique opportunity to engage in participant observation in order to situate the views and perspectives of health care professionals and speakers whose main focus is reducing vaccine-preventable disease within the context of my thesis research.



I attended four lectures over the course of the day: Current Vaccines and Recommendations for Young Children; Current Vaccines and Recommendations for Adolescents; Closing the Gap in Immunization Disparities NOW!; and Rural Health: Challenges and Solutions to Improving Immunization Rates in Rural Communities. One of the first observations I jotted down was that in the initial “Welcome” reception in the morning, counties with the highest immunization rates were announced and the audience cheered them on enthusiastically as representatives from these model counties were given awards. All of the presentations that followed focused on the new recommendations put forth from the CDC and informed the audience of the importance of “catching” individuals up on their immunizations, offering this advice: “when in doubt, give them the second dose.” The latter suggestion was mentioned particularly with regard to the Varicella (chicken pox) and flu vaccines. Because increasingly more individuals immunized against chicken pox are experiencing what is referred to as “break through illness,” the speaker articulated, “Either we put everyone in a bubble or everyone gets a second dose.”

During the first presentation on Vaccines and Recommendations for Young Children, the speaker also discussed potential issues with the rotavirus vaccine that had just been removed from the market because of some adverse events reported on VAERS (The Vaccine Adverse Event Reporting System). He made the argument that while certain reactions seemed to be associated with the old rotavirus vaccine, it was impossible to establish causality when the background rates of these associated illnesses in the general population were unknown. Therefore, vaccine safety cannot really be criticized. He then made a comment regarding parents’ “irrational concerns” with respect to vaccine

safety, to which some members of the audience laughed. This speaker closed with a particularly interesting story about a mother (a picture of whom was displayed in the power point slide as he spoke) who had “killed her baby” with pertussis. He emphasized the importance of individuals around infants and children being immunized as well, as the source of infection is often older children or adults, and, largely, the mother.

The presentation that I came specifically to hear on Adolescent Immunizations was more of the same rhetoric regarding the importance of “catching everyone up,” with the addition that Florida’s immunization rates in adolescents are missing national targets, particularly because of a large gap between Medicaid and commercial insurance payers. The presenter stressed the importance of protecting adolescents, adding, “you may not get sick, but that doesn’t mean others around you won’t.” The HPV vaccine was rather simply and succinctly discussed as another effective new vaccine that had been put on ACIP’s list of recommended vaccines.

The final two presentations on Immunization Disparities and Rural Health provided the audience with tangible suggestions and creative ideas on how to reach these diverse populations. An example included taking vaccine “carts” out into the streets or wherever people are congregating and attempt to immunize them there. The presentation on Rural Health shared the results of a CDC study on migrant communities’ perceptions of vaccines and offered advice on how to reach this population more successfully.

A common thread throughout all of the presentations involved invoking the image of vaccines as an extremely successful public health prevention strategy. Similarly, “protecting” the herd, or our state’s children, or adolescents, was also a frequently used tactic. Finally, the suggestion that health care providers should vaccinate when in doubt,

even if a previous dose was given -- just in case -- was evident, particularly in the first two presentations, the reasoning being: better to be safe than sorry.

### **Semi-structured Interviews**

This section will describe the results of the 25 in-depth interviews conducted with mothers of girls, which will be presented in six overarching thematic topics. These are Demographics and Medical Orientation; Perceptions of Prevention; Narratives of Risk; Sex; HPV and Gardasil; and Government and Health. Each topic will be divided according to key themes that emerged from the analysis.

### **Demographics**

Table 4.1 shows the major demographic characteristics identified from the interview protocol. The age of the participants ranged from 39 to 53. The median age of my study group was 45 years old. The mode of the group was 49 years of age. Participants had varying levels of education, with 23 out of 25 women having obtained at least a Bachelor's degree. Nine women had obtained a post-graduate degree, such as a Masters or JD. Just over half of the sample considered themselves to be full time moms in addition to being employed outside of the home (n=15). This does not include women who home schooled their children but did not have employment outside of the house, of which there were seven. Eight participants had ever home schooled their children, and six did so at the time of the research. Participants in my study were largely from a self-identified Caucasian background. Specifically, 21 out of 25 of the interviews were conducted with White women. The other self-identified ethnicities represented were

Jewish, Hispanic/Latina, Cuban American, and Asian/Pacific-Islander. Political affiliations varied, with 13 classifying themselves as Democrat, Liberal, or Progressive. 10 considered themselves either Conservative or Republican, with one mother describing herself as Moderate and another as Independent. Similarly, religious affiliations varied widely, as Table 4.1 illustrates. The dominant religion represented was Christianity, with several denominations mentioned, including Catholic, Unitarian, and Lutheran. Additionally, three of the 25 women identified as Jewish, with several also describing themselves as not being religious.

The number of children participants had varied from one to five, with the most prevalent response being two. Additionally, just over half of the sample reported having two daughters, with the rest having either one or three. As described in the previous chapter, one of the eligibility criteria for participation was having a daughter in the age range of eight through 17. The group was further divided into mothers with girls between the ages of eight through 12 and 13 through 17. 12 women had daughter(s) only between the ages of eight and 12; nine had daughter(s) only between the ages of 13 and 17; and four women had daughters who fell into both age ranges.

**Table 4.1: Demographics of Participants**

Age	Edu	Occupation	Ethnicity	Political Affiliation	Religious Affiliation	# of child- ren	# of daughters	Ages/age ranges	Home school
42	JD	Lawyer	Jewish	Democrat Liberal	Jewish	2		6, 11 (8-12)	No
45	PhD	Professor	Hispanic	Democrat Liberal	Non-religious/ lapsed Catholic	2		7, 13 (13-17)	No
49	BA	Graphic designer	White	Democrat	Unity denomination	2		18 (8-12)	No

53	MBA	RN - hospice	White	Liberal in most situations	Catholic	2	8, 11 (8-12)	No
45	BA	Home-maker	White	Conservative Republican	Christian	2	14 (13-17)	Yes
39	Post-BA	Social worker, massage therapist, mom	White	Very liberal	Spiritual, not into organized religion	3	4, 8 (8-12)	No
40	MA	Student, researcher, midwife, mom	White	Progressive, social democrat	Unitarian/ Universalist/ Pagan	3	19 (8-12)	No
49	BA	Computer support	White	Democrat	Very neutral	1	16 (13-17)	No
50	BA + some grad	Writer	White	Liberal	Unitarian	2	22, 16 (13-17)	No
44	BA + some MA	CPA and CFP	White	Democrat - but loyal to the person	Catholic	4	12, 13 (both ranges)	No
45	BA + some MA	Mom, teacher 1-12th grade	White	Conservative	Christian	3	20, 14 (13-17)	Yes
41+	College	Finance Director	White	Republican	Christian	2	7, 10 (8-12)	No
47	JD	Attorney	White	Moderate	Jewish	2	110 (8-12)	No
44	BS	Radio journalist + broadcaster	White	Liberal progressive	None	2	18 (8-12)	No
40	BA	Full time mom	White	Democrat	Jewish	2	12, 8.5 (8-12)	No
49	MA	Full time home school mom	White	Conservative	Christian	2	14 - twins (13-17)	Yes
43	BA + some MA	Full time mom, sometimes farm hand	White	Independent	Lutheran	2	11, 13 (both ranges)	Yes
47	MA	Home maker	White	Conservative Republican	Born again Christian	5	12, 9 (8-12)	Yes
47	High school	Home maker -- real estate license + massage therapy	White	Conservative	Conservative Christian	2	13 (13-17)	Yes

45	BA	Full time mom - home school teacher	White	Republican	Christian	3	13 (13-17)	Yes
44	MA	Science Teacher	Cuban American	Republican	Roman Catholic - attend Episcopal church	1	112 (8-12)	No
44	1 year college	Home school mom	White	Fiscally conservative	Conservative Christian	4	18,15,10 (both 3 ranges)	Yes
42	BS	Math + history teacher	Asian-Pacific Islander	Democrat	Catholic	1	110 (8-12)	No
49	BS	Home maker	White	Republican	Catholic	3	17,14 (13-17)	No
49	MA	Home maker	White	Liberal	American Catholic /Lutheran	3	17, 12 (both 2 ranges)	No

### Medical Orientation

Introductory questions in the interview guide were designed to elicit from participants how they made health care decisions for their children, and who was involved in that process. From these responses, a code was developed called “medical orientation.” Participants’ responses ranged widely, from some citing a heavy reliance on their pediatrician, to others feeling confident to treat their children almost entirely at home. A little more than half of the sample could be characterized as adopting a mainstream approach to health care (n=13). About one-third of the participants cited utilizing both mainstream and alternative approaches, and not rushing to the doctor right away (n=9). Finally, about one-eighth of the sample described their approach to their children’s health care from a more alternative, or holistic approach (n=3). There were not

any major differences between the moms who aligned themselves with more mainstream medicine, alternative approaches, or somewhere in-between; however, mothers of girls in the older age group did appear to characterize themselves as straddling the fence between mainstream and alternative medical orientations more than did the moms of girls in the younger age group. Below are several quotes from participants that reflect the diversity of responses:

One self-identified “liberal” mother of three adopted an alternative orientation to her daughter’s health care:

“I’m very confident in my abilities and knowledge concerning her health. I don’t rely on a doctor at all; we rarely go to a doctor. I try to do as much at home with my own knowledge that I can...we go to a chiropractor regularly – my daughter goes. But she tells me when she needs to go. And I believe that’s more of a whole health kind of system...”

Another mother of one 16 year-old daughter relied heavily on her pediatricians:

“The pediatrician... the pediatrician is now a pair of them. I go there if there’s something I have questions about or anything, that’s the first thing you do. I have a very supportive pediatric staff.”

A response that was typical of mothers who aligned themselves with elements from both mainstream and alternative medical orientations was:

“I have one foot in each camp. And that’s pretty much my approach to health care for my kids... I really try holistic, I don’t go with the remedies and that kind of stuff...I’m not a homeopath, but I do kind of home remedies and simple things. But I do trust my pediatrician enough that when he feels strongly about something, I do it.” [44 year-old participant with two children]

Perhaps not surprisingly, medical orientation appeared to be associated with attitudes about vaccination. For example, participants who placed themselves more firmly in the “alternative” medical orientation camp were more likely to be wary of biomedical

initiatives such as vaccine mandates, and in most cases, vaccines themselves. The results regarding vaccines specifically will be presented in the next section.

### **Perceptions of Prevention**

Attitudes about the utility of vaccinations as a primary prevention public health strategy varied widely among the study population. Open-ended questions posed to participants were intended to tease out beliefs relating to the range of vaccinations offered to children, including Gardasil, which has been added to CDC's immunization schedule at the end of 2006. Participants rarely offered a straightforward black and white response regarding vaccination; on the contrary, many of the participants expressed ambivalence and, for some, mistrust, about the use of this primary prevention strategy. Below are several quotes from participants that reflect positive responses about the use of vaccinations for children.

“If you look back into the 1800s with all these terrible diseases, we've eradicated them. It's [vaccines] obviously been a good thing.” [45 year-old mother who home schools her 14 year-old daughter]

A 43 year-old woman with two daughters who has home-schooled her children stated:

“...I mean, we take things for granted because there's just there... and I think that no one ... none of us have a memory... because we weren't there... of what people had to deal with a long time ago, the major diseases and things that your children died of and there was nothing you could do about it... so with vaccinations they got wiped out. I think vaccinations are a very good thing. Even though there is some risk associated with them like there is with everything, I think the overall good is much better. There are things that you just never worry about your child having... Whooping cough, tetanus... people died of tetanus... and you don't worry about that anymore. It's no big deal. And I think that a lot of people, if there are people who go out say, I don't want my kid to get vaccinated, I think maybe they really don't have an understanding of the history that came behind some of this stuff... why the need existed in the first place, I mean... ”



because if all of these people aren't getting the vaccines, then these things will have the opportunity to have a host that will be there..."

Some mothers shared a cautiously optimistic view of the concept of vaccines, as

illustrated by the quote below:

"I'm not anti-vaccine, but we need to be more judicious: when do we do it, how often, and for what reason?" [49 year-old mother of two daughters and one son]

Frequently, the women with whom I spoke expressed ambivalence about whether

vaccination is always a good idea:

"I really like my doctor a lot on a personal level... but if you choose not to vaccinate, he cannot be your doctor. Because he has to recommend that. And unfortunately the timing of all of these decisions ... you don't really think about it before you get pregnant, and depending on how confident you are in your own abilities to make decisions about your children's health care... I mean a lot of my friends just run to their doctor if their kids have a fever. They don't feel confident enough to deal with that at home. And when you have new children, you're so tired, you're not thinking clearly, you've barely slept and these options are being presented to you... oh, they're not even being presented to you actually, they're not options, they're just you've got to have these shots and they're 2 weeks old that's what you have to do, and it's just like uhhhh... It wasn't until a year and a half or two years later that I thought, what did I just do to my kids?" [39 year-old participant with two daughters]

A 49-year old mother of one daughter explained:

"Science changes... so you have to somewhat question this generic message that we're giving everybody... it concerns me that we think we're so right. And it's such a limited time frame that we're making these decisions. This is all we know at this point... so you make the decision, but you know you're not making it... People have been around a lot longer than the vaccines, in all sorts of forms."

Some women I interviewed also described a mistrust of the collusion of biomedicine and

big pharmaceutical companies and skepticism about what really drives vaccination:

"...I don't know. I don't believe everything that's told to me anymore by the AMA or FDA or whoever." [49 year-old participant with two children]

"I'm also really leery of pharmaceutical companies anyway. I just feel very strongly that they are in it for the money. They are not doing this to save little

girl's lives in the future... they're not in it for the humanitarian effort." [39 year-old mother of three children]

"I think from a pediatrician standpoint, he's very sincere in his thoughts, that, "why would you not do something that is going to help people not be sick?" And I think that's extremely sincere. But you just have to wonder about how hard they market the doctors, how hard they're lobbying the legislators." [49 year-old woman with one daughter]

For many of the mothers I interviewed, the concept of vaccination was looked upon with at least some skepticism and trepidation (n=17). This is not to say, however, that these women chose not to vaccinate their children. These concerns will be addressed further in subsequent themes presented in the chapter. Again, the mothers who aligned themselves with mainstream medical beliefs did not appear to have as much difficulty seeing the utility in vaccinating their children. The next section, Narratives of Risk, will delve more into these concerns.

### **Narratives of Risk**

While not phrased explicitly as "risk," questions in the interview guide also attempted to elucidate how mothers assessed the relevance and importance of vaccines, including Gardasil, for their children, and specifically, their daughters. Several important sub-themes emerged through an analysis of these responses. The first theme encompasses responses from mothers that teased out responses by participants about the harm caused by vaccines or the safety of vaccines themselves. As outlined in the previous section, many women had concerns, to varying degrees, about the potentially negative consequences of vaccines in the bodies of their children. Nonetheless, the majority of the sample had never declined to vaccinate their children against any

illnesses, temporarily or permanently (n=21). Several mothers did develop risk reduction strategies, such as spacing the vaccines out or delaying immunization until their children were older. Below are some quotes from participants that reflect these concerns about the safety of vaccines in general.

One 45 year-old participant with two children stated:

“I now hear or know about how they preserve them [vaccines] with mercury, and sometimes I think I’ve heard preserving them with other stuff that isn’t great, so you’re introducing toxic things into your body, which we don’t know how it will react, adding to our toxic load which we all have...”

Another mother of two daughters, ages four and eight, explained:

“I’m not convinced that vaccines are safe and um, a lot of my background with holistic health or healing, the general belief is that vaccines are very harmful to you. I don’t buy into that completely, because I’ve had my kids vaccinated for some things...I’m just not really convinced that they’re safe for long term effects. I don’t feel like people know the long-term effects of putting all these things into young bodies.”

Additional responses included:

“...I had a lot of concern when we did the first shots when she was an infant... because you hear... people have a lot of stories about what these vaccines do and it’s hard to separate you know, what is realistic, what is the greater danger [the vaccine or the illness itself]...” [woman with one 16-year old daughter]

“I just took steps to having them [vaccines] all not bundled together... Too much is too much. When the body adjusts, you take the next one, when the body adjusts, you take the next one, you don’t just put them all in one syringe... here, take it all.” [42 year-old mother of one 10 year-old daughter]

## **Autism and Risk**

An interesting unprompted response continued to come up during the interviews was the mention of the link between autism and vaccines. Over half of my sample discussed the potential link between autism and vaccines with me and shared their

opinions about the degree to which they believed that this link was real (n=14). One 49 year-old woman commented,

“I’m not crazy about vaccines anymore, in general, because of what I know about some of them...the mercury, that people are complaining about that their child got inoculated and now they’re autistic...”

Another mother expressed more skepticism regarding the purported link between vaccines and autism:

“There have been studies on both sides, and I think the studies showing that there is no link between MMR and autism are more convincing, but my mind is still kind of open on that.” [40 year-old woman with three children]

A common conversational device utilized by participants was to cite anecdotal evidence about the link, usually in the form of a close friend or relative who had experienced changes in their children, who eventually became autistic. This 49 year-old mother of three with two teenage daughters explained:

“...my husband’s nephew, my sister in law swears that his nephew became autistic from one of the vaccines because he had a huge blistering yelp after that second shot, and I don’t even know if they took the 3<sup>rd</sup> shots... I think maybe don’t give all the vaccines in one shot. Maybe give the Diphtheria one time, the tetanus one time...I think they all need it, but autism is another thing that we’re learning about... maybe it is a possibility because he was fine up to then...”

Finally, with respect to Gardasil specifically, many mothers described the reservations they felt about having their daughters vaccinated. As described later on in this chapter, HPV vaccination intentions varied widely, with more than half of the respondents being either unsure or opposed to vaccinating their daughters with Gardasil (n=17). Some of their issues with the vaccine pertained to the sheer newness of it and the potential unknown side effects involved in the future. Other mothers expressed cynicism about having their daughters used as “experimental test subjects” for a vaccine about

which we just don't know enough. One 49 year-old woman with 14 year-old twin daughters explains,

“You know there are side effects to anything... I mean we take the pill and they say it's wonderful you won't get pregnant and it lessens our chances of cancer, one of those, but it increases your chances of breast cancer... so what are the results of this thing [Gardasil]? Is the rate of breast cancer or fibroid cancer going to go up? There is no way of knowing what the side effects of putting that in our bodies will be... and I think you just have to wait... and in this case, there's just not enough data yet...I think it's wonderful [a vaccine for cervical cancer], but I am not letting my child be a mouse... and a guinea pig and part of their experiment because I don't think they educate the American public enough to really know what we're getting...”

Another participant said,

“My first impression was this is great. They're promoting 70 percent reduction in cervical cancer, this is wonderful. A concern is this is a new vaccine...maybe it's not as new as I feel it is, but I haven't seen information on this...In the short term you think, of course I'm going to prevent 70 percent of cervical cancer, but on the other hand, do we know what we're doing, has this been thoroughly tested, do we have any clue what we're doing?” [43 year-old mother of two daughters]

### **Perceptions of the Severity of Illness and Risk**

Another major theme that emerged when discussing vaccines was that differing perceptions among mothers about the severity of certain illnesses (and not others) changes the potential “risk” it poses. For example, several participants (n=3) expressed frustration with the chicken pox vaccine Varicella because they didn't perceive chicken pox to be particularly life threatening:

“I think that getting the chicken pox naturally, let's say, is the body's way of building up its own immune system, and I don't feel like it's a life... I think there's no fear based in that. My doctor would argue that terrible things happen if you get the chicken pox...and it's very fear based and I don't buy into that. Now some of the other ones, you know all of them I've argued with my doc, and he gives you these terrible stories, and it's just like ok, I'll feel guilty if my child got those things...” [39 year-old woman with three children]

This 49 year-old mother of two questioned the need for chicken pox immunizations:

“...Chicken pox, I have a hard time with that one.... I know that there have been children who have died from chicken pox, but is that not like a really really really really small percentage? It’s kind of like, why do this? The medical community says, why do we do this? Because we can.”

On the other hand, certain diseases were frequently mentioned by mothers for comparison regarding their severity and, therefore, the necessity, of vaccinating their daughters:

“I mean ok if small pox ... you should get vaccinated against small pox, small pox kills people pretty regularly. Polio is nasty. Bad bad things happen. But the rest of them? You know? I mean I think vaccines have their place just like everything... if they can eradicate a horrible life threatening disease then the risk is worth it... but mumps are not... chicken pox, not...” [49 year-old mother of three]

This 42 year-old participant with two daughters articulated:

“I know historically polio had a tremendous impact. Tons of my friends’ parents had polio and you can see how it affected them. The beautiful thing is, no one my age has it, and I don’t know anybody’s kids who have it now, thank God, and that’s the benefit of inoculations...”

With regard to HPV, if participants did not feel as though it was particularly dangerous or had the ability to cause significant harm, they generally did not see the relevance of the vaccine for their daughters. This 53 year-old mother of two explained:

“I think well it’s an STD [HPV], so the ability to infect someone else is there, but I think much of it doesn’t lead to cervical cancer...[HPV is] very minor in and of itself, not life threatening.”

Additionally, other participants commented:

“...It’s not like ovarian cancer where people die readily... so how many people die from cervical cancer? I guess if it was your daughter it’d be one too many. I think if they had one [a vaccine] for breast cancer, wouldn’t we all take it? Cause you’ll hear on TV, people aren’t wearing little blue things in support of HPV. And

we don't know anyone who's been affected, where as we do know people who've been affected by breast cancer..." [45 year-old participant with two children]

"No.. I don't think HPV is serious... I think that if you get HPV, there are other...that was one of my research...that it is easily cured." [45 year-old mother of three children]

On the converse, women who perceived either HPV or the potential consequences of it (genital warts or cervical cancer) to be severe were more willing to consider vaccination, if not outright support it, as this quote from a 45 year-old woman with two daughters reflects:

"HPV – well, if it can lead to cervical cancer then it's very serious. So any form of cancer, I know we've made great strides in cancer research, but most of us think of cancer and we think of fatal...I see 70 percent and I see the link between HPV and cervical cancer...that would definitely impact my going to get my daughter vaccinated and how I made decisions."

Similarly, this participant with one daughter stated:

"...I mean, you're talking about women dying of cancer... and men actually too, because they are saying it's implicated. So I mean, if you can prevent something that's going to kill you..."

### **Transmission Matters**

Another aspect of risk that participants continued to bring up was the issue of transmission. How does the person actually acquire the disease? For some women, it was simply a distinction in their mind that measles, for example, is acquired casually, and HPV is acquired sexually. For others, that avenue of causation was imbued with a moral subtext. Were you an innocent or passive victim of an illness? Did you engage in risky behavior and bring it upon yourself? Even if participants supported the HPV vaccine for their daughters specifically, several of them expressed concerns about it being made

mandatory because of the mode of transmission. The issue of vaccine mandates is explored later on in this chapter.

The quotes below reflect when mothers simply made distinctions between those diseases that are casually transmitted and those that are not. For these women, the logic behind vaccines, and the legal justification for vaccine mandates, was to protect the public's health. It was difficult for several of the mothers I interviewed to see the relevance of the public's health in HPV prevention. A 40 year-old mother of three explained:

“...Right now schools basically focus on vaccinations that involve things that are very easily spread and can affect the school. HPV doesn't really affect the school, so I'm not sure if that's the proper place for it. Most of the diseases that schools require vaccines against affect school attendance and participation and HPV doesn't affect those things.”

Another participant commented:

“This isn't like diphtheria...but it is in a different sense. People do die, but it's not spread, you don't just show up to school and somebody catches it.” [49 year-old mother of one daughter]

This 44 year-old mother of a 12 year-old daughter reasoned:

“Um, well this is my thing... there are still students who refuse to take vaccines. The regular vaccines that babies get at birth and then again at kindergarten and then again at 7<sup>th</sup> grade. There are certain diseases we've been vaccinated against that are certainly contagious.... Measles mumps rubella all that stuff...But you're not going to get cervical cancer from the kid sitting next to you, unless of course you're having sex with them. So it's not a contagious disease, outside of sex. So sitting in the classroom, there's no risk there. Umm...so that's one issue that I have a problem with...And I view the other vaccines as public health... and that's why it's in a public place...the coughing the sneezing the boogers all that...”

On the other hand, some mothers indicated a lifestyle choice or intention on the part of the individual with regard to certain diseases, namely those that are sexually



transmitted. This “choice” on the part of the individual not to engage in “risky” behaviors changed the need for vaccine, particularly if it were to become mandatory.

A 45 year-old conservative Christian woman who home-schooled her three children explained her perspectives on the transmission of HPV with particular detail:

“Already we have made such a difference with early treatment, Pap smears...If they have a vaccine against HPV and you have a high risk lifestyle, even if it’s a minor...and her parents think she’s got a high risk lifestyle and she’s sleeping around, or they suspect she’s sleeping around, and she goes to the pediatrician or the walk in clinic or whatever kind of clinic they go to, and get that vaccine, this is America that’s absolutely fine. They can definitely offer that. I’m happy for them if it would keep somebody from getting sick and getting cancer...that’s good for them. Good for them. Personally, we won’t need it. I’m sure of this...It [an HPV vaccine] is different, because of the fact that they’re gonna vaccinate such a large population um when it’s [HPV] behaviorally connected and could be prevented behaviorally. Where if you really believe in the germ theory, uh, then measles can’t be prevented... if the school has an outbreak of measles, the school kids get measles...they can’t not go to school, but the girls can not have sex, even though I know people are gonna say that’s impossible, um. But really, a lot of that just depends on education, how you... how you train your children, and what they believe... you know?”

Another woman stated:

“I mean the [Gardasil] commercials just seem very innocent... you just don’t know all the details. And from that viewpoint, yes, if it would prevent my daughter from getting cervical cancer, then absolutely, but whenever it comes from sex out of marriage, that changes it a little for me.” [47 year-old conservative Christian mother of two who has home schooled her children]

Finally, this self-identified 44 year-old conservative Christian woman who home-schools her four children shared:

“... You’re mass marketing to children that don’t even know why they’re getting this shot for a life style choice...and I do think it’s a lifestyle choice... well we’re going to prepare you to be promiscuous, and involve in risky behavior. Or even encouraging, “Well you can do this and not worry about that nasty cervical cancer,” which isn’t true...you can get it from other behaviors...I took my daughter...she had a bad cough like a month ago...I saw the commercials [for Gardasil], that was when I became aware of that...and then at the doctors we were talking about if she’s up to date with our vaccines...[daughter is in the

background singing the Gardasil “One-less” commercial]...so he said that it’s recommended and that the earlier that it’s administered the more effective they think that it is. Shock and awe. I was like...Ahhh! I was just mortified!...Let’s just accommodate this behavior and make it painless and reduce the consequences because...we’re going to accommodate, we’re going to give you products that...I mean I’m all for preventing cervical cancer, I have female cancer in my family and it’s very scary...but I just think it’s ridiculous...it gives a false sense of security that the only detriment...that the only thing that’s gonna hurt my body is an STD, you know, if I engage in this behavior...when the truth is, in my opinion, it creates a disease in your heart that they’re never going to have a cure for...”

Most of the women I interviewed who incorporated morality into their perception of the HPV vaccine also had quite strong religious convictions that supported abstaining from sex until marriage, which will be explored further in the next section. In addition, speaking more generally about the entire sample, making such a vaccine required for sixth-grade girls became problematic to most of the women I interviewed, regardless of religious beliefs or the lack thereof (n=21).

## **Sex**

Because HPV is a sexually transmitted infection and Gardasil is the first vaccine of its kind to protect against certain strains of a virus that are only contracted sexually, I was interested in eliciting from participants the types of conversations they have or are planning to have with their daughters about sex and reproduction; I also wanted to know if communication about sex was not occurring in the home. In addition, I was interested in finding out the extent to which mothers felt that their political and religious beliefs impacted the ways in which they approached the subject of sex with their daughter(s). Also, I wanted to explore mothers’ perceptions of the average age of sexual debut among

the majority of American girls, as well as for their own daughter(s). This topic was divided into five themes.

### **Sexual Discourse in the Home**

The mothers I interviewed approached the topic of sex and reproduction with their daughters in a multitude of ways. Most, even those with younger girls, discussed sex and/or reproduction in some form and to varying degrees of detail. All of the mothers interviewed were essentially in charge of that discussion with their daughters and other family members were rarely involved. Many of them used accompanying books to read with their daughters.

One 47 year-old mother of two explains:

“When she was 7½, I got the book – The Care and Keeping of You, The American girl book – under the recommendation of my pediatrician. That talks about everything in terms of hair care, skin care, breast development, menstrual cycles...all that, anything...male care, how you look, braces, just real basic. It’s a great book. Then just recently I can’t remember the name of the book, I got another one, but I read it with her and prior to that I had a conversation about babies. It’s been several conversations, especially with The Care and Keeping of You. We’d pick a page or 2 to read at night - that was ongoing. And is still ongoing...”

Several of the mothers I interviewed broached the conversations about sex as a result of their daughter’s exposure to the general topic of sex by a friend, the media, or another subject. This 40 year-old woman with two daughters shared the following:

“It’s been a series of conversations...Most recently she has asked me about condoms because she watches MTV and there are condom commercials...so she asked, can you get pregnant if you wear a condom? And she was 11 and I almost died. So that’s come up. She also recently asked about...that kind of stuff, sort of more questions about sex. When I was growing up, we didn’t talk about it my family, my mother gave me the talk and I was like ah I don’t want to talk to you about this...and so I’m a little embarrassed, but I try not to, because she’s not, and

I don't want her to be. I want her to be able to talk to me, and she is able to talk to me, so that's a good thing. I try to be honest with her; I told her where babies come from. I asked her if she knew how babies were made -- this was when she was 11 and she was going to summer camp and I wasn't sure...I didn't want her to learn the wrong thing...we've talked about pregnancy and you don't want to get pregnant until the right time and all that. She asks me, "When do you think I could kiss a boy (she asked me in 5<sup>th</sup> grade)?" She said, "In 6<sup>th</sup> grade?" I said no...you have to be much older...I don't know how to answer that."

A 43 year-old participant with two daughters who were formerly home schooled

explains:

"I'd home schooled them until last year, and we'd already talked about getting your period, and what's a uterus and ovaries and this is what happens...but I hadn't gone into any more detail other than you have an egg and then when you have your period. I didn't explain like how the egg is fertilized. We'd never even discussed the guy part...but then we'd gone over a botany section in school. And it talked about how flowers have ovaries...and she went from that to women...and how the flower needs pollen, so is there something that women need in order to get the egg fertilized? ...Over time, we talked about how, yes, the father has the sperm, the sperm has to get together with the egg, but I still hadn't explained it. So once she kind of knew, this is what sex is. But she didn't know this is what people do on a regular basis...when they love each other, and that it's an expression of their feelings, for her it was just...when two people have a baby, this is what you have to do to have a baby. Now that she's going to school, and she's getting a steady diet from the kid next door, she probably knows more than I do by now..."

Interestingly, several women I interviewed spontaneously brought up a reticence on their part to discuss the topic of oral sex with their daughters (n=3). While the subject of sex and reproduction in general was manageable, the idea of sharing information regarding oral sex was overwhelmingly uncomfortable to some. A 44 year-old mother of four explains:

"I'll tell you a topic that I have not talked about which bothers me, I know it's happening out there but I just can't bring myself to physically talk about it is, I'm not talking about oral sex with my children. I just cannot bring myself...but I know that that's happening in the world and it's way more prevalent than probably it was when I was growing up, but I'm just not willing to talk about it. They haven't asked me any questions and I haven't made that part of the

conversation...I cannot have that conversation with them directly because they'd tug on their ears and scream...Ahh! It's shocking...I know that they...I don't know what they know...nor do I want to find out what they know. If they ask me a question, let's have a conversation about it, but I'm not bringing it up."

This 50 year-old participant with two daughters echoed similar sentiments:

"I wouldn't feel good [talking about] about oral sex...I don't want to know. I don't really want to talk about it...and I wouldn't bring it up to her. If she did want to talk about it, I'd approach it with an open mind, and be ok with that, but I'm not going to bring it up first...even though I found out that a 16 year old in public school, that oral sex was common in middle school, and I was horrified. I'm not of that generation...I mean, kids being like, 'Sure, what not?' I was stunned. It just seems like...it's too sophisticated for a 12 or 13 year old. It's just too much. I would hope that I would not have to talk to her about it."

## **Sex and Religion**

The extent to which religious beliefs played a role in the conversations mothers had with their daughters about sex varied greatly among participants. Out of the eight mothers I interviewed who had home schooled their children at any time, all self-identified as some denomination of Christianity. For seven of these women, sex and religious beliefs were inextricably linked, and the importance of sharing these values with their daughters was paramount. Below are several quotes from these women that elucidate that connection:

"As far as the sex thing though, that's always been a natural topic, but it's not something we OD [overdose] on. As far as our faith goes, we have different mores than others or what would be right or wrong. We believe that sex belongs within the marriage relationship, that it's best for the people involved, it's best for any children who come as a result of that, and that sex is a great thing it's a good thing, it's not a horrible or a nasty thing, it's exciting, it was meant to be pleasurable, and it will be the most pleasurable if you get that cart behind the horse where it's supposed to be...driving along...and you find the person you really want to spend the rest of your life with and make that part of that relationship." [45 year-old self-identified conservative Christian mother of three home-schooled children]

A 47-year old born-again Christian woman with five home-schooled children explained:

“Yes...I would say my religious beliefs affect it in the sense that I have certain aspirations for her...like, I do hope she waits until she gets married to have sex, and so that’s definitely reflected in our discussions...that I feel that’s appropriate...”

Another participant stated:

“Very much so. I wonder about people who don’t have those [religious] convictions...how do they talk to their children? I guess they give them condoms...our thing with our kids is, if you follow God’s plan, you won’t have any regrets and your life will be so sweet. If you stay on God’s path, then dreams come true. You can deviate off the path, but they need to understand those serious consequences.” [45 year-old mother of two children who are home-schooled]

A 45-year old woman with three children who are home-schooled articulated:

“We actually went on a very special weekend...when she was younger, we answered some very direct questions...and when she was about 11, she was exposed by a neighbor girl to some words that she had questions about, and that started more questions so we went away for a weekend called Passport to Purity...a lot of our friends have done it. It’s a very special weekend where we go through a series of audiotapes and journaling and reading materials...and it’s in depth call to a higher standard of purity. It’s a well-known program in our community...That particular weekend was the nuts and bolts of it, and then after that, like in 2 years, there will be situations...because, see, that weekend we discussed there will be times that you will feel this or see this or want this, and it was kind of like...here’s the road...and these are the warning signs, and walking down the road, remembering that weekend where we talked about you may feel this or that, so now she’s finding the applications to what we had discussed, so she is prepared.”

The extent to which religious beliefs played a role in discussions about sex among the rest of the sample varied extensively. A few mothers who also felt strongly about their religious beliefs but did not home school their children considered discussing sex within that context important as well (n=4). This 49 year-old self-identified Catholic participant with two teenage daughters stated:

“Yes [my religious beliefs influence the ways in which I talk to my daughters about sex]...because like I said, we are Catholic, um, I just feel you know, that God does not want us going jumping from bed to bed, plus it affects you emotionally if you did that, ok? You don’t value that one night. I will still remember when I was almost 31, my honeymoon night, because it was something...and that’s the reason why that night was so special...not only morally but emotionally, you won’t know what real love if you’re just jumping in bed with every Tom Dick or Harry...and then you’ll get your mind all screwed up and you’ll never find that right man.”

Some participants (n=7) felt that their personal religious beliefs, or lack thereof, had no impact whatsoever because sex and reproduction were viewed as predominantly health or medical issues, so religious beliefs had no place in it.

“We’re Unitarian...so very liberal religious beliefs...sex isn’t something that’s going to be dictated by religious beliefs. It’s a health issue not a religious issue. I suppose you can say that there’s a moral issue, but really, it’s a health issue.” [50 year-old woman with two daughters]

A 44 year-old mother of two children stated:

“I have no religious aesthetic at all, so there’s none of that informs the way I communicate. There’s no Adam and Eve or any of that. So my communication is much more scientific/psycho-social. I don’t want to say just scientific, but it does not include a dynamic that includes a spiritual influence, or a religious influence.”

Still other participants didn’t feel that their religious beliefs played a huge role, but still expressed ambivalence about the extent to which their attitudes about sex were influenced by religious beliefs during the interview (n=3).

“[Do you feel that your religious beliefs affect the ways in which you talk to your daughter about sex?] No, because my beliefs are personal. What I believe and my concerns and my issues are really all me. Of course my religious beliefs may impact that but not really.” [47 year-old self-identified Jewish mother of two children]

This 44 year-old woman with one daughter explained:

“Well, I’m trying to encourage her to wait until she’s married...and I’m not sure if that’s necessarily religious. I know that’s what...I was raised a Catholic and

now we go to Episcopal Church. But aside from that, I think there's value to that for me..."

### **Sex and Politics**

Similarly, the extent to which political beliefs played a role in the conversations participants had with their daughters about sex varied as well; however, generally, participants were less likely to think that political opinions had an impact on the ways in which they approached the topic of sex with their daughters than their religious beliefs. For the most part, if political beliefs did come into play, it was in terms of being pro-life or pro-choice. A 50 year-old self-identified "liberal" participant explained:

Because [I] have a liberal attitude and I believe in education, I take a lot of political beliefs out of it when it's an educational issue."

This 39 year-old mother of three stated:

"...I'm not anti-abortion, I'm not very very religious, we go to Unity church and just no... I don't think so. I can see where people would be like that, but no [I do not feel that my political beliefs affect the ways in which I talk to my daughter(s) about sex]."

Another participant explained:

"Well I'm a Republican...so I mean...the only thing would be I guess the abortion issue, right to life, we're definitely right to life... but I don't think politics has anything to do with sex, besides the after effect." [49 year-old women with three children]

### **Perceptions of Sexual Debut**

As discussed in Chapter Two, ACIP recommendations for administering the Gardasil vaccine, as well as the age range for girls who would be impacted by HPV vaccine mandates nation-wide is 11 to 12. This age range was chosen because clinical



trials demonstrated that the vaccine had the highest immunologic response among these ages and that it is most effective before the onset of sexual activity. In order to address my research questions regarding the relevance of the Gardasil vaccine for their daughters, I was interested in finding out from the women I interviewed what they thought the average age of sexual debut was for the majority of American girls, subsequently followed by the same question about their own daughter(s).

Most of the participants felt that the onset of sexual activity for their own daughters would be after what they perceived was the age at which the majority of girls in the United States would have sex (n=21). The most frequent responses given for the majority of girls were 15 or 16, with most of the responses falling between 14-17 years old (n=20). Eight mothers, roughly one-third of the sample, felt that their daughters would realistically wait until marriage to have sex. Perhaps not surprisingly, these were the home school mothers and those that expressed the importance of religious beliefs. There was no difference in the types of responses given by mothers with girls in the younger, older, or mixed age ranges.

Fewer mothers had a more “realistic” outlook on where their daughters fit into the spectrum of sexual debut, either citing their own sexual behavior or a sense of practicality as to why they thought their daughters would be part of the majority and not the exception. A 44 year-old participant with four children stated:

“Um, I’d like them to wait until they leave college, how bout that? But I would be an idiot if I believed that there’s a good chance of that. I don’t believe there’s a good chance of that... I think everybody gets to make mistakes... and everybody’s vulnerable in their teenage years and they think they’re in love. I mean I had sex when I was 16, so how can I sit here and say oh yeah they should wait until they get out of college. I just don’t believe it’ll happen.”

Another participant shared:

“I hope...19, 20? When I think it will? I guess probably...I’d probably say 16, 17...I mean hopefully not...hopefully when she’s not living in my house, but...there are too many opportunities and too much time, and too much transportation...” [42 year-old mother of one daughter]

Another woman, a 40 year-old mother of three, expressed:

“Uh, I have no idea...I don’t have a problem with people being sexually active. I’d like for her to wait to be a little older because sex has so many consequences physically, emotionally...but because of her personality, anything I tell her to do she does the opposite of. In reality, probably earlier than the curve. She’s already told me, I want to have a boyfriend when I’m 12.”

Other participants wouldn’t give ages for their daughters but rather levels of maturity, albeit, still after the majority. A 47 year-old mother of a 10 year-old girl stated:

“I’m hoping [that she will have sex] way after the curve...I don’t think till marriage, just until she’s mature enough and in the right circumstances with the right person. Hopefully within a committed relationship.”

Another woman explained:

“I don’t know...I’ve made it really clear to them that high school is not the time to have sex...because I don’t think anyone in high school is prepared...they’re not emotionally ready...I’m hoping college. I’m not hoping they’re married first because I don’t care about that...that’s not important to me. I just want them to be old enough to know that it changes relationships and it attaches you to that relationship in a way that it maybe doesn’t for the guy.” [49 year-old mother of three children]

### **Children as Actual or Potential Sexual Beings**

Related to the previous theme, another important finding that emerged from the interviews was participants grappling with the idea that their child would, at some point in the future, have sex. However, as the previous section showed, the time frame in or milestone at which that would happen was quite variable. Several of the mothers I

interviewed expressed difficulty being able to process this fact, though they knew it would become a reality. Because acquiring HPV is tied to sexual activity, acknowledging that their child will be sexually active, to some mothers, seemed to be an important step towards considering the vaccine (n=10). Additionally, and returning to the notion of transmission, several participants distinguished between casually and sexually contracting a disease for which there is a vaccine within the context of their perception of their daughter's potential sexuality. Again, for some women, their daughter(s) engaging in sexual activity was imbued with a moral choice. Also, if participants felt that their child's sexual debut was not imminent, some did not see the urgency, or for others, the need, to have their daughters vaccinated against HPV at this time (n=9). A 49 year-old mother of an 8 year-old girl explained:

“I’m suspecting the fact that they’re vaccinating these girls at a young age means they expect them to be sexually active any moment now or something, I mean why aren’t they saying ok girls 5 years old, we’ll vaccinate them so we won’t even get into the topic of it [sex]. Here, when they’re older, you need to tell them why or I don’t know...it just opens up this other can of worms or discussions you’re going to have to have, or thinking about that...Oh my god...my child is one day going to have sex! Denial! We’re all in denial about these things.”

Additionally, another participant stated:

“I think it’s very difficult [to discuss sex with your child]...very, very hard, I mean, I don’t know...you’re talking about a little tiny person that is suddenly somebody else...You look at a 10 year old girl...and you think, “I’ve got lots of time. Why am I worried about this?” You don’t want to make that connection... and that’s a huge problem. The fact that we don’t want to make that connection... because there’s plenty of evidence to state otherwise...” [49 year-old woman with a 16 year-old daughter]

A 47 year-old mother of two home-schooled girls, aged nine and 12 stated:

“I would see that this particular disease and the transmission of it involves the choice on the part of the child, where as all the rest don’t...a choice for sexual promiscuity. And that’s forcing parents to have to view their child in that light...”

and they don't want to...that's not very professionally said, but no one wants to view their young lady at 12 years of age as having sex...I got this vaccine so let's go ahead...parents just don't want to go there."

Finally, another woman expressed:

"Um...I don't know, I wish I had a videotape of her doctor explaining it to me. He dropped that bomb and he saw my face...it's like he anticipated my shock... because I didn't say anything I couldn't...I was just caught totally off guard and ...I think it was so shocking because it's how young...it's just weird, it's like saying you're going to give a boy a vaccine at 10 so he'll never have erectile dysfunction. I mean it's so off the wall. I know it wasn't just me; because he said it so cautiously, like...don't throw anything at me! And he kept telling me, he said it 3 times, they're recommending it...like, we're not saying your daughter's gonna have sex tomorrow! I know it's not just me and my religious convictions...he's obviously gotten some flack about it. I don't know if that's religious or a parental...it's hard to think of your 10 year old... like do I really need to prepare her for this for 6<sup>th</sup> grade? It's weird!" [44 year-old participant with four home-schooled children]

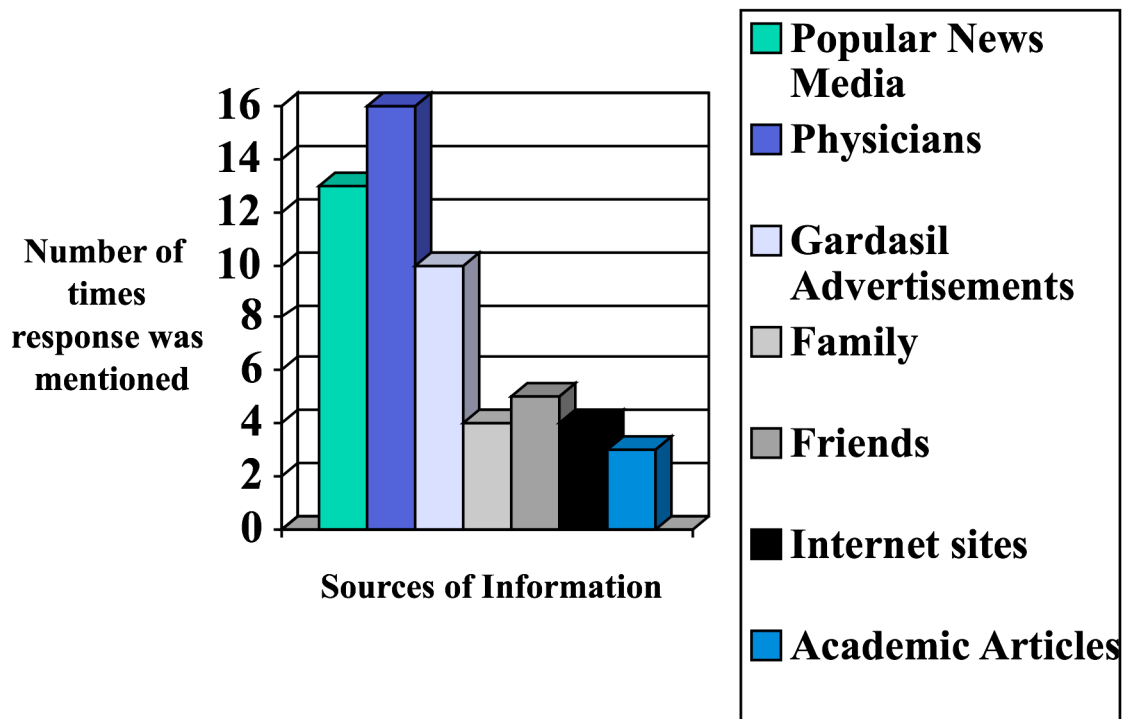
## **HPV and Gardasil**

Because the HPV vaccine Gardasil has been powerfully positioned in public discourse through intense media coverage and has frequently been presented in a controversial tone, part of my interview protocol attempted to address where mothers obtained and/or received information about the vaccine and HPV and what they knew about these topics. Figure 4.1 outlines where participants said they received and sought out information regarding HPV and Gardasil. The total n in Figure 4.1 does not add up to 25, as most women cited multiple sources of information.

Approximately two-thirds of the sample received some information from a medical source such as their daughter's pediatrician, a family member in the medical field, or their gynecologist (n=16). About half of the mothers interviewed obtained some information from a popular news source, such as newspapers, blogs, or magazine articles

(n=13). A little less than half of the sample cited the Gardasil advertisements as a source of information (n=10). Finding or seeking out information from non-medical community family members, friends, specific Internet sites such as the CDC, or academic journal articles were not commonly utilized sources of information in my sample; one-fifth or less of the women interviewed mentioned these resources. Additionally, many of the women remembered these sources of information being presented in a controversial light, particularly regarding the vaccine mandate debate in the state of Texas.

**Figure 4.1: Where Participants Obtained and Received Information about Gardasil and HPV**

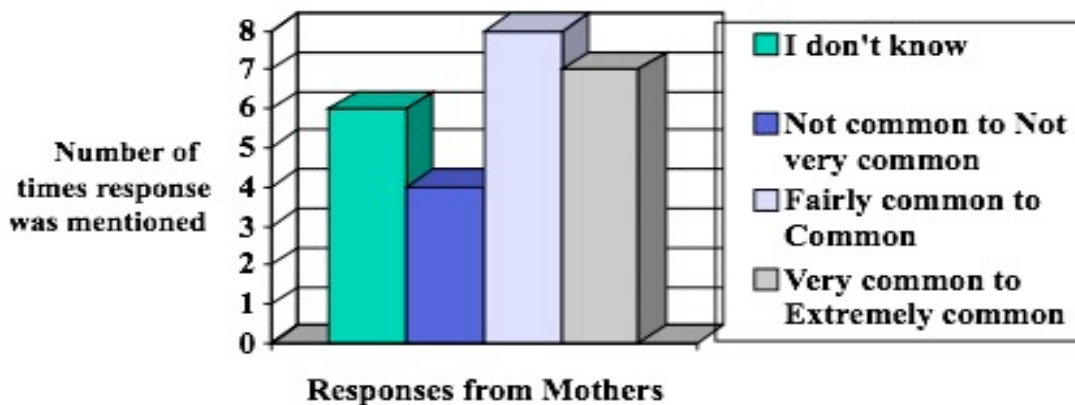


## Mothers' Biomedical Knowledge about HPV and Gardasil

My research questions also intended to explore what mothers knew about HPV – its prevalence specifically – and Gardasil – namely, what this vaccine claims to do. Further, I wanted to examine how mothers' perceived the relationship between HPV and cervical cancer. Biomedical knowledge regarding the prevalence of HPV, phrased in the interview as “How common do you think HPV is among sexually active people?” was quite diverse, as Figure 4.2 illustrates.

Over half of the sample (n=15) thought that HPV was “fairly” common to extremely common. About one-fifth of the sample had no idea how prevalent HPV was (n=6), with the rest responding that it was not very common (n=4). The lack of awareness about the high prevalence of HPV occurred more frequently with mothers who were also not planning on getting the vaccine for their daughters. HPV vaccination intentions will be described in more detail in the next section.

**Figure 4.2: Mothers' Responses to the Question: “How common is HPV?”**



Another question in the interview guide pertaining to knowledge asked participants what they thought the connection was between HPV and cervical cancer. The vast majority of women offered an explanation of the relationship between HPV and cervical cancer that included HPV's role as a virus that could turn into cervical cancer. There were varying degrees of sophistication in their responses regarding the relationship between HPV and cervical cancer. Widespread knowledge about the connection in my sample is perhaps not too surprising, as an inclusion criteria for participation was at least having heard of the HPV vaccine. Additionally, due to the recent development of a genetic test for HPV and the Merck and Co., Inc. media campaign "Tell Someone," describing the relationship between HPV and cervical cancer, the link between the two has received more extensive public attention.

Knowledge regarding the Gardasil vaccine itself varied as well, although most of the women knew that it was supposed to protect against HPV. Responses pertaining to when it should be administered (age criteria), dosage numbers, how many strains of the virus it protected against, and what the vaccine contained (a live HPV virus, heavy metals) were mixed. In addition, when I asked mothers what they knew about Gardasil, several discussed the potential mandates and other controversial aspects of it that were heavily featured in the popular media during the time in which I was conducting interviews. A 49 year-old participant with two children described her perceptions of the social and political trajectory of Gardasil:

"I remember hearing that it was going to be obligatory...they were going to pass some kind of legislation or something, and all girls between such and such would have to be inoculated whether they liked it or not... and it was just this big break through, that it's going to save women's lives, blah blah blah. That's what I heard about it at first. And then it was still in the news, and then it became...people

started saying wait a minute, we're not going to pass that here. Certain parents were saying, we're not going to pass that, we don't want to be guinea pigs. And then Merck backed off, because they were in cahoots with the government. And then it came out that it was only going to be effective against 1 strain or something? It wasn't going to protect women against all cervical cancer."

Another mother of two girls commented:

"They're recommending it to girls in early adolescence or preadolescent years... the idea being that it works better before you become sexually active. Apparently American Pediatric Society is saying to do this, so on the one hand there is this government seal of approval on it, but yet controversy still seems to be swirling around it."

### **HPV Vaccination Intentions**

A key part of my interview protocol examined whether or not participants indicated that they were planning on getting the Gardasil vaccine for their daughter(s) or had done so already. This quote by a 42 year-old mother of a 10 year-old girl provides an example of the various issues involved in whether or not mothers choose to vaccinate their daughters against HPV:

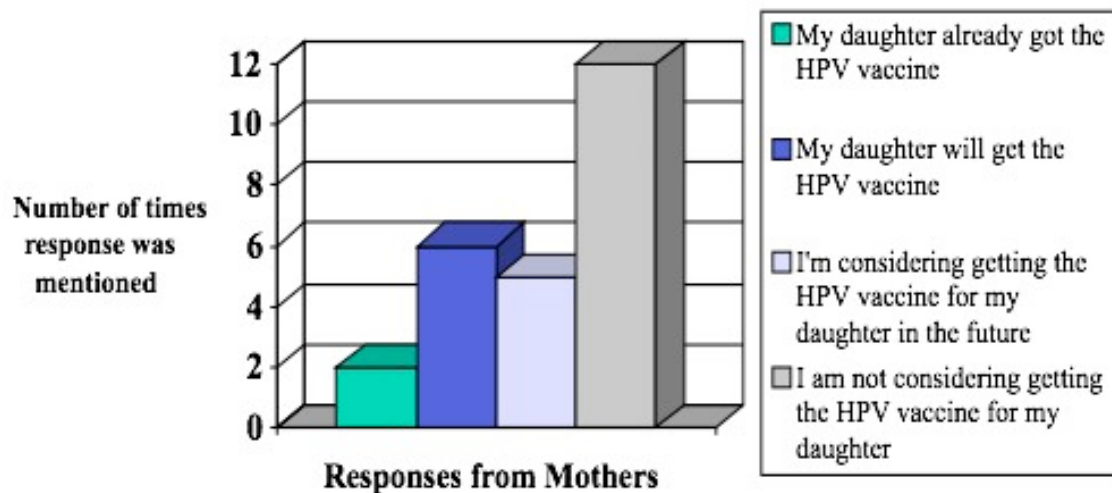
"I was sitting with a group of mothers, having lunch, there were 4 of us. Elizabeth brought the conversation around to this survey, and so we were talking about it. And we were all very anti-getting the shot...I mean it was just...we were almost rabid... and I'm looking at my friend at the end of the table and she's just incredibly quiet and in her lunch... and I was thinking what's wrong with her, and I'm watching her... and I just sort of stated my opinion that it's not time honored and time tested yet... and I'm like, Sarah? And she looked at me and goes... yeah I already gave her the vaccine... we just... went... (Makes facial expressions of shock)... you could have heard a pin drop. The girls were sitting on the other end of the table... they weren't paying attention to us...so we all just grabbed our sodas and started taking a drink. And she just said, well I just believe in it... we didn't say anything to her, we'd already commented. And she just felt the need to defend herself... all of us have known each other for 10-12 years... and we're all looking at each other, and she just felt the need to defend herself, and the only thing she could say in her defense, was, well I trust my pediatrician, and he said it was going to be fine... and I trust him. And I don't trust my pediatrician, as you know... so I was just like, well that's alright Sarah, no big deal... I mean I didn't



want to grind her into the stone... and that's the only thing she could say... was that she trusted her pediatrician... and I just thought, I don't trust my pediatrician as far as I can throw him. It's not trusting him, but believing in him to the point where I would let him make the decisions here."

Figure 4.3 outlines the responses I received from the women in my sample. Two mothers had already had their daughters vaccinated at the time of the interview. Six mothers expressed that they were going to do it in a relatively short period of time. Five participants were, at that point, unsure, but would possibly consider it with more research and/or time. Twelve mothers were against their daughters being vaccinated and had no intentions of getting the vaccine in the future.

**Figure 4.3: HPV Vaccination Intentions**



In addition to other concerns about the potential risk vaccines posed to their children, half of the participants who were against getting the vaccine for their daughters were also more unaware of the prevalence of HPV (n=6). Many of the participants who

were not considering the Gardasil vaccine for their daughters (n=12) had also expressed the importance of religion in their lives (n=8). Out of the eight mothers who had ever home schooled their children, seven were not considering having their daughters vaccinated, while one was considering it for the future. This 49 year-old participant who home-schooled her two daughters explained:

“I knew a woman who had it done (Gardasil)...The same doctor that we have. She did it, and she asked me what I thought about it and I said I wouldn’t do it... and she said well I did. Her daughter got nauseous, got a fever, got sick, and now she’s afraid to go for shot number 2. I think she’s like, ‘What’s this doing to my kid?’ And I didn’t want to say to her, “Gee I don’t know because there’s no way on God’s green earth I’m going to do this.”

Other reasons mothers were against the vaccine or unsure about vaccinating their daughters involved aligning oneself more with alternative or middle of the road medical orientations and/or expressing skeptical views of the medical community. There were no differences between mothers of daughters in the younger, older, or mixed age range. Additionally, much of the doubt expressed by those who were considering it in the future centered on the newness of the vaccine, as seen in previous sections of this chapter:

“I think it’s an incredibly good thing, but neither of my daughters have had it or started the series, because it’s so new I worry about the newness...do we really know what the long term effects are? Everything seems to have a plus and a minus...and I’m not ready to dump my daughters in yet. I feel confident enough right now that they still have time for us to find out where that vaccine is going. Is it as good as they say? If I trusted that it was really not going to have bad side effects down the line, I would take both my daughters down to get it done as soon as they were old enough to do it...that’s the only drawback, the only thing I worry about...do we really know for sure?” [43 year-old mother of two girls]

## **Conversations about Gardasil between Mothers and Daughters**

The convoluted junctions of morality, risk, susceptibility, sexuality, and the extent to which mothers aligned themselves with biomedicine were evident in conversations some had with their daughters about getting the HPV vaccine. Regardless of the extent to which Gardasil has been marketed as a cancer vaccine, the link between the behavior and outcome has clearly not been diminished in the public's perception, as evidenced by the controversial nature of the vaccine presented in the media. Because acquiring HPV is linked to a behavior, some participants felt that it was important to discuss the necessity for the vaccine with their daughters from several angles. Others felt that it was unnecessary to explain the details of transmission and that the topic of sex did not really need to be broached at all.

One mother of two teenage girls had already taken them to be vaccinated. She explained the need for getting the vaccine from both a cancer and sexually transmitted infection perspective:

“I basically told them, both of them, that it [Gardasil] was a protection against that virus thing and as they get older and they have more than one partner maybe, so the likelihood that they might get one of those diseases increases, so here's something that can help prevent that.”

Another participant with two daughters skirted around the topic of sex and appealed to the trust she and her children have with the medical community:

“I'm very explicit. It is, you get it now... I don't say because you're going to have sex tomorrow, but you get it now because something really bad could happen to you. They know they're gonna to have the shot, they know their aunt [who is an OB/GYN] recommended it, they know their pediatrician recommended it, it's a good thing to do and you should do it between 12 and 13 because that's what they said and they're the professionals... They know it's about both sex and cancer.

They probably know it more as a protection against cervical cancer... and less about because the way it would all happen for you to have sex.”

This 41-year old participant, who was planning on having her 10 year-old daughter vaccinated in a short period of time, did not feel the need to discuss the vaccine as anything other than cancer prevention with her daughter:

“...I think when I talk to my child about it, I’m not really going to bring up sex, probably, depends on when I do it. It’s more as a prevention of cancer... it’s totally medical.”

Conversely, other mothers felt that not informing your daughter about the nature of the transmission of HPV was inappropriate:

“I know that [my daughter] has a friend at school now and her mom said she had to get the vaccine...and her friends know...so they tease her, in a good natured way...“Oh, we know what your mom thinks you’re gonna do!” And she just like rolls her eyes...I would hate to do that to my daughter and say no it’s a cancer vaccine, and for her to walk in unprepared and have someone say to her, oh no it’s a vaccine against HPV which is a sexually transmitted vaccine so what are your parents thinking? Without her being prepared and understanding...that’s just chopping them off at the knees.” [43 year-old women with two daughters]

One 40 year-old mother shared a similar story regarding the experience her daughter had after her friends found out that she had received the vaccine:

“...Interestingly enough, my [12 year-old] daughter told her friends that she was having it done [Gardasil] and she came home upset one day and said that her friends were saying that she’s having the shot because she’s having sex or something about her having sex. And I was like oh my God no! You’re having it...her friends did not understand and she didn’t understand I guess so I clarified it. I told her she’s having the shot because if there’s a chance that she could you know, not have this horrible disease...” The fact that 12-year-old girls are aware of the sexual implications of this vaccine reflects just how widespread discourses about it have reached.

Another participant had a candid conversation with her 13 year-old daughter about the relevance of the vaccine, which demonstrates the thorny and intricate thought processes that are involved for some in deciding whether the vaccine is necessary:

“[My daughter] and I had a discussion about it. She had an ad in her magazine, and it says show this to your mom, and she says, well I’m not going to have sex until I’m married...and I’m going to marry someone just like me, so he won’t have sex until we’re married, so it won’t be necessary. So I said well unfortunately you don’t know what life has to offer you. You don’t know...you could be forced, or you pull up your end of the bargain and your husband is embarrassed that he had a little transgression and he doesn’t want to tell you...and he unknowingly infects you...and then you could end up with cervical cancer...you have no idea what can happen. She’s young enough that she thinks black and white...this is what I want, this is what will happen...and she might just be pigheaded enough to make it happen that way, but ya know...sometimes...people change too...you go off to college, you sew your wild oats, you test your boundaries...and I’m hoping that she doesn’t have a hard road, and that she stays with the church and with our beliefs...and she does what she says what she’s going to do...but I’m also realistic in that everyone’s going to do what they’re going to do...”

## **Government and Health**

The final topic that I wanted to explore in the interview protocol, which has been alluded to in other sections of this chapter, is the extent to which government, on a state and national level, should interfere with decisions parents make about their children’s health. I asked several open-ended questions regarding health standards, as well as vaccine mandates specifically – the extent to which parents find these appropriate, and how they would respond to an HPV vaccine mandate, if it were to happen in the future. Regarding the use of federal or state health standards in general, many of the mothers I interviewed felt that there was a huge gray area between what is necessary and what is bordering on intrusion. The majority of the sample expressed this ambivalence (n=23) though some felt more comfortable drawing lines in the sand than others. A 42 year-old mother of two girls explains:

“There has to be standards...and as a parent I feel comfortable that I would always make the right decisions for my child...But you have parents out there

who don't have the best interests. And I really stand by the state's right and obligation to say that a parent is negligent. But there's a lot of gray area...I don't want the government telling me...there's just a lot of gray in between."

Another participant with two daughters expressed the tension between individual rights and autonomy versus the greater good:

"I mean to a certain extent, when it's something for the greater society as a whole, I see how there have to be overarching laws to ensure safety and health of everybody. That said, there have to be some kind of provisions for cultural, religious, ethical considerations. We're not vegetarian for example. There has been a lot of stuff out there on children being raised as vegetarians and they're not developing the same way. So are those parents maltreating their children? Putting a child on no dairy, no meat, no eggs diet, and let's say that the government says, no you really can't...can you mandate that? What are you going to do with a devout Hindu? There's gotta be some kind of provision made for individual...but I don't know to what extent."

This 42 year-old mother of a 10 year-old girl offered tangible guidelines for the basis of what she considers necessary:

"... I mean, I think every child should see a doctor, I think every child should have a blood test, just ordinary things that could...does your child weigh too much, those kinds of things...you have to be able to compare your child to your child...but in terms of you have to have this injected into your body, or you have to have this medicine, then no. Basic medical care but nothing invasive should ever be mandated. Most people don't have children to have someone else tell them how to be a good parent..."

Those participants who self-identified as constitutionally conservative and/or Republican typically expressed their preference for less governmental control over parent's decisions regarding their children's health:

"Well...I'm a constitution person, so I'd have to say that...the government's role in the family stops with neglect or criminal behavior...that's their boundary...is enforcing laws against neglect or criminal behavior...I'm a less government person, I'm for small government...I don't believe in government intrusion, so anything that the government tries to condone, you should this or you should do that, I kind of feel infringed upon. That's not really a moral thing, it's just what I believe being an American is." [44 year-old self-identified "fiscally conservative" mother of four]

In terms of vaccine mandates, several factors that have been discussed previously in this chapter, such as the nature of the disease transmission, the severity of the illness, perceptions of vaccines as dangerous, medical orientation and political beliefs coalesced to produce complex, sometimes contradictory responses from the women in my sample. These responses could superficially be classified as leaning more towards individual choice or social responsibility; however, they were not clear-cut or consistent, and neither were the boundaries between parental choice and social responsibility. For the majority of the women I interviewed (n=21), even if they saw the utility of certain vaccinations and the need for some of them to be required, it was considered ethically sound for parents to have the choice to decline to vaccinate their children. This “opt out” part of vaccine mandate legislation provides parents with that choice, though the ease of doing so is debatable. Below are quotes that reflect a mother’s desire to have the ability to primarily make decisions about her children’s health. One 44 year-old woman with four children stated:

“I would have a problem if they ever required the flu vaccine. I’d be so angry. I go out of my way not to put my kids on lots of antibiotics, they eat healthy foods, they’re active in sports, and they have an amazing immune system. And they are never sick, ever. And if someone told me I had to get the flu vaccine, I’d be hopping mad. Because I think giving vaccines for frivolous things, I just don’t think that’s a good idea. That’s a problem with this country -- people’s immune systems are weakening because they’re not taking care of themselves. More should be done to educate people...in some ways I think I’m intolerant. It’s not that I don’t want to have empathy, but why don’t we try to find out what’s happening here before we go and put band-aids on everything?”

Another participant’s mistrust of vaccines and the risk it posed to her children also contributed to her opposition in requiring them:

“I willingly vaccinated – but I waited till they were a bit older. To pump a baby full of vaccines is beyond insane. I have a friend who had twins who were brain

damaged by vaccines...both had the same response to the pertussis of the DPT. And it was horrible. They didn't die but they were vegetables. It was heartbreaking. And you get some money, but who cares? Who wants money? You just want your healthy baby back. There are so many things horrible things in this world that you don't have a choice over...babies are born with defects, you're exposed to environmental stuff you can't do anything about, so it's not like you can plan this perfect life. But if you're going to willingly take something you know is going to damage your health, then it's unfair to make it mandatory. It takes away parental choice...it takes away a parent's right to raise their children the way they believe they should be raised, and that includes their health." [45 year-old self-identified conservative Christian mother of three]

There were also participants who identified with various aspects of this issue and grappled with the ethical integrity of vaccine mandates:

"Ohh...I'm always struggling with that line between individual rights and public health. Vaccinations have reduced the incidence of really serious diseases. I guess I support them being mandatory, I just...I want people to be more open-minded to consider the possibility of the side effects and/or unintended consequences. Like with the chicken pox vaccine, now we have an increase in shingles. People tend to think in black and white...yes there are benefits, but there are also other things to consider." [40 year-old mother of three children]

A 43 year-old woman with two daughters articulated:

"It's kinda like, you lock your doors to keep the honest people out because you know if there are people that are going to get in, they'll find a way in. So you lock your doors to keep most people honest. If you had the vaccines mandatory, I think a lot of people would get the vaccines anyway, because it's what I'm supposed to do...I think if it wasn't mandatory, there might be a lot of people out there who go, "Well, oh well...not a big deal...it's not mandatory I don't have to deal with it..." And I think a lot less people would get it done, so...umm...I hate people telling me what I should do or have to do...that kind of fed into the home schooling thing...and so when somebody says it's mandatory, it makes you go, why? Why are you trying to tell me what to do with my kids? But if it wasn't, you'd have so many people who would have just marched in and had it done, period, that um might not do it now...And so...that's a tough one. I really don't know, I really can't say."

A little over half of the women interviewed (n=14) explicitly expressed the necessity of requiring certain vaccines on the basis of societal good. As discussed in previous sections in this chapter, this is not to say that the women in my sample declined



to have their children vaccinated; on the contrary, only three mothers had declined to vaccinate against any diseases (chicken pox and Hepatitis B), while a few others delayed vaccination or gave the vaccines one at a time to their children. These contradictions and inconsistencies perhaps reflect how complicated the myriad of concerns and issues are that impact some parents' decisions to vaccinate their children.

This participant with two daughters supported making vaccines mandatory on the grounds of communal well-being:

“You wouldn't send your kid to school with a runny nose, I mean there's got to be a little bit of responsibility. With infectious diseases, you have to put a certain amount of responsibility. People who choose not to do it for medical reasons, but...I have a tendency to see a little bit more of the people who pick and choose, 'Oh I don't want inoculations but I don't really care...'; it's their sort of idea. And it's not religious reasons; it's just that they don't really want to do it. They can't really tell you why; they just don't want to do it. They've heard things about vaccines. They should think about it more as a whole. Look at the big picture.”

A 49 year-old mother of a 16 year-old girl explained:

“Look at the public schools. You're sitting in a classroom, sandwiched in with 40 other people in close contact...they make it impossible to stay home, because if you do, bad things happen to you academically. There's nothing supportive about letting this resolve naturally. The other side is, you do have 40 people in there... You cannot have diphtheria running rampant...Then, this is no longer your choice. You're making choices for other people. If you are on a farm out in the middle of a field and you home school your kids, and you don't wanna do vaccines, don't go into town man! But when you're dealing with population in close contact, I just don't see how you cannot do it. It's not like, “Oh gee well I have nothing better to do today.” There were real issues that people were trying to cope with of illness. We don't live alone...we don't live alone...If you choose not to do it for your child, are you exposing some one else's child? People need to think about why these things were created...because of really really bad situations.”

Aside from four women who were intending to get the HPV vaccine or had already done so for their daughters, the majority of the mothers I interviewed did not and would not support a vaccine mandate at this time (n=21). The responses I received

regarding whether or not mothers would opt out of a future HPV vaccine mandate were mixed and, of course, hypothetical. In addition to the issues explored in the previous section regarding parental autonomy, the newness of the Gardasil vaccine, concerns about long-term safety, and the avenue of transmission (sexual, not casual) provided further impetus to reject the idea of requiring it.

“Even though I think that it’s a good thing to do and that any responsible parent should investigate it and make a decision for their child’s health, I don’t think it should be mandatory because it’s not ... it’s not like something you can spread... I mean you have to have an intention. And I just think that maybe that is something that parents should decide for their daughters... the state shouldn’t tell you what to do in that regard.” [50 year-old woman with two daughters]

A 41 year-old mother of four children stated:

“I don’t think there’s a valid reason to make it mandatory because I don’t think it kills other people...like, it does, in that years and years and years later cervical cancer could show up, but the parent can choose to protect their own child from that, where as measles, which was a killer, was highly contagious and could kill others. Because I would be really offended if they ever made a vaccine for AIDS, and they remotely suggested that that was a required vaccine. Because it’s that same... life choice issue...”

Finally, this conservative Christian mother of two home-schooled girls articulated:

“There is a shift towards thinking that we the American public cannot protect ourselves and therefore the government is going to tell us what we have to do. I can understand it in some cases like polio, like things that are communicable, that can be transferred to other people for public safety. But because I have cervical cancer doesn’t mean I’m going to pass it to somebody else. So I think they have no right to make that mandate. I can almost understand, like I said, if it’s going to affect the public. If I’m coughing on you and you’re gonna get it too? Makes more sense. And the same thing with like we have now, kids have to have all those various shots and things... Personally, I don’t agree with those being required. I think again that the government has taken away our rights as individuals...but in this case parents have the right to make decisions for their child. The government has decided they know better than we do. To what level of control is this going to lead? You see it happening...to what level of control?”

## **Conclusion**

The constellation of social, moral, and health issues interlaced with the widely used prevention strategy of vaccination became very apparent in my thesis research. In addition to the widely perceived gray area around governmental infringement upon parental choice, subjective assessments of risk, and concerns over the medical integrity of vaccines, HPV vaccines introduce differing conceptions of morality and sexuality into the discussion. It became quite challenging for many participants to separate these highly contested and deeply personal beliefs and motivations from one another, as indicated by the widespread ambivalence expressed throughout the interviews. While vaccines are not new, the changing climate of increasing skepticism towards biomedicine by some groups and greater access to various types of information for some populations has affected the ways in which parents make health care decisions for their children. Additionally, the traditional perception that vaccines are solely meant to prevent diseases that are easily spread and casually contracted contributes to the anxieties about the HPV vaccine that the mothers I interviewed shared with me. The next chapter will present a discussion of the results presented in this chapter, as well as offer limitations to this study, implications for anthropology and public health literature, recommendations, and conclusions.

## **Chapter Five: Discussion**

### **Introduction**

This chapter will summarize and draw conclusions from the results presented in the previous chapter. In addition, findings from the study will be related to the disciplines of anthropology, applied anthropology, and public health. Limitations of this research project will also be described and recommendations regarding the issues outlined will then be offered.

### **Media Analysis Findings**

Several overarching and important themes emerged from the media analysis, some of which relate to the interview findings presented later on in this chapter. More than half of the sample (n=17) adopted a pro- or defensive position about the Gardasil vaccine. Most of the pro-vaccine articles in general could be considered editorials or opinion pieces, a forum in which authors' perspectives are considered appropriate to include. Over half of these more positively slanted articles (n=9) came from Salon.com, a liberal online news magazine. The authors' biases were most powerfully felt in the articles from this news source, where conservative perspectives about the vaccine were frequently attacked.

Regardless of their orientation, almost all of the articles depicted Gardasil as being mired in controversy for one reason or another, indicating the widespread public

ambivalence about this vaccine (n=26). Polarizing and sensationalist language was frequently used to highlight and describe the contentious debates about Gardasil occurring across the nation. Headlines such as “Yikes! An STD Vaccine for Sixth-Graders” and “Injected into a Growing Controversy” immediately presented the topic in this way (Sayre 2007; Ramirez 2007). In many of the Salon.com articles, for example, conservative views were ridiculed, as exemplified by this quote: “Conservative forces like the Family Research Council decided that mandating the vaccine is as good as sending our nation’s girls into a “Girls Gone Wild” audition with their tiny pocket-T’s bulging with lubricant” (Lloyd 2007a).

The controversy was most frequently attributed to the bill that was introduced and passed temporarily in Texas by governor Rick Perry, as well as other bills subsequently introduced across the country. About 25 percent of the articles sampled presented views by parent organizations or public health/medical professionals that vaccine mandates were premature and/or intruded on parental decision-making regarding their children’s health. In addition, many of the articles presented viewpoints reflecting some parents’ and religious groups’ concerns about the vaccine promoting promiscuous behavior among teenage girls. Other reasons for the controversy surrounding Gardasil described in the articles sampled included the perceived collusion between the government and Merck Pharmaceuticals, the newness of the vaccine and concerns about its safety in the long-term.

Approximately one-third of the articles sampled provided epidemiological information regarding the prevalence and incidence of HPV and cervical cancer, as well as what protection Gardasil offers. This information was frequently disseminated in

quotes or paraphrases from the CDC, public health researchers, and the American Cancer Society (ACS). Salon.com articles almost never included this information; if authors did describe HPV and its potential sequelae, it was much less detailed than information found in the other media outlets. Finally, about 25 percent of the articles sampled presented information on the role of HPV in male cancers and/or the potential for Gardasil or another HPV vaccine to be administered to males in the future.

The media analysis revealed several popular trends depicted in the public discourse of the vaccine, many of which were shared by participants in the semi-structured interviews. These include most of the reasons identified in the analysis regarding the controversial aspects of the vaccine, particularly the intrusiveness of an HPV vaccine mandate, the perceived inappropriate relationship between pharmaceutical companies and the government, the newness of the vaccine, and concerns that it may lead to more promiscuous behavior among girls.

### **Interview Findings**

The semi-structured interviews conducted with mothers of girls provided an excellent opportunity to explore their attitudes towards health seeking behaviors, and in particular, vaccination for their children. Additionally, the ways in which mothers approach the topics of sex with their daughter(s), the HPV vaccine specifically, and governmental involvement in decisions parents make about their children's health were examined through the interviews. While my sample size was not large enough to discern generalized themes, there were several important observations and trends discovered.

First, the medical orientation of mothers appeared to be of significance when

discussing the utility and importance of vaccination as a primary prevention strategy and the HPV vaccine in general. While the majority of mothers placed at least some level of confidence in their children's physicians, those who shared more skeptical perceptions of the medical community and those who valued alternative medical systems were, in general, more leery of vaccines, including an HPV vaccine. This finding is also shared by Leach and Fairhead (2007) in their assessment of mothers in the UK who declined to vaccinate their children with the MMR vaccine. Additionally, these exploratory results seem to corroborate with what anthropologists Whyte et al. argue has been a worldwide resurgence of the use of "herbal medicine and other natural products" (2002:74). They explain, "In high-income societies the revival of natural medicines is mainly the expression of unease with the iatrogenic character of biomedical products and the popularity of 'back-to-nature' and 'New Age'-type movements" (2002:74).

Further, the mothers I interviewed who were of a more "alternative medical orientation" were typically more outspoken with regard to the extent that the government should or should not meddle in decisions parents make about their children's health. These findings also correlate with Colgrove's (2006b) characterization of the values held by parents who were in opposition to vaccination. These values included supporting more natural forms of healing and approaching health care from an alternative viewpoint. They also included opposing the obligatory nature of vaccine mandates and "what [parents] viewed as an overweening government bureaucracy attempting to dictate choices about health that should be left to individuals" (Colgrove 2006:238).

The notion of vaccines as potentially or actually risky was quite prevalent throughout my sample. Many mothers expressed concern about what vaccines actually

contained (heavy metals, toxins, or live viruses) or what they could lead to (autism, unanticipated and unforeseen side effects in the future). I did not explicitly ask any questions about the popular perception that vaccines are related to autism, but over half of the women I interviewed shared their opinions about the supposed connection and the level of validity it held for them. These discussions provided a unique opportunity to explore the degree to which this correlation, which has been given little scientific credence (see Colgrove 2006:229-251), is embedded in the public's consciousness. The prevalence of responses from mothers linking autism and vaccines in some way indicates relatively high levels of awareness about this purported, as yet unproven, relationship.

Another aspect of risk related to vaccination that I observed was the widespread subjectivity about the severity of disease. Mothers frequently made distinctions about the seriousness of a disease like polio, for example, versus chicken pox. These differing perceptions of disease severity also played out in the attitudes women held regarding HPV and the importance of the Gardasil vaccine for their daughters.

Despite the prevalence of comments from mothers indicating concern about vaccine safety and the risks vaccines posed to their children, however, most of the women in my sample did not decline to vaccinate their children against any of the required vaccines. Out of the 25 women I interviewed, only three had ever declined to vaccinate against either Hepatitis B or chicken pox. More frequently, mothers negotiated required vaccines by delaying inoculation or having their children receive one vaccine at a time.

In terms of Gardasil specifically, the majority of participants had not obtained the vaccine for their daughters, and about half were not considering it in the future. The



narratives of risk portrayed by my participants about vaccines in general also carried over into their concerns about this new vaccine, but were additionally compounded by several other factors. These included the sexual transmission of HPV and a mistrust of the medical community's motives. Mothers frequently noted that the difference between a vaccine to protect against HPV and all of the other recommended vaccines was the route of transmission, which was sexual, as opposed to casual. For others, particularly those mothers who stressed the importance of religious faith in their lives and imparted sexual health information to their daughters through this lens, the transmission of HPV was not only sexual, but a moral choice on the part of the female. These mothers comprised the majority of women in my sample who home schooled their children, and several others who emphasized the importance of religion in their lives. The words and phrases promiscuity, high-risk, and life style choices were frequently used to convey the "moral" aspects of acquiring HPV.

Another prominent trend I noted throughout the interviews was the discord between when mothers thought the majority of American girls would have sex for the first time, and when they thought this would occur for their own daughter(s). While it was easy for many to acknowledge that most girls would reach sexual debut in their teenage years, it was difficult for them to place their daughters in the majority. Mothers with younger daughters appeared to have had a particularly hard time answering this question. A similar trend that correlated with this discord was conceiving of your daughter as a potential or actual sexual being. The women I interviewed often expressed difficulty thinking about their daughter becoming sexually active, which becomes

important when contemplating the relevance of a vaccine that protects against a virus that is only transmitted sexually.

The extent to which knowledge about HPV and Gardasil correlated with mothers' interest (or lack thereof) in obtaining the HPV vaccine for their daughters was not consistent. In general, a mothers' level of knowledge about these topics did not necessarily indicate that they would consider vaccination for their daughters at this time. This seems to suggest that solely educating parents about HPV and Gardasil may not be sufficient in improving HPV vaccine acceptance and coverage rates. Again, this finding correlates with Leach and Fairhead's (2007) assessment that the medical community frequently cites "misunderstanding" or "ignorance" on the part of the medical consumer as barriers to compliance with vaccines; if we could only develop a way to give them the "correct" information, parents would embrace vaccination. The fact that some participants who exhibited higher awareness about HPV's prevalence and the role it played in cervical cancer were not necessarily in support of getting the HPV vaccine for their daughters demonstrates that other issues in vaccination are important as well. Some of these issues, identified by the women in my sample, are an increasing skepticism towards medical "breakthroughs," a desire to wait until, in their mind, the vaccine had proven itself to be safe, and a belief that this vaccine is not relevant to their daughter's health.

Additionally, many of the women in my sample sought out various sources of information about HPV and Gardasil, perhaps indicating an increasingly active role on the part of the medical consumer. Much of this information was from family doctors and gynecologists, but a considerable amount was obtained through the popular news media

and Gardasil advertisements. Therefore, the range and quality of information these women received was quite variable. Historically, vaccination campaigns have played upon an array of emotions to encourage vaccination, as exemplified in the quote below:

Many of the campaigns overtly sought to characterize the failure to immunize a child as morally culpable neglect. A 1978 radio spot featuring Marion Ross, the actress who played the mother on the popular television sitcom *Happy Days*, made this charge: 'If your child comes down with polio, measles, diphtheria or mumps, it's probably your fault, because your child was not properly immunized.' Along with inducing parental guilt, a prominent rhetorical tactic in persuasive efforts has been to create a sense of urgency by emphasizing—or magnifying—the risk of illness. (Colgrove 2006:11)

With the FDA approval of direct-to-consumer advertising (DTC) in 1997, Americans have increasingly received information about prescription drugs, including vaccines, from commercials and advertisements. While perhaps less explicit than the previous example of a vaccine campaign from the 1970's, I would argue that the ubiquitous Gardasil advertisements, with their campaign slogan of "One-less," (meaning, one less cancer statistic) play into widely held societal and cultural fears regarding cancer as a death sentence. Additionally, because HPV does not always progress to cervical cancer and in fact clears on its own more often than not, the overt message presented in this vaccine campaign to prevent cervical cancer may be perceived as exaggerated by some.

Finally, mothers conveyed ambivalence about the extent to which the government should be allowed to regulate decisions parents make for their children's health. This ambivalence was typically not represented by the women in my sample as a clear-cut division between individual rights and social responsibility, which is often the dichotomy presented in the popular news media and, particularly in terms of vaccination, in some of

the public health and bioethics literature. Rather, mothers I interviewed often saw the justification for both having the ability to solely decide what is best for their child and also the societal expectations that come along with living in a community. Many participants expressed difficulty in answering questions pertaining to governmental involvement in the health care decisions parents make for their children. Moreover, the frequently ambiguous and contradictory responses they gave perhaps reflect how complex and intertwined some of the issues involved in vaccination decisions are for some.

In terms of vaccine mandates specifically, however, most felt that parents should have the right to opt out of a required vaccine if they so chose. Because of the newness of the HPV vaccine Gardasil, skepticism about the intentions of policy makers and pharmaceutical companies, and the avenue of transmission indicating a “choice” on the part of the child, the majority of women I interviewed did not support a mandate at this time. Considering the massive public outcry over the vaccine mandate in Texas in February of 2007, it is perhaps not surprising that this measure would also not be popular among participants in my sample.

### **Implications for Anthropology and Applied Anthropology**

First, the use of methods such as participant observation and in-depth semi-structured interviewing in this research project contributed an important perspective regarding vaccination. In particular, anthropology’s epistemological contributions,

including the use of emic points of view, holism and context have been of utmost importance in this study, as the analysis of data included positioning the perspectives of participants within the larger social, political, and biomedical structures that support vaccination.

Second, findings from the research conducted for this thesis have several implications for the anthropological literature presented in Chapter two. As described earlier in this chapter, the women I interviewed shared varying attitudes and beliefs about what constitutes risk in terms of disease severity and susceptibility and vaccines for their children. These findings seem to support anthropological research on risk from Leach and Fairhead (2007), Douglas and Wildavsky (1982), and Pool and Geissler (2005) presented in the literature review of this thesis. While the contexts of these research endeavors were divergent -- vaccines, pollution, and HIV/AIDS, respectively -- the underlying discourses regarding differential representations of risk were present in all.

Several interview questions posed to participants attempted to examine their opinions regarding some of the bioethical considerations about government health standards, vaccines and mandates that were presented in the literature review. Findings from this part of the research were frequently contradictory and the questions posed were often difficult for participants to reconcile. Prevailing traditional perspectives in bioethics that tend to unequivocally position values such as autonomy against the "common good" are not consistently supported by the findings from this study. The diverse ways in which participants contextualized their vaccine experiences and

narratives of risk does seem to support contributions made to the field of bioethics by anthropologists such as Marshall (1992) and Muller (1994) regarding the subjectivity of morality in health standards. The ambiguity of responses seems to suggest that more research is needed to adequately explore these beliefs from an emic perspective.

Many of the women I interviewed offered detailed accounts of their experiences not only with vaccination, but with biomedicine in general. These included both positive and negative experiences concerning their children, and frequently, themselves. An examination of biomedical culture and its intersections with technology provide anthropologists with opportunities to explore issues of ideology, power, and the dissemination of knowledge (Casper and Koenig 1996). Robert Hahn articulates,

...The culture of a society constructs the way societal members think and feel about sickness and healing. That is to say, the members of a society are taught by others about different sicknesses and their names, their characteristic symptoms and courses, their causes and mitigating circumstances, their cosmological and moral significance, and appropriate responses. (1996:77)

The results of this thesis research are very relevant in an examination of biomedicine as a cultural system, as widely differing representations of what constitutes risk with regard to vaccines, sexual behavior, and disease prevention were evident throughout all of the interviews.

Finally, the findings from this exploratory study do seem to support anthropological research presented in this thesis on medications and vaccines put forth by Whyte, Van der Geest, and Hardon (2002), as well as Leach and Fairhead (2007). In particular, an increasing skepticism towards pharmaceuticals by consumers in Western contexts described by Whyte and colleagues (2002) was evident in the responses of many

of the women I interviewed. Most findings presented in Leach and Fairhead's research (2007) in the United Kingdom on parental framings of and concerns regarding vaccination were also of significance in this research. The key concepts of trust (or lack thereof in the medical community), risk, and rumor, as defined by Leach and Fairhead (2007), were present in the ways in which mothers described their attitudes, beliefs, and behaviors regarding vaccination. The findings from this study in many ways reiterate Leach and Fairhead's position that an understanding of the ways in which parents interpret and contextualize vaccination are just as critically important as the ways in which the medical community does (2007). By exploring where and how these often differing "framings" intersect, more appropriate and relevant public health policy decisions regarding vaccination can potentially be developed.

### **Implications for Public Health**

This research also has important implications for public health and the larger medical community because as a discipline, public health is responsible for advocating the use of vaccines as a primary prevention strategy and improving vaccine coverage. First, definitions of risk must continue to take into account that people conceive of their and others' susceptibility to illness in very different ways. This differential risk, therefore, does not easily lend itself to being standardized and considered acceptable by the multitude of diverse stakeholders impacted by such a definition.

Second, the research completed for this thesis does not tend to support the results of several public health studies conducted on parental acceptability of an HPV vaccine (Constantine and Jerman, 2007; Ogilvie et al. 2007; Lenselink et al. 2008). While those

studies cited acceptance rates between 70 and 88 percent, the participants in my study indicated a much lower acceptance rate, with only about 50 percent having already obtained or considering obtaining an HPV vaccine for their daughter(s) in the future. This discrepancy could be the result of numerous confounding variables or due to the lack of a representative sample in my study. Additionally, my study was conducted only a few months after the HPV vaccine received widespread public attention in the context of the Texas mandate controversy, about which many of the women I interviewed were familiar. This information could have also impacted the opinions voiced by many of the participants in my sample.

Third, ethical implications regarding an HPV vaccine mandate, as outlined in the literature review, were largely supported by the results of this study. Specifically, the distinction between the sexual nature of HPV versus other diseases for which there are vaccines that are contracted casually was reiterated by most of the women in my study. Additionally, Colgrove's commentary (2006a) on an HPV vaccine mandate being opposed not just on religious grounds, but also for philosophical reasons, mistrust of pharmaceutical companies, and a preference for alternative medicine was also substantiated by the results of this study.

While I did not find the presence of a well-defined "anti-vaccine" movement among my sample, I did hear smatterings of comments by participants regarding ways to negotiate vaccine mandates if one was opposed to them. For example, some of these mothers alluded to alternative networks of doctors who would agree to see your non-vaccinated child. In addition, there were mothers in my sample who had developed risk



reduction techniques such as spacing out vaccines or having them administered one at a time to their children. Leach and Fairhead write,

The emergence of parental networks and mobilization around vaccination...should not be written off in negative terms simply as problematic 'anti-vaccination' movements. Again, there are often more positive dimensions, striving for child health, sometimes appreciating some aspects of vaccines, but expressing concerns and uncertainties about others. Such mobilizations are an inevitable corollary of the fact that there are diverse experiences and ambiguities that, at certain moments, clash with public health perspectives to such an extent that controversy results. Mobilizations need to be taken seriously as valid forms of public participation in the politics of knowledge around vaccination, as indeed around the directions and impacts of science and technology more broadly. (2007:173)

Again, an exploration of the ways in which mothers negotiate vaccines and vaccine mandates, including those methods or decisions that might be deemed subversive or non-compliant by the medical community is important in developing appropriate public health policy with regard to vaccination.

Finally, a response often advocated by researchers assessing the HPV vaccine's acceptability among parents has been education (Gonik 2006; see also Waller et al. 2006). While beneficial to a certain extent, the idea that parents simply need new and better information with which to make sound scientific decisions ignores the complex array of factors involved in making this decision for some parents. For example, numerous literature reviews, commentaries, and academic opinion pieces have mentioned the popular concern that an HPV vaccine might be seen as promoting or encouraging teenage sexual activity (Adams et al. 2007; Constantine and Jerman 2007; Dailard 2006; Dempsey et al. 2006; Gonik 2006; Kahn 2007; Lenselink et al. 2008; Mays et al. 2004; Monk and Wiley 2006; Ogilvie et al. 2007; Sturm et al. 2005; Waller et al. 2006; Zimet

2006). Some health researchers have attempted to refute this claim by asserting that the argument that a preventive tool such as vaccination would encourage a particular behavior is not sound logic (Monk and Wiley 2006). The research conducted for this thesis found that some participants expressed a concern that saying yes to the vaccine was also saying yes to pre-marital or premature sexual activity. Not surprisingly, these participants also identified the importance of religion in their lives. Therefore, utilizing education to counteract or “disprove” what may be considered by health professionals to be illogical or unfounded beliefs regarding sexuality is probably not very realistic in this context. As Dempsey et al. (2006) report and this research echoes, many other factors come into play when weighing the pros and cons of vaccination for some parents, not simply biomedical knowledge. This includes belief systems that may conflict at times with the perceived underlying assumptions of some biotechnologies.

Because this is an exploratory study, more research is needed to evaluate the extent to which these beliefs impact such health care decisions. It is of importance, then, that the other concerns described by the participants of this research be considered by public health and medical researchers and practitioners charged with improving vaccine coverage rates. Dempsey and colleagues’ study (2006) on HPV vaccine acceptance among parents acknowledges the limitations of a traditional health education approach, reflecting shifting and diverse perspectives within the discipline of public health. Dempsey et al. report,

Our results suggest that although providing parents with an HPV information sheet did seem to improve knowledge levels about HPV, at least in the short term, this increased knowledge had little effect on the acceptability of HPV vaccines by parents for their children. These results suggest that simply “educating” parents about HPV and HPV vaccines may not be sufficient to influence their attitudes towards HPV vaccination, as attitudes may be driven by other, non-informational preferences. (2006:1491)

### **Limitations of the Research and Future Directions**

There are several limitations of the research that restrict the ability of the findings to be extended to different groups and contexts. In addition, several future avenues for research have been identified. First, the size of my sample (n=25) was only sufficient to uncover trends and observations. A larger scale study would need to be conducted in order to confirm the findings from this exploratory research project. Additionally, dividing the sample into groups to compare and contrast for differences between age ranges or whether the participants had home schooled their children proved even more limiting, as each group typically contained fewer than ten participants. Also, the sampling design utilized was snowball, or convenience, which does not produce a representative sample. Furthermore, one-third of the women in my study belonged to some type of Christian-denomination and currently or at one time home-schooled their children, which also reduces the generalizability of the results. In addition, the majority of women in my sample identified themselves as being “Caucasian” or white. It would be interesting to conduct a similar study among other self-identified ethnic backgrounds and see if any significant differences emerged.

Another important limitation of this study involved the level of education among the participants in my sample. Almost all of the women had obtained at least a Bachelor’s

degree (n=23) and an additional one-third held post-graduate degrees. This educational level could have impacted the lower rates of HPV vaccine acceptance found in my sample as compared with previous studies' findings outlined in Chapter two that found significantly higher rates of parental acceptability of an HPV vaccine for their daughters. A potential future direction for research might be exploring the extent to which educational attainment among parents, and mothers specifically, impacts attitudes towards this particular vaccination.

An additional limitation was that the questions regarding a potential HPV vaccine mandate were hypothetical, as no such legislation passed in Florida. Therefore, an interpretation of responses from the women must take that into consideration. If such legislation is mandated in Florida, it may be important to assess mothers' perceptions of an actual mandate and how they decide to negotiate that legislation.

Finally, interviews were conducted only with mothers of girls, not fathers or other caretakers. The justification for doing so was determined sound by the PI and her thesis committee members; however, participants were asked how health care decisions were made for their children generally in the introductory portion of the interview protocol. Interestingly, many of the participants with husbands stated that while they may discuss child health care-related issues together, the decision ultimately rested with the woman. One participant shared a particularly powerful experience regarding her husband's infuriation at their daughter receiving the first dose of the Gardasil vaccine without his consultation. This may indicate that this particular health care decision, perhaps because of the Gardasil vaccine's sexual connotation, necessitates different dynamics in conversations between partners about their daughters' health. Future research should

consider taking this into account by interviewing partners separately and together in order to better understand if and to what extent differences exist between how health care decisions are made with regard to HPV vaccination.

## **Recommendations**

The need for collaboration and communication between the medical and governmental institutions who promote vaccines such as Gardasil and the public has been apparent throughout my research. There has been widespread ambivalence and apprehension about this vaccine and potential mandates from a variety of stakeholders due to a diverse constellation of factors. Therefore, it would likely be very important for states considering mandating HPV vaccination to understand and take into account stakeholders' needs and concerns. The "good science" frequently touted by the medical community regarding this vaccine is clearly not the only factor influencing why people would support or reject it. Leach and Fairhead articulate,

Many debates about and explanations for controversies over public issues involving science are framed in terms of public (mis)understanding or lack of understanding of science, technology or its risks. In an extension of this 'deficit model', the lack may not just be of knowledge, but of trust – in both science itself and in its governance. The emphasis is on the negative – deficits of knowledge, deficits of rationality, deficits of trust – on the part of the public. And in response, scientific institutions are called to respond by winning hearts and minds. But this well-established set of perspectives, in focusing on what people do not think or understand, misses what they do think and understand. It obscures why what they do think might make sense, as part of their everyday lives and experiences, values and conceptualizations of the issues involved. It misses the opportunity to identify the 'framings' – forms of knowledge, value, and social commitment – that people bring to an issue, and which shape their anxieties about it, whether positive or negative. And it misses opportunities to identify mismatches between people's framings, and those of the institutions involved with science or governance. (2007:4)

While Leach and Fairhead (2007) certainly bring up pertinent points that are extremely relevant to this research project, it should also be pointed out that many of the women with whom I spoke saw the HPV vaccine and therefore a potential mandate as a complete surprise. This finding correlates with public health studies that have indicated that general awareness about HPV and its potential sequelae have been low (Gonik 2006:1). Public health education about HPV, cervical cancer, and the vaccine by itself will likely not increase HPV vaccination acceptance given the multitude of other concerns expressed by the women in my sample, but it may be marginally useful when one considers the relative lack of awareness about HPV.

Moreover, the Gardasil vaccine is in a unique position in the immunization landscape in that it protects against a disease that is only contracted sexually, but can lead to cancer, which is an entirely novel concept in both vaccines and cancer prevention. The traditional utility of vaccines, from the perspectives of the mothers I interviewed, was to protect children from diseases that are acquired casually and spread easily. Many of them could not see how this vaccine fit into that paradigm, since its transmission is not, in their minds, casual or easily spread. That some parents and other stakeholders find it difficult to conceive of vaccines as protecting against other diseases that do not fit this model, particularly those that are sexually transmitted, needs to be considered and incorporated into public discussions and policy development.

Additionally, as Leach and Fairhead (2007) argue, dismissing parents' concerns and fears about vaccines as irrational is ultimately not a helpful perspective for the

biomedical community. Increasing numbers of parents, albeit currently a small percentage of the population, are choosing to opt out of vaccination because they do not know what to make of the risk vaccines pose to their children. This reality should be acknowledged and discussed openly by the medical community, rather than regarded as illogical or unfounded. Quoted in Colgrove (2006b), Edgar Marcuse, a former member of CDC's ACIP articulates, "Just as war is too important to be left to the generals, so immunization mandates are too important to leave to public health authorities... We must explore how better to involve the public in the issue of mandates as policy is formulated..." (240). As state vaccine mandates for HPV are unlikely to disappear from the political landscape, it will likely be important for any future politics regarding an HPV vaccine to be communicated in an open, dialogic way to stakeholders and interest groups.

## **Summary**

The research conducted for this thesis attempted to address several overarching anthropological issues involved in the socio-cultural context of childhood immunization in the United States, with particular attention paid to the HPV vaccine Gardasil. One of the most prominent and relevant concepts relating to immunization is how risk is perceived and understood by the diverse stakeholders impacted by such a widely used primary prevention strategy. As discussed in Chapter two of this thesis, anthropological research on risk has examined the ways in which, in various settings, risk is differentially

understood and interpreted (Douglas and Wildavsky 1982; Pool and Geissler 2005; Leach and Fairhead 2007). The results of this thesis reiterate that an exploration of the ways in which risk is framed and an identification of where divergences lie may be important in developing more informed health policy and health education messages.

Another overarching anthropological issue of importance to this research has been an examination of the ways in which mothers respond to and negotiate biomedicine as a cultural system. More specifically, an examination of the values underlying this particular type of ethnomedicine and the subjectivities inherent within it relating to vaccines and disease prevention has been of relevance for the research questions investigated in this thesis. Another theme covered in this thesis was the importance of understanding the ways in which the biomedical community and parental perspectives on the purpose of immunization and the dissemination of vaccines are sometimes not in agreement. An argument made in this thesis was that an understanding of the ways in which mothers interpret and approach vaccination is of significance to the biomedical community, even if they are not in agreement, because this discord has implications for health policy and education messages geared towards parents. Finally, the research conducted for this thesis has critiqued a still prominent but shifting perspective among the biomedical community that providing parents with “correct” biomedical information regarding vaccines and thus “improving” their knowledge will increase vaccine acceptance and coverage rates.



Because vaccines remain, in both the developing and developed world, the most widely used primary prevention strategy, it is imperative that both anthropologists and public health professionals explore the meanings communities and individuals ascribe to these strategies. In the United States, compulsory vaccination laws, which have been responsible for very high vaccine coverage rates, are the norm rather than the exception. The ways in which parents interpret and negotiate such mandates has been and continues to be of relevance to the public's health. The results of the study conducted for this thesis, while exploratory, do seem to indicate that there is a growing concern for the extent to and purpose for which this biotechnology is being utilized. New vaccines continue to be created and recommended to the general population. Additionally, clinical vaccine trials for other sexually transmitted infections such as Herpes and HIV are ongoing, so understanding how these kinds of prevention tools will be received in various social and political contexts is critical. Applied Anthropologists, and applied medical anthropologists in particular, have a unique role to play by situating diverse stakeholder perspectives across interdisciplinary fields in order to help develop more appropriate and informed public health policies with respect to vaccination.

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## **Appendix A: Interview Guide**

1. How many children do you have?
2. How many daughters do you have? What are their ages?
3. How many people live in your household?
4. Tell me about some of your hopes for your daughter.
5. What are some things that concern you the most as your daughter is growing up?
6. How are decisions about your children(child)'s health made?  
PROBE: Who is involved in that decision making process?
7. Who do you go to when you have a problem concerning the health of your children?  
(i.e. for advice or services)  
Could you give an example?
8. Please describe how and when you would begin/began a conversation with your daughter(s) about sex.  
PROBE: How do you see that conversation starting?  
PROBE: Would you start it or would she?
9. Have you discussed what you'd like to include in this conversation with anyone else?  
(Probe: partner, other family members, etc.)
10. What sorts of things would you want to talk about or have talked about in this conversation?
11. What topics, if any, would be difficult for you to discuss with your daughter(s)?  
Why?
12. Do you feel that your political or religious beliefs affect the ways in which you talk to your daughter about sex? How?
13. At what age do you think the majority of girls in the U.S. have sex for the first time?
14. At what age do you think your daughter(s) will likely have sex for the first time?

15. What are your thoughts, if any, on sex education programs in schools that teach abstinence only?

16. Tell me about how you first heard about the HPV vaccine.

PROBE: What do you know about it?

PROBE: How do you think HPV is related to cervical cancer?

PROBE: How common do you think HPV is among sexually active people?

PROBE: How serious do you think it is?

PROBE: Where have you obtained information about HPV? About the vaccine?

| 17. What do you think about the HPV vaccine?

18. Who do you think should get the HPV vaccine?

19. Have you considered vaccinating your daughter(s)/already done it? Why or why not?

| 20. How relevant do you feel the HPV vaccine is to your daughter's health? Please explain. (PROBE: do you think your partner shares your viewpoint on this?)

21. What have you heard, if anything, about recommendations in the future to require the vaccine for school entry?

22. If the vaccine were to be made mandatory for admittance into middle school for girls in the future, what are some concerns you might have, if any, about it?  
(PROBE: do you think your partner shares your viewpoint on this?)

23. Currently, DPT, Haemophilus influenzae type b (Hib), Hepatitis B, MMR, Polio, and Varicella vaccines are required for school entry in the state of Florida. What have your thoughts been about these being required for school entry?

24. Have you ever declined to vaccinate your children against any school entry required vaccine? (DPT, MMR, HEP B, Varicella, etc.)

IF yes: Can you explain why?

IF no: What do you think about some parents declining to vaccinate their children against certain illnesses for which a vaccine is mandatory?

25. Do you agree that these other vaccines should be mandatory? Why/why not? Who should be in charge of deciding that?

26. Should a parent's decisions about their children's health be limited or controlled by state or federal health standards? Please explain why or why not.

27. If the HPV vaccine were to be required for school entry for middle school girls in the future, what, if anything would make it different from other vaccines that are required for admittance into school?

28. What, if anything, have you heard about the controversy around the HPV vaccine?

PROBE: What do you think the controversy is about?

PROBE: How, if at all, do you think politics play a role in this controversy?

PROBE: How, if at all, do you think religious beliefs play a role in this issue?

28. In what ways, if any, do you see your religious views or beliefs impacting your opinions about the HPV vaccine?

29. In what ways, if any, do you see your political opinions or affiliations impacting your feelings about the HPV vaccine?

30. Is there anything else you want to add?

**Demographics:**

Age?

Highest level of education obtained?

Occupation?

Self-identified ethnicity?

How would you identify yourself politically?

How would you identify yourself religiously?