January 2011

"Not If, but When": Sex, Risk, and Trust in Timing Gardasil Vaccine Decisions, An Exploratory Study among Healthcare Providers and Middle-Class Parents in the U.S.

Kathleen Marie Brelsford
University of South Florida, kbrelsfo@mail.usf.edu

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“Not If, but When”: Sex, Risk, and Trust in Timing Gardasil Vaccine Decisions

An Exploratory Study among Healthcare Providers and Middle-Class Parents in the U.S.

by

Kathleen M. Brelsford

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy
Department of Applied Anthropology
College of Arts and Sciences

and

Master of Public Health
Department of Community and Family Health
College of Public Health
University of South Florida

Major Professor: Nancy Romero-Daza, PhD
Linda M. Whiteford, PhD, MPH
Heide Castañeda, PhD, MPH
Julie Baldwin, PhD
Ellen M. Daley, PhD

Date of Approval:
November 04, 2011

Keywords: medical anthropology, HPV, immunization, decision-making, sexuality

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Dedication

To Uncle Bobby, who taught me the value of blow-dart guns, family lineages, machetes, waterproof matches, Cheshire smiles, and laughter.

I wish you were here.

And to Dr. Linda Taylor, who helped me realize my own potential and who challenged me to see the world, and my place in it, differently. You are the reason I made it through those first few years of college.

I will forever be grateful for your “tough love” approach.
Acknowledgements

This research would not have been possible without the support and guidance of my committee members; I will always be grateful for the opportunities, mentorship, and support you have offered me. I also want to thank Carol Bryant for chairing my defense, and for modeling the type of relationship I someday hope to have with graduate students.

Perhaps more than anyone, I owe a debt of gratitude to my family. Mom and Dad, I know you don't always understand what I do or why I do it, but thank you for your patience and support throughout the process. Emily, thank you for understanding why I do what I do, for paving the way, and for all of your help, guidance, and support. To Ernesto, thank you for indulging my never ending conversations about reproductive health; your help and support have been immeasurable. Your help and support have been immeasurable. To Lorena, Sofia, Nadia, Eugenia, Manuel, and the rest of the Ruiz-Madrigal family, thank you all for your long-lasting encouragement, support, and love.

I also owe thanks to all of my friends. To Jennifer and Edgar, thank you for the sharp commentary, bad movies, great food, and loyal friendship. You got me through some of the most difficult times of my life crying with laughter. To Ryan and Aimee thank you for being my surrogate family; to Hollie, thanks for hugs, compassion, FW potatoes, shopping, and knowing me so well; to Elizabeth, for helping me to appreciate the beauty of southern drawls and roommates; and to Jose, Dani, Ali, the Monteverde Institute, and everyone else who has made this doctoral journey so meaningful.
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Abstract

This dissertation research explores how values regarding sexuality, morality, responsibility, protection, trust, and risk – expressed through parent, daughter, and healthcare provider relationships and interactions – inform parental decisions regarding the Gardasil® vaccine. In particular, the research examines the competing and conflicting meanings that parents and providers ascribe to vaccination and how actors position the vaccine within a wider set of negotiated, value-laden discourses. Because these narratives are situated within a larger structural field that shapes the landscape in which providers and parents interact, relevant historical and structural factors, including vaccine policy, cost, and compensation are discussed. In-depth, semi-structured interviews with 17 healthcare providers and 26 parents were conducted to explore these relationships. Results suggest that in considering the Gardasil vaccine, parents balance concerns regarding the newness of the vaccine with assessments of their daughters’ sexual maturity and vulnerability. The primary vaccine frame that parents ascribe to Gardasil – as a cancer-prevention technology or vaccine to prevent a sexually transmitted disease – shifts the angle from which parents approach the decision. Trust in government and public health establishments, pharmaceutical companies, healthcare providers, daughters, and their social environments operate at multiple levels to both inform and complicate decisions. In making decisions to accept, refuse, or defer Gardasil uptake, parents rely on different vaccine frames that focus upon specific aspects of the vaccine or of HPV risk.
Human Papillomavirus

Human papillomavirus (HPV) is the name of a group of viruses belonging to the family Papovaviridae (WHO 2007). In the United States alone, more than 20 million people are currently infected with HPV, and there are 6.2 million new cases each year (Frazer 2006). Over 100 types of HPV have been described molecularly and 40 of these types infect the genital tract (Munoz, et al. 2003). Each genital HPV type is categorized as high or low risk, depending on the strength of the association between an HPV type and lower genital tract cancer (Frazer 2006). Between 2003 and 2005, sentinel surveillance for cervical infection with high-risk HPV types (16, 18, 31, 33, 35, 39, 45, 55, 52, 56, 58, 59, or 68) was conducted in 26 STI, family planning, and primary care clinics in six cities nationwide. Results indicated a high-risk HPV prevalence of 23% (CDC 2009a). The prevalence rate was higher in STI (26%) and family planning clinics (26%), compared to primary care (15%) clinics. Similarly, rates were highest in younger age groups. Females ages 14 to 19 years of age carried the greatest burden (35%), followed by women ages 20 to 29 (29%), 30 to 39 (13%), 40 to 49 (11%), and 50 to 65 years of age (6.3%) (CDC 2009a).

High risk HPV types are associated with up to 99.7 percent of cervical cancers (Frazer 2006), as well as with cancer of the cervix, vagina, vulva, anus, and penis (Cox 2006; Organization 2007; WHO 2007). Recent studies have also linked HPV infection to head and neck cancers; high-risk HPV infection has been found in 15-20 percent of head
and neck cancers independent of smoking and alcohol use (D'Souza, et al. 2007; Pintos, et al. 2008; Pintos, et al. in press; Smith, et al. 2004a). In 2007, 12,280 women in the U.S. were diagnosed with cervical cancer and 4,021 died from it (CDC 2011c). It is estimated that at least 2,900 new cases of HPV-associated vulvar and vaginal cancer, 1,700 incident cases of HPV-associated head and neck cancers, and 1,600 new cases of HPV-associated anal cancers will be diagnosed among females in the United States each year (CDC 2011d). While there are at least 15 high-risk genital HPV types (Frazer 2006), types 16 and 18 are responsible for the greatest disease burden. HPV type 16 is responsible for more than half of all invasive cancers, and HPV types 16 and 18 account for between 70 and 75 percent of all cervical cancer cases worldwide (Frazer 2006; Pollack, et al. 2007; WHO 2007).

While low-risk HPV types are usually clinically benign and rarely progress to neoplasia (Frazer 2006), they are a significant source of morbidity and economic cost in the U.S., accounting for five percent of all visits to sexually transmitted infection (STI) clinics (Insigna, et al. 2003; Wiley, et al. 2002). Genital warts are also highly infectious; the transmission rate from an infected to non-infected sexual partner is approximately 65 percent (Lacey, et al. 2006). HPV types 6 and 11 are the two most common low-risk HPV types, responsible for approximately 90 percent of genital warts (Cox 2006; Frazer 2006). National Health and Nutrition Examination Survey (NHANES) results from 1999 to 2004 reveal that 5.6 percent of sexually active adults between the ages of 18 and 59 year self-reported a lifetime diagnosis of genital warts (CDC 2009a) and recent data from the National Disease and Therapeutic Index (NDTI) suggest that the incidence of genital warts might be increasing (CDC 2009a). Results from the NDTI show an overall
increase in the number of American seeking initial treatment for genital warts. For example, in the year 2000, approximately 220,000 people were initially seen for genital warts, compared to 357,000 in 2009 (CDC 2009a). Treatment is often complicated, expensive, and ineffective: up to 75 percent of cases recur within six months of treatment (Frazer 2006; Lacey, et al. 2006).

The economic costs associated with low and high-risk HPV infection are high. Each year in the United States, approximately $200 million are spent on managing genital warts, $300 to $400 million are spent on care associated with invasive cervical cancer, and a staggering $3.5 billion is spent annually on follow-up for abnormal Pap tests and the management of pre-invasive cervical disease (Dempsey and Freed 2008).

HPV infection disproportionately affects young people; 15 to 24 year olds comprise only 25 percent of the sexually active population (usually defined as those between 15 and 44 years of age) in the U.S., but they account for nearly half of the STIs (Frazer 2006). Approximately 75 percent of incident HPV infections (4.6 million) occur among 15 to 24 year olds (Frazer 2006). By the age of 50, an estimated 80 percent of U.S. women will have acquired HPV in the genital tract (SAM 2006).

**HPV Vaccines**

Immunization is arguably one of the greatest public health successes in history. The Centers for Disease Control and Prevention (CDC) list vaccination first on a list of the top ten public health achievements in the twentieth century (1999a). The widespread distribution of vaccines has led to the worldwide eradication of smallpox and the near eradication of polio in the Western hemisphere (CDC 1999b). Despite their successes, vaccines have always been a controversial public health intervention, fueling ethical
debates about the rights of parents and the State vis-à-vis children’s bodies and about ethical obligations to protect one’s own health (or the health of a child) and the health and welfare of the community (Blume 2006; Colgrove and Bayer 2005; Fenner, et al. 1986; Spier 2001; Stern and Markel 2005). Recently, parental concerns regarding the safety, effectiveness, and necessity of vaccines have grown, or at least been illuminated through increased media coverage, celebrity interest, and political battles regarding vaccine mandates (Leask 2002; Offit 2008; Smith, et al. 2008; Stern and Markel 2005).

In the past, controversies focused on vaccines administered during infancy and early childhood, with discussions of long-term side effects and State control of vaccines dominating the debates (Freed 2005; Isaacs, et al. 2004; Link 2005). More recently, discussions regarding the risks and benefits of vaccines have coalesced around the HPV vaccine. Developed to provide protection against four types of HPV that are the leading causes of cervical cancer and HPV in the population, the Gardasil® vaccine introduced vaccine-specific concerns into the general vaccine debate, while fanning the flames of historically rooted cultural and political tensions regarding vaccine campaigns, vaccine mandates, and state and parental rights.

While vaccines against STIs can drastically reduce the stigma, suffering, and death associated with these infections, development of these particular vaccines has been slow. For example, until a few years ago, the Hepatitis B vaccine was the only Food and Drug Administration (FDA) approved vaccine in the United States to prevent an STI (FDA 2006). Two pharmaceutical companies have independently developed vaccines to prevent HPV. Cervarix®, the name of the HPV vaccine developed by GlaxoSmithKline, protects against HPV types 16 and 18; Cervarix received FDA approval for use in
females ages 10 through 25 in October 2009, three years after the Gardasil vaccine was initially FDA approved (FDA 2009a).

Manufactured by Merck, Gardasil is a quadrivalent vaccine that protects against four HPV strains: 6, 11, 16, and 18. The vaccine is administered in a series of three doses delivered over the course of six months (the additional doses are delivered two and six months after the initial dose) (Merck 2011). Common side-effects associated with the vaccine include “pain, swelling, itching, bruising, and redness at the injection site, headache, fever, nausea, dizziness, vomiting, and fainting” (Merck 2011). Since sexual contact is the primary mode of transmission and Gardasil is most beneficial as a prophylactic, it is important to vaccinate individuals before sexual debut (Pollack, et al. 2007; SAM 2006; Siddiqui and Perry 2006).

Initial FDA approval for Gardasil was granted in 2006 for use among females ages 9 to 26 in the United States, but the Advisory Committee on Immunization Practices (ACIP) to the CDC recommended that 11 and 12 year old girls be specifically targeted for vaccination (CDC 2007). Given the young age of vaccination, parents play a significant role in determining the vaccination status of their daughters. It is therefore important to understand the factors that shape and influence parental vaccine decision-making, particularly in regards to STI-related vaccines.

The primary goal of this dissertation research was to examine the contextual landscape in which parents make HPV vaccine decisions: how (and from whom) parents ascertain, value, and weigh information regarding HPV and the vaccine to prevent it, and

1 The vaccine contains the following ingredients: proteins of HPV Types 6, 11, 16, and 18, amorphous aluminum hydroxyphosphate sulfate, yeast protein, sodium chloride, L-histidine, polysorbate 80, sodium borate, and water for injection (Merck 2011)
how such information is positioned vis-à-vis daughters and within wider structural and historical frames to inform decision-making.

The introduction of the Gardasil vaccine in 2006 evoked new moral and ethical questions surrounding vaccination. Conflagrations regarding morality spread as parents and religious leaders questioned the need, or even appropriateness, of a vaccine to protect individuals from a disease that is primarily sexually transmitted. That the vaccine would target children and young adults only further fueled debate (Colgrove 2010; Epstein and Huff 2010).

Apart from the fact that it has become an object of moral and ethical debate, the HPV vaccine is also a relatively new technology. And while any new technology can induce feelings of anxiety and fear, the events surrounding the development and roll out of the Gardasil vaccine increased anxiety regarding the vaccine, as will be discussed in Chapter Six.

The controversies coloring the moral landscape of HPV vaccination were also layered with ethical concerns regarding the target age group. At the time of its approval in 2006, Gardasil was the only STI-vaccine offered during adolescence – a period of time when many youth begin to explore their own sexuality and can potentially take a more active role in the vaccine decision-making process. What role, if any, would (or should) girls have in the vaccine decision-making process? If girls knew what the vaccine protected against, would they interpret it as parental or societal permissiveness of adolescent sex? Would adolescents misinterpret the breadth of protection provided by the vaccine and have a false sense of security?
In 2009, the FDA later extended Gardasil approval for boys within the same 9 to 26 year age range (FDA 2009b). At the time that I conducted this dissertation research, Gardasil had not yet been approved for use in males. However, in anticipation of possible FDA approval, and recognizing the role that universal versus gendered-availability might have on decisions, I asked parents and providers to discuss their views regarding a future HPV vaccine for boys.

Although there is potential for adolescent girls to participate in vaccine decisions, parents remain the primary Gardasil vaccine decision-maker (Constantine and Jerman 2007; Dempsey, et al. 2006; Friedman and Shepeard 2007). Even before Gardasil became available to the public, public health practitioners, economists, reproductive health advocates, and healthcare practitioners were trying to predict the cost-effectiveness of a vaccine, provider acceptability of a vaccine, and parental intentions to have daughters vaccinated (Davis, et al. 2004; Goldie, et al. 2004; Kulasingam and Myers 2003; Mays, et al. 2004; Mays and Zimet 2004; Olshen, et al. 2005; Raley 2004; Sanders and Taira 2003; Zimet, et al. 2005; Zimet, et al. 2005b). Efforts to predict parental HPV vaccine decisions had to do not only with the potential economic costs of implementing such an expensive and massive vaccination campaign, but also with the likelihood of transforming the epidemiology of HPV-related diseases as a result of it. The vaccine’s potential to reduce the rates of cervical and other HPV-related cancers, as well as genital warts, largely depended upon – and continues to depend on – the willingness of parents to vaccinate their daughters.

Despite significant efforts to identify factors associated with HPV vaccine acceptance, an examination of the HPV vaccine acceptance literature – both prior to and
following approval in the United States - reveals little consensus about the significance of different attitudes, beliefs, values, knowledge, or perceptions on HPV vaccine acceptance (Allen, et al. 2010; Boehner, et al. 2003; Dempsey, et al. 2006). A detailed discussion of the variability in past findings will be presented in Chapters Two and Three of the dissertation, but for now, it suffices to say that researchers have not demonstrated a predictive relationship between HPV knowledge and vaccination. Demographic variables are commonly measured in parental HPV vaccine acceptance studies, but like other measures, the association (the strength and direction) between variables and acceptance varies widely.

Like parents, healthcare providers are part of the social and interactive experience through which vaccines are discussed and decisions are made. Provider recommendations appear to be key factors influencing parent vaccine decisions (Kahn, et al. 2005; Klein and Wilson 2002; Mays and Zimet 2004; Millstein, et al. 1996; Raley 2004; Riedesel, et al. 2005; Sussman, et al. 2007; Torkko, et al. 2000); therefore it is important to understand when and how providers initiate vaccine conversations, what they discuss or leave out of conversations, and to whom conversations are directed. Studies describing variations in provider recommendations by patient and provider attributes are presented in the following chapter.

An Anthropological Approach to HPV Vaccine Decision Processes

As I will also argue more thoroughly Chapter Two, the parental vaccine acceptance literature has been, and continues to be, largely shaped by the Health Belief Model (HBM) and the Theory of Reasoned Action (TRA). Like all theories, the HBM and TRA approach a phenomenon from a particular angle; as such, analyses will always
be limited in what they reveal. The problem is not that all theoretical models are limited, rather, the problem arises when one or two theories or models underlie the bulk of the literature regarding a phenomenon. The countless studies of parental vaccine acceptance based on HBM and TRA models provide compelling evidence that the factors shaping parental vaccine decisions vary significantly. That so many studies have revealed so little consistency suggests that parental vaccine decisions are complex; no single set of factors or beliefs can predict parental vaccine choices. While these two models help to identify vaccine acceptance factors that need to be explored in greater detail, they cannot adequately answer the “how” or “why” questions.

One of my goals in selecting this dissertation topic was to use an anthropological perspective to explore the “how’s” and “why’s” of parental HPV vaccine decisions, without reducing the complexity of decisions down to single, quantifiable variables. Rather than viewing an HPV decision as a dichotomous outcome – such as a final choice to accept or refuse the vaccine – I viewed parental vaccine decisions as processes that often unfolded over extended periods of time, in the context of particular events, and shaped by various actors. In order to describe the contextual landscape within which parental vaccine decisions occur, I sought to understand the roles that daughters, healthcare providers, spouses, the media, and other actors may have in directly or indirectly shaping vaccine decisions. At the same time, I tried to position parental vaccine decisions within their larger historical and socio-political context, for many of the fears, risks, and hopes shaping HPV vaccine decisions result from and speak to deeply rooted ideas and understandings of a world beyond Gardasil or vaccines in general.
In order to achieve these goals, I chose a research design plan based on the theoretical and methodological assumptions outlined in the Local Vaccines Culture approach (LVC) (Nichter 1996c; Streefland, et al. 1999). An in-depth discussion of the LVC approach is provided in Chapter Two; here, I highlight only that the approach calls for a heavily qualitative analysis of both provider and parental perspectives, especially in relation to the provider-patient interaction, in order to understand acceptance from multiple levels. In brief, I conducted 26 semi-structured, in-depth interviews with parents residing in Pennsylvania and Florida to elicit how they situate vaccines within their larger social worlds. Perspectives were sought both from parents who had already made definitive HPV vaccine decisions and from others who had not yet made a final vaccine decision.

To develop an understanding of provider perspectives, semi-structured, in-depth interviews were conducted with 16 providers in Pennsylvania and Florida, including pediatricians, nurse practitioners, school nurses, and a chiropractor who work with adolescent girls and who have discussed the Gardasil vaccine with parents. Interviews were designed to elicit information about providers’ personal approaches to and beliefs about vaccination, their perspectives toward this particular vaccine, their perceptions of parental vaccine concerns, and the meanings that they ascribe to parental vaccine choices. Additional factors, such as vaccine protocols, procedures, and billing were also explored during provider interviews.

In order to couch both provider and parental narratives within their larger sociocultural milieu, a literature review was conducted to better understand historical developments in vaccine policy, mandates, and resistance; the economics of vaccination,
both generally and pertaining specifically to the HPV vaccine; the process by which the
Gardasil vaccine was developed and marketed to the general population; and the wider
media representations of vaccines.

Contributions

While anthropologists possess the perspective and tools necessary to provide in-
depth, thorough understandings of complex decisions that exist within larger structural
fields, anthropological contributions to the vaccine acceptance literature are almost non-
existent. The few anthropological studies that do exist primarily focus on infant and
early childhood immunization programs in developing countries (Cassell, et al. 2006b;
1999) or in the United Kingdom (Casiday, et al. 2006; Casiday 2007; Poltorak, et al.
2004; Poltorak, et al. 2005). At the time that I began this study, there existed, to my
knowledge, no anthropological literature that explored the values, meanings, and
processes underlying decisions regarding uptake of an adolescent vaccine, particularly
one that protects against a sexually transmitted infection.

Providing socioculturally-informed research on parental HPV vaccine acceptance
that expands the scope of inquiry beyond parental beliefs, values, and perceptions can
positively contribute to the vaccine literature. Inhorn and Brown (1997:21) note that
anthropologists can make some of their greatest contributions to public health by
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“helping to explain why people behave as they do.” An anthropological contribution can also provide new ways of conceptualizing parental HPV vaccine decisions, which can expand the scope of HPV prevention strategies and generate new research questions.

By using anthropological methods and theories to inform a public health issue, I hope to expand the scope and perceived utility of anthropological perspectives, while simultaneously providing useful and practical recommendations pertaining to HPV vaccination protocols, communication, and education. The lack of anthropological attention to this particular topic also offers an opportunity to contribute meaningfully to anthropological theory. Specifically, this research question provides an opportunity to further explore and explain how parents conceptualize issues of autonomy, power, responsibility, and control in making HPV vaccine decisions, and how such processes are shaped by and reproduce ideas about the maintenance, performance, and construction of a child’s body.
Chapter Two – Theories of Vaccine Acceptance

“Nothing in science – nothing in life, for that matter – makes sense without theory. It is our nature to put all knowledge into context in order to tell a story, and to recreate the world by this means” (Pasick and Burke 2007:4.2).

The story of parental vaccine acceptance has largely been a single-authored work, shaped predominantly by psychologically-based understandings of the world. However, the story, as currently conceived, is incomplete and researchers with other theoretical perspectives are beginning to suggest some revisions. In the first part of this chapter I attempt not to tell the story of parental vaccine acceptance, but to critically discuss the biographies of its contributors – the theoretical orientations that give shape and form to the parental vaccine acceptance literature. After considering the strengths and limitations of available theoretical approaches, I present a research framework that offers theoretical flexibility.

Rational Actor Approaches

To begin, we need to examine how the word “theory” is used and what it is used for. Researchers interested in health promotion and public health often conceptualize theory differently from anthropologists. From an anthropological perspective, the definition of theory commonly used in public health is rather limited. Many of the most
commonly used health behavior theories are concerned with explaining and predicting associations between attitudes, beliefs, and behaviors (Lupton 1995). The purpose of these models is not “an overarching attempt to construct an epistemology of public health” but to “produce a particular result under specific conditions” to more effectively target interventions and improve public health (Lupton 1995:55). Model-building is normalized and valued in public health and researchers strive to produce models that can explain the relationship between beliefs and behaviors in multiple contexts. In public health, the terms “theory” and “model” are often used interchangeably, as illustrated by the names of the two most common theories used in the vaccine acceptance literature: Health Belief Model (HBM) and Theory of Reasoned Action (TRA).

While the HBM and TRA differ in important ways, which will be discussed shortly, they also share a set of common epistemological and ontological assumptions that need to be recognized. Both prominent models of behavior change used in health promotion, the HBM and TRA share roots in social psychology, drawing from Stimulus Response Theory (SRT) and Cognitive Theory (CT)³ (Lupton 1995; Rosenstock, et al. 1988). Because of their historical roots in SRT and CT, the HBM and TRA are theories within a larger cognitive/learning perspective (CLP). The CLP is a rational-choice framework, underpinned by value-expectancy (VE) and subjective expected utility (SEU) theories (Connor and Norman 1996; Mellers, et al. 1998). In models drawing from the CLP, rationality refers to the reasoning process in which people engage to make

³ SRT combines assumptions from classical conditional and instrumental conditioning theories to posit that people learn from “reinforcements” (i.e. events) that then reduce the physiological stimuli that induce behaviors. Within this framework, human behavior can be explained by reinforcements alone without accounting for human thought or reason (Rosenstock et al. 1988). Cognitive theory emphasizes the importance of an individual’s subjective expectations in explaining her behavior, where her perception of an outcome and the probability of it occurring will lead to behavior.
decisions, which is thought to be deliberate, systematic, and rule-driven – and hence, measurable and explainable (Connor and Norman 1996; Vernberg 1998; Vernberg and Murphy 1996).

Rational actor approaches like the HBM and TRA are “value-expectancy models” (VEM) (Prentice-Dunn and Rogers 1986; Weinstein, et al. 1998). Fundamental to VEMs is the assumption that the expected benefits to risk reduction must be measured against the expected costs of acting, although the particular components included as benefits or risks, and their relative weights, vary by model (Weinstein 1993). This cost-benefit analysis revolves around the individual. Drawing from SEU theory, the CLP assumes that the “maximization or optimization of utility [and] strict methodological individualism” primarily motivate human action (Taylor-Gooby and Zinn 2006:398). Cognition is central to CLPs because behaviors are seen to be the result of individual-level processes that are volitional (Vernberg 1998). However, the study of cognition is limited to cognitive perceptions that are assumed to contribute to a rational cost-benefit approach to choice (Vernberg 1998: 34). Theories drawing from the CLP are structural, in the sense that structures (cognition) determine behavior (Kippax and Crawford 1993). While the TRA and HBM are underpinned by many of the same theoretical assumptions, there are important differences between the two.

**The Health Belief Model (HBM)**

The HBM essentially posits that if a person perceives a disease to be a threat to her health, then she will be motivated to take actions to avoid or minimize that threat (Noar 2005). The perceived threat (e.g., cervical cancer, genital warts, or HPV) is measured by two factors: perceived susceptibility to the disease and perceived severity of the disease (Hornick 1991). The action (e.g., vaccination) is more or less likely to occur depending on the individual’s perception of two additional factors: the perceived benefits and perceived barriers associated with the action (Coreil, et al. 2001). The model also assumes that demographic variables affect how a person perceives these four factors, and cues to action (e.g. media, a specific experience) are stimuli that trigger the decision-making process (Noar 2005).

While self-efficacy is not an original component of the HBM, it is often added to the model to assess a person’s belief that she can initiate a behavior (Garcia and Mann 2003). By examining the relative weight of each factor in the model, researchers can determine which factors appear to be most important to parental vaccine acceptance. However, unlike other health-behavior models, the HBM provides no clear combinational rules for analyzing the relationship among factors (Montano 1986). Researchers generally use multiple regression equations to explore the relationship between factors, where behaviors are outcomes and components are predictors (Prentice-Dunn and Rogers 1986).

*The Theory of Reasoned Action (TRA) and the Theory of Planned Behavior (TPB)*

Both the TRA and TPB assert that individual beliefs are the motivators of individual action and that behavioral intentions to perform an action are the most proximal prediction of whether a behavior will actually occur (Noar 2005). In the TRA,
intentions are comprised of attitudes and subjective norms. Attitudes are made up of behavioral beliefs (i.e., beliefs that a behavior has positive outcomes) and an evaluation (i.e., the value one associates with a given outcome). Subjective norms are comprised of normative beliefs (social norms about a behavior) and motivation to comply (how motivated one is to comply with these norms). The more positive one’s attitudes and subjective norms, the more likely one is to form a behavioral intention (Noar 2005).

While not traditionally part of the TRA, self-efficacy is often added to the model (Garcia and Mann 2003).

The Theory of Planned Behavior includes the same components as the TRA, but adds perceived behavioral control as a third major contribution in predicting intention. Perceived behavioral control includes two components: control beliefs, which refer to the perceived factors and resources that facilitate or impede a behavior, and perceived power, which refers to the impact that each factor has on behavioral intention. Many researchers also add a construct of self-efficacy to the TPB, which has been shown to increase the model’s predictive abilities\(^4\) (Garcia and Mann 2003). The TPB asserts that behavior is most likely to occur when the TRA requirements are met \textit{and} when there is a high degree of perceived behavioral control (Noar 2005).

Because the TRA and TPB include a normative component, they require that the researcher conduct pilot testing, usually in the form of focus groups, to elicit the basic concerns of the group that will then be integrated into a survey instrument (Brewer, et al. 2007a; Weinstein 1993). The use of pilot testing, advocates argue, allows for the model

\(^4\) In the TPB, self-efficacy is usually measured in terms of one’s confidence to complete a behavior while behavioral control is measured in terms of the difficulty or ease associated with completing the behavior.
to be used in cross-cultural settings, although this is questionable because these models are still based on utilitarian, individualistic assumptions that do not always hold in the United States, let alone cross-culturally (Kippax and Crawford 1993; Poss 2000).

The TRA and TPB are commonly used in the vaccine acceptance literature, although rarely as the sole theoretical perspective. Nearly all of the studies using the TRA or TPB use it in conjunction with the HBM (Dempsey, et al. 2006; Gerend, et al. 2007; Kahn, et al. 2005; Mays, et al. 2004; Paulussen, et al. 2006; Rosenthal, et al. 1995). Most commonly, researchers use the basic constructs of the HBM, adding a normative component from the TRA/TPB models (Poss 2000). The primary difference between studies using the HBM model compared to the hybrid HBM/TRA model is that analyses based on the latter hybrid model often include an evaluation of the relative importance of social network norms on acceptance.

Several studies of HPV vaccine acceptance using these models indicate that for at least a subset of parents, social norms regarding vaccine acceptability would affect their likelihood of vaccinating (Kwan, et al. 2008; Marlow, et al. 2007a; Ogilvie, et al. 2007). For example, in a study of HPV vaccine acceptance conducted among mothers in England, Marlow and colleagues (2007a) found that mothers who perceived vaccine acceptance to be more normative were also more likely to anticipate vaccinating their daughters. In another study conducted with Chinese adolescent girls in Hong Kong, researchers reported that perceived peer and family support of the vaccination was associated with higher intention to vaccinate (Kwan, et al. 2008).
The HBM and TRA – What they Tell Us, What they Don’t

Results from individual studies using the HBM/TRA in the vaccine literature do suggest that certain factors are more important to parents than other factors; however, there is little consistency in the findings across studies. A review of studies that used the HBM to examine parental acceptance of an HPV vaccine yields varying results. The most important factor related to parental acceptance of an HPV vaccine in some studies has been perceived susceptibility (Brabin, et al. 2006; Friedman and Shepeard 2007; Marlow, et al. 2007a; Olshen, et al. 2005; Riedesel, et al. 2005; Waller, et al. 2006), although other studies have found no association between susceptibility and vaccination (Litton, et al. 2011). Perceived severity has been significantly associated with vaccine acceptance in some studies (Zimet 2005), but not in others (Dempsey, et al. 2006; Kahn, et al. 2003). Several studies report that higher perceived vaccine effectiveness is associated with greater parental vaccine acceptability (Davis, et al. 2004; Dempsey, et al. 2006; Gerend, et al. 2007; Zimet, et al. 2000; Zimet, et al. 2005b). However, perceptions regarding what the vaccine protects against varied in these studies. For example, Fazekas and colleagues (2008) found that vaccine effectiveness against cervical cancer was related to parental vaccine acceptance, but perceived effectiveness against HPV infection was not. Perceived barriers associated with sexuality have been a significant predictor of non-acceptance, but only for small portions of the sample population (Constantine and Jerman 2007; Davis, et al. 2004; Moraros, et al. 2006; Zimet, et al. 2005).

Demographic factors are also assessed in the HBM, although the association (the strength and direction) vary widely. Education level, maternal employment, clinic type, income level, insurance type, household type, parent age, and ethnicity have all been
positively, negatively, and not associated with vaccine acceptance (see Table A1). I have included a detailed description of these diverse associations, along with findings related to the other HBM/TRA factors in the appendix. The results are simply too diverse to include here in anything other than a brief summary. The variability found in different studies likely results from multiple factors, including the use of different methodologies; different state or national laws related to immunization services, health care coverage, and mandates; the type of vaccine explored in the study; and the complexity of factors that account for childhood vaccination status (Bardenheier, et al. 2004; Rosenthal, et al. 2004).

The primary feature that distinguishes research using the HBM from those using a combined HBM and TRA approach is an emphasis on social influence. Studies using a combined approach highlight the important role that family, friends, and partners have in shaping vaccine perceptions. Multiple studies suggest parental vaccine acceptance is affected by what other family members, including partners and parents (Dinh, et al. 2007; Friedman and Shepeard 2007; Marlow, et al. 2007a) and other parents or peers (Dempsey, et al. 2006; Rosenthal, et al. 2004) think about a vaccine.

Perhaps more than any other group, healthcare providers appear to exert a significant degree of social influence on parental vaccine perceptions. The importance of a healthcare provider recommendation appears to be one of the most consistently reported factors associated with parental vaccine acceptance (Dempsey, et al. 2006; Dinh, et al. 2007; Esposito, et al. 2007; Rosenthal, et al. 1995).

Despite the suggested importance of the clinician recommendation, relatively few studies have examined provider perceptions of the HPV vaccine and factors associated
with recommending it. Several studies using the TRA have identified professional medical associations as influential in providers’ HPV vaccine perceptions; pre-licensure studies found that providers would be more likely to recommend a vaccine that was endorsed by a professional medical association (Mays and Zimet 2004; Raley 2004; Riedesel, et al. 2005).

Patient age continues to be associated with clinician recommendation practices; providers are more likely to routinely endorse vaccination as a girl’s age increases (Esposito, et al. 2007; Kahn, et al. 2005; Mays and Zimet 2004; Raley 2004; Riedesel, et al. 2005; Tissot, et al. 2007; Vadaparampil, et al. In press). A healthcare provider’s own comfort discussing sexual health concerns may also affect when providers talk about the vaccine, the types of information they share about it, how they share it, with whom, and when (Cheng, et al. 1999; Esposito, et al. 2007; Keating, et al. 2008; Rupp, et al. 2005). Clinician specialization can also influence recommendation practices. Results from nationally-representative (Daley, et al. 2010b; Ishibashi, et al. 2008a; Vadaparampil, et al. In press) and smaller studies (Barnack, et al. 2010) indicate that pediatricians are more likely than OB/GYN, family, and general practitioners to routinely recommend the HPV vaccine to patients and are more likely to begin recommending the vaccine at younger ages. More recent post-licensure studies have noted an association between HPV vaccine reimbursement policies and provider recommendations. Providers reporting insufficient insurance reimbursement were less likely to recommend the vaccine to patients (Kahn, et al. 2009; Vadaparampil, et al. In press; Young, et al. In press).
Knowledge and awareness about HPV infection, cervical cancer, and the HPV vaccine are commonly assessed, although neither is a formal construct of the HBM or TRA. However, their incorporation into these models reflects researchers’ beliefs that knowledge and awareness are “prerequisites for making informed decisions about vaccination” (Brewer and Fazekas 2007:2). It remains unclear how important knowledge and awareness actually are in vaccine acceptance, because despite many studies on HPV knowledge, few researchers have demonstrated a predictive relationship between knowledge and vaccination. In several studies, knowledge of HPV was found to have a significant effect on parental willingness to vaccinate (Chan, et al. 2007; Davis, et al. 2004; Fazekas, et al. 2008), but in several others, adults with very little biomedical knowledge about HPV were willing to accept an HPV vaccine for themselves or their daughters (Chan, et al. 2007; Friedman and Shepeard 2007; Lazcano-Ponce, et al. 2001; Lenselink, et al. 2008; Zimet, et al. 2000). None of these studies measured a change in knowledge (e.g. baseline compared to post-education scores), which makes them difficult to validate.

Other studies show no association between knowledge and acceptance (Boehner, et al. 2003). In a randomized intervention study (Dempsey, et al. 2006), 1,600 parents with children between the ages of 8 and 12 completed a survey on HPV vaccine acceptance. The researchers hypothesized that parents in the group that received HPV information would not only score higher on knowledge scales about HPV, but also be more likely to report vaccine acceptance. While there was significant improvement in knowledge among this group compared to others, there was no significant change in parents’ ratings of vaccine acceptance.
When compared, the HBM and TRA each have relative strengths and weaknesses. One of the main criticisms of the TRA and TPB is that they measure behavioral intentions rather than actual behavior. Proponents of these models argue that intentions are the best predictors of actual behavior (Montano 1986), but anthropologists have long noted the discrepancy between ideal and real behavior. The assumption that intentions are adequate proxies for behavior has seldom been tested and when tested, reveals inconsistencies (Weinstein 1993). Perkins and colleagues (2010), for example, found that in studies of HPV vaccine intentions, anywhere from 46 to 75 percent of parents reported the intention to vaccinate their daughters, but a subsequent assessment of actual vaccine rates found that only 38 percent of vaccine eligible girls had received at least one HPV dose. Unlike the HBM, the TRA does not include any measure of vulnerability or susceptibility, which likely affects behavioral choices. This reflects the original purpose of the TRA, which was to explain behavior generally, not simply behavior under conditions of uncertainty (Cameron 1997).

One of the main strengths of the TRA, compared to the HBM, is the inclusion of social factors, although many researchers argue that by reducing social norms to cognitions (beliefs) in the TRA, they are relegated to subjective, individualized factors (Kippax and Crawford 1993). Unlike the HBM, the TRA also includes a priori interaction rules which specify how variables in the model interact and how statistical tests of the model should be performed. These rules provide for more uniform comparison of studies using the TRA (Vernberg 1998).

A primary weakness of the HBM is that, in its original form, the HBM does not account for behavioral intentions, perceived control, or other factors that have been
demonstrated to influence vaccine acceptance, such as previous experience or social network factors (Hausmann-Muela, et al. 2003). Another weakness relates to its lack of specificity. Because the HBM does not articulate any clear combinational rules to explain how cognitive factors translate into behavior, there is no unified way to measure the strength, direction and interaction of factors (Abraham and Sheeran 1997; Pack, et al. 2006). Critics argue that without delineating the relationship between beliefs and action, the HBM is more akin to a short list of variables, rather than a theoretical model (Connor and Norman 1996; Weinstein 1993). On the other hand, the flexibility of the HBM allows researchers to easily incorporate factors from other theories into the model – which might explain why researchers tend to add elements of the TRA into the HBM, rather than the other way around.

The summary of findings from the HBM and hybrid models tends to support this characterization. Few of these studies provide a probabilistic model to explain how factors relate to one another and are thus limited in their predictive abilities (Sturm, et al. 2005; Weinstein 1993). Sturm and colleagues (2005), who have published extensively on parental vaccine choices using the HBM and TRA models, have recently questioned the utility of assessing parental attitudes, beliefs, and knowledge using the HBM, pointing to the weak predictive power of attitude measures in the HBM and outdated measures to assess parental perceptions of children’s susceptibility. The HBM has also been criticized for lacking a social norm component, which is a comparative strength of the TRA and TPB. Despite these criticisms, the HBM continues to be a popular model among vaccine acceptance researchers.
The HBM and TRA also share similar strengths and weaknesses. As discussed earlier, the HBM and TRA developed from similar assumptions about human behavior and those shared underpinnings are the target of many criticisms that apply to both the HBM and TRA. One of the main criticisms of the models is the over-emphasis on the role of psychological and individual factors on behavior at the expense of social and structural factors (Hausmann-Muela, et al. 2003). The focus on perceived risks, benefits, attitudes, intentions, and susceptibility can lead to a somewhat narrow understanding of the context within which parental vaccination choices occur. The models tend to portray people as autonomous agents existing in a social vacuum (Lupton 1995). While the TRA and TPB acknowledge the role of one’s social network in decision-making, the conclusion that individuals ultimately make their own decisions about health behaviors reflects cultural assumptions: researchers have demonstrated that in many cases, individuals do not make their own healthcare decisions (Good 1994; Kippax and Crawford 1993).

The theoretical preoccupation with the individual’s role in preventive health care choices often leads researchers to search for “discrete, measurable variables” that relate to particular behavioral outcomes. Often a population is segmented by personal characteristics, such as mother’s education level, income, or ethnic identity, which presumably make some individuals more or less likely to engage in a particular behavior. Unfortunately, such distinctions, when significantly correlated with specific health behaviors, reveal little about why, for example, a mother’s education level predisposes her to seek or decline vaccination (Millimouno, et al. 2006; Nichter 1996c). In addition, the emphasis and preoccupation with behavioral outcomes (e.g. acceptor/non-acceptor),
neglects the “pathways and processes associated with vaccination acceptance” (Nichter 1996c:337).

Researchers with very different theoretical positions criticize the lack of emphasis that the TRA and HBM place on process. Some cognitive theorists – who agree that individual cognition leads to behavior – argue that the TRA and HBM are inadequate because they fail to articulate the cognitive processes that shape particular attitudes or beliefs. For these cognitive theorists, it is not enough to say, for example, that intentions, which are shaped by attitudes, predict behavior. While the HBM/TRA can help target interventions for behavior change, the models cannot specify how the underlying cognitive processes work. As Mathews (1998:190) observes, “Predicting the points at which people will make decisions based on assessment of cost or likelihood of cure, however, is not the same as understanding how they do so.” This point has not only theoretical, but practical importance. One must understand how particular cognitive processes (or biases) influence attitudes or beliefs for interventions to work effectively\(^5\) (Connor and Norman 1996).

Many anthropologists are critical of the assumption that the processes underpinning behavior change are the result of individual cognitive factors (Coreil, et al. 1994; Garro 1998a; Garro 1998b; Kippax and Crawford 1993). The inattention to process denies the importance of context in decision-making. Decisions do not occur in vacuums, but are shaped by broader social, economic, and political circumstances, as well as individual experiences and emotions, that provide the context and meaning in

\(^5\) In Chapter Three, I describe the particular cognitive biases that these theorists use to explain particular risk responses.
which individual behavior takes place (Cameron 1997; Kippax and Crawford 1993). Additionally, “thought (or cognitive activity) may not occur until after the behavior in question has been enacted” (Kippax and Crawford 1993: 255). These concerns related to the causal effect of cognition on behavior are legitimate – most studies using the HBM and TRA are cross-sectional and therefore unable to measure a causal relationship between cognition and subsequent behavior (Sheeran and Abraham 1997).

Like all theories, the HBM and TRA provide a limited understanding of a social phenomenon. They help to identify factors that need to be explored in greater detail, but do not adequately answer the “how” or “why” questions. Studies of parental vaccine acceptance using the HBM/TRA models reveal that the factors – and the relative weight of these factors – affecting parental vaccine decisions vary significantly. The lack of consistent findings using these models suggests that parental vaccine decisions are complex, and that no single set of factors or beliefs can predict parental vaccine choices. The findings also suggest that the exclusive focus on subjective, individual beliefs, as conceptualized in these models, is insufficient.

Yet the use of the HBM and TRA within the vaccine acceptance literature is nearly monopolistic; researchers from diverse disciplinary backgrounds overwhelmingly frame their vaccine research using theories of the HBM and TRA. As a result, current findings in the literature reflect one perspective. One of public health’s strengths is its multi-disciplinary heritage, and drawing on this heritage to incorporate other theories that emphasize social and cultural factors can provide important information on vaccine acceptance that both situates some of the individual-level findings and encourages a reexamination of previously held assumptions.
Anthropological Theories and Contributions

A more nuanced understanding of parental vaccine acceptance can be achieved by expanding our scope of inquiry, particularly through the application of anthropological theories and approaches. Anthropologists sometimes argue that culture is the factor underlying behavior, though it is more likely that cultural factors, like cognitive factors, shape behavior, rather than determine it (D'Andrade 1999). While anthropological approaches have been used to understand many public health issues, anthropologists have had a more limited role in vaccination research. Therefore, to understand how anthropologists can (but have not necessarily) contributed to vaccine studies, it is helpful to examine how anthropological theories have been applied to related fields, including parental acceptance of oral rehydration therapy (ORT) and parental decisions regarding fetal genetic screening, breastfeeding, and the use of certain childhood medications.

Attempting to parse out theoretical approaches to parental acceptance of technological innovations within the anthropological literature is a sticky and somewhat interpretive affair. Unlike many of their public health counterparts, many anthropologists do not explicitly articulate the theoretical orientations that frame their research questions. In addition, anthropological results are often descriptive and theoretically ambiguous.

While anthropologists often espouse theoretical rhetoric which is polemic – suggesting that anthropologists strictly adhere to specific theoretical approaches – in practice anthropologists tend to borrow from several theoretical traditions. For this reason, any attempt to group theoretical contributions under one rubric or another is artificial and limiting. However, in order to make general sense of these theories, I have chosen to organize them into two very broad categories: meaning-centered and critical
approaches. Within the meaning-centered category, I discuss cognitive and symbolic/interpretive theories. I discuss political economy, Foucauldian, and feminist approaches within the critical category.

**Meaning Centered Approaches**

While cognitive anthropological theory draws from diverse schools of thought, theorists from this tradition generally agree with Goodenough’s assertion that culture consists of a set of shared mental models that includes “whatever it is that one has to know or believe in order to operate in a manner acceptable to its members” (Geertz 2001: 345). Because culture is located in the mind, anthropologists need to examine the “*organizing principles underlying* behavior” to understand “how different people organize and use their cultures” (Tyler 1996:353). Cognitive anthropologists are particularly interested in the relationships between linguistic units and units of cognition, which leads to a heavy emphasis on linguistic analysis (Agar 1974; McGee and Warms 1996).

In the 1980s, cultural models were understood as “pre-supposed, taken-for-granted models of the world that are widely shared . . . by members of a society and that play an enormous role in their understanding of that world and their behavior in it” (Garro 2004:18). These studies were largely descriptive and concerned with understanding the emic perspective. Medical anthropologists using this approach tended to focus on categorizing and classifying semantic illness categories, folk taxonomies, and cognitive illness domains that people used to organize information about disease etiology, symptoms and treatments (Agar 1974; Farmer and Good 2007; Trotter 1997). Anthropologists working in the international health arena during this period drew heavily
from cognitive approaches (Chowdury, et al. 2002; Good 1994; Nichter 1996b). For example, Nichter (1996b) found that the ethnosemantic classification of a respiratory condition as either “weak lungs” or “tuberculosis” affected local perceptions of the purpose of tuberculosis medication, which contributed to delays in health care treatment and drug misuse.

Cognitive anthropology in this vein was criticized for several reasons, one of which related to the supposed homogeneity of cultural models. Anthropologists focused on the shared elements of cultural maps but largely neglected to account for intra-cultural variation (Garro 2004). Other criticisms of cognitive theory are shared with the HBM and TRA: anthropologists focused on the end product (cultural maps) without explaining the processes that contributed to these shared models (Garro 2004). In addition, findings exclusively derived from descriptive cultural maps were often used to explain conflicts between biomedical and traditional illness categories (Good 1994). However, like researchers using the HBM and TRA, few cognitive anthropologists observed actual behavior to see if it coincided with mental models (Chavez, et al. 2001).

More recently, however, cognitive anthropologists have attempted to address some of these limitations. New techniques, such as cultural consensus analysis, allow anthropologists to examine cultural homogeneity and cultural dissonance (Dressler 2001). Cognitive anthropologists also shifted their attention from the “formal properties of illness models to their relation to natural discourse, and thus to context and performance characteristics of illness representations” (Farmer and Good 2007). By focusing on illness narratives and exploring them in the context of decision-making, some cognitive anthropologists have sought to understand how people use cultural
knowledge to make health care choices. As Garro (2004:19) explains, “narrative is an active and constructive form of cognitive engagement that reflects participation in specific social and moral worlds and depends upon personal experience and cultural resources, including culturally available models.” This approach recognizes that decision-making is affected by individual and cultural factors – many decisions cannot be understood or predicted based on shared cultural models. However, advocates of this approach argue that in cases where recurring decisions take place and there are alternative choices, group members develop a set of shared standards and criteria for making choices (Garro 2004:16).

The reshaping of cognitive anthropology has aligned cognitive interests more closely with those of interpretive anthropologists. Indeed, much of the recent literature on acceptance of health innovations draws both from cognitive theory and interpretive/symbolic theory, making it difficult to separate examples into one school or the other (Green, et al. 1994).

Symbolic and interpretive theories, to which I now turn, are also meaning-centered anthropological approaches. Margaret Lock argued that neither technologies nor the human need for them are independent of culture – we need to analyze the “attribution of meaning to technologies and their application” (Lock 2004:86). Anthropologists drawing from symbolic and interpretive traditions (SI) are particularly interested in the multiple meanings that technologies embody. SI approaches have been hugely influential in medical anthropology, particularly in understanding medical innovation, compliance issues, and physician/patient communication (Blume 2006; Good 1994; Kauchali, et al. 2004; MacCormack and Draper 1988; Mull and Mull 1988; Nichter 1988; Nichter 1996a;
Like cognitive anthropologists, anthropologists from the SI tradition largely treat culture as a mental phenomenon. However, SI anthropologists reject the assertion that culture can be modeled or studied by searching for cognitive domains within people’s minds. While SI theorists agree that culture cannot exist apart from individuals, they argue that it is better studied by examining how people interpret the events and materials around them. Geertz, a pioneer in interpretive theory, explained that “Whatever sense we have of how things stand with someone else’s inner life, we gain through their expressions, not through some magical intrusion into their consciousness.” Culture is “embodied in public symbols and actions” where symbols work to transmit meaning (McGee and Warms 1996:430).

Rather than studying linguistic taxonomies, Geertz asserted that the study of culture was a study of everyday life. In Geertz’s (2001:341) opinion, “behavior must be attended to, and with some exactness, because it is through the flow of behavior – or, more precisely, social action – that cultural forms find articulation.” Axiomatic to this approach is that humans imbue the world with meaning and significance. Social groups are connected to one another through a system of shared meanings and symbols and social life is seen as the process by which people create and negotiate meaning (Moore and Sanders 2006). By observing social life and everyday activities, one can study culture. In this sense, culture is used as an analytic concept to explain “an ordered system of meaning and symbols, within which actors interpret their experience and order their actions” (Moore and Sanders 2006:10).

This approach has been used to understand how vaccines develop multiple meanings in a cultural group and how these meanings affect the success or failure of a
program. Two examples will illustrate this point. In The Gambia (Fairhead, et al. 2006b), blood is powerful and health-promoting – to lose blood is risky. While vaccines do not draw blood, locals connected vaccines with past health programs that did draw blood samples. Coupled with suspicions about the uses of African blood (to help white people at the expense of Africans), vaccines took on multiple meanings among locals that complicated vaccine decisions. Conversely, in the village of Kérú in Burkina Faso, vaccines were generally accepted not because of what they contained but because of how they were administered. Local incision techniques require healers to penetrate the skin in order to mix medicine with blood – the medicine becomes meaningful when it is dispensed in this manner to infuse with the blood. Because of their similar route of penetration, vaccines were widely accepted by healers and parents (Samuelsen 2001a).

Arthur Kleinman’s “explanatory models” (EM) approach draws largely from a meaning-centered perspective (as well as cognitive anthropology) and is a commonly used framework to understand physician/patient interactions and health care seeking behavior. EMs originally developed as a framework to improve provider-patient communication in clinical settings. Kleinman posits that both the patient and the provider bring their own EMs to the clinical encounter and that EMs include explanations of etiology, onset of symptoms, pathophysiology, the severity of type of sickness, and treatment. Additionally, Kleinman argues that “EMs are tied to specific systems of knowledge and values centered in the different social sectors and sub-sectors of the health care system” (Hausmann-Muela, et al. 2003:6). Kleinman insists that explanatory models cannot be ascertained through formal elicitation techniques; rather, EMs emerge through discourses and often change depending on the illness event (or stage of an
illness). Therefore, health behaviors need to be understood as responses to a “particular episode of illness within specific clinical and life-world contexts” (Hunt and Arar 2001:349). Kleinman’s approach has been used in many studies of patient-provider interactions to examine risk communication practices (Lazarus 1988), health seeking behavior (Hausmann-Muela, et al. 2003), and “compliance” issues6 (Hunt and Arar 2001).

Despite differences between cognitive and interpretive theoretical perspectives, the meaning-centered anthropological theories have been criticized on similar grounds. Theorists within these schools have been accused of casting individuals as “supremely knowledgeable” – aware of an association between their beliefs and their actions and capable of articulating these connections (Moore and Sanders 2006:11). While individuals are supremely knowledgeable (in the sense that anthropologists can learn everything about a culture from individuals), they simultaneously lack agency – a difference from the HBM and TRA models. In cognitive and SI theories, individuals are largely conceptualized as vessels through which culture flows – their interpretations, thoughts, and ideas are largely structured by cultural values and beliefs. While Geertz might argue for the importance of observing how meaning is interpreted in everyday life, the underlying assumption is that the cultural script with which people are acting has already been written (Roseberry 1982).

6 The EM approach can be used to explore broader issues beyond the physician-patient dyad. For example, Princeton (1988) contrasted the EM’s of public health officials and members of a small Colorado cult to understand why a diphtheria vaccine intervention failed in the midst of a community epidemic. After examining the incompatibility of epistemological beliefs held by the group members and public health officials, the broader meanings that each group associated with particular health practices, and the way that the intervention was approached, Princeton concluded that the public health campaign was bound to fail.
One of the primary critiques of these anthropological approaches is that they fail to articulate the relationship between “systems of ideas and patterns of behavior” (Moore and Sanders 2006: 11). In other words, how are meanings and values transmitted between groups and individuals and how do group values and beliefs relate to individual actions?

While few anthropologists would likely dispute the importance of meanings and symbols, many anthropologists are interested in understanding the importance of these meanings and symbols in action.

Some critics of the meaning-centered theories dispute their application in studies, many of which focus on the differences between public health and lay population beliefs about the body, disease, and treatment. These studies, critics argue, conceptualize cultural groups as discrete and bounded wholes that have particular, somewhat homogenous health beliefs that vary to a relative degree from the biomedical disease model (Brodwin 1997; Good 1994; Streefland, et al. 1999). This criticism is directed both at the theory, for failing to explicitly examine or expose power differences, and at the ways that anthropologists have used these theories. To examine this latter point, it is worth discussing the history of medical anthropology’s engagement in public health interventions, especially internationally.

In the 1950s, public health programs were introduced in developing countries with the overarching goal of altering local behaviors to improve population health (Good 1994). Despite well-meaning, if ethnocentric intentions, innovations were met with apathy or resistance, falling victim to the fallacy of the empty vessel (Scotch 1963). Anthropologists argued that the internal logics of a cultural system had to be understood before public health interventions could be successfully implemented (Good 1994).
These early anthropological works developed an adversarial model to explain local resistance to technologies where “scientific and traditional medicine were locked in a battle, each trying to win (or hold on to) the allegiance of the community” (Foster 1977:528). While early anthropological work was often sharply critical of health planners’ naiveté and ethnocentrism, it nonetheless was framed upon assumptions about the validity and superiority of biomedical technologies. The anthropologist’s job was to understand how cultural beliefs interfered with the transplantation and acceptance of biomedical knowledge, which was largely unquestioned as superior. Moreover, anthropologists focused nearly exclusively on the local beliefs that could interfere with a public health program, while ignoring service-level factors. As Foster (1977:528) noted, “many of the apparent resistances to acceptance of health services commonly attributed to villagers’ apathy and their cultural barriers, are, in fact, the result of administrative and professional inadequacies.”

While anthropologists have become more aware of biomedicine’s western, epistemological foundations and are more skeptical of innovation and development, critics argue that the same assumptions guide research today. Viewing resistance to technology as a product of cultural miscommunication, anthropologists often become cultural mediators, who attempt to identify the disparate beliefs in order to “negotiate between the two cultural worlds and craft the health-education messages recommended by biomedical science in appropriate, locally acceptable idioms” (Brodwin 1997:71).

These goals are clearly stated in Kauchali and colleagues’ (2004:82-83) examination of diarrhea care-seeking behavior among parents in a rural district of South Africa. As the authors noted in their paper,
The purpose of this study was to contrast caregiver’s beliefs and concepts pertaining to childhood diarrhoea with bio-medical concepts and care guidelines used by health workers and researchers. The aim was also to identify possible differences that could lead to delayed care-seeking, improper diagnoses and treatments by health workers or which could invalidate data on diarrhoea prevalence and severity in research.

The issue highlighted here is the adoption of an uncritical “liberal reformist position,” which assumes “that health development provides practical and apolitical tools for solving specific human problems” (Brodwin 1997:72). Critics argue that innovations and interventions cannot simply be seen as altruistic attempts to improve the lives of others; rather, they need to be viewed within a larger historical and political context that recognizes shared and competing interests. While I agree that interventions need to be considered critically before anthropologists decide whether to contribute to their implementation, I would also oppose a wholesale rejection of such involvement on the supposition that it might advance biomedicine or the interests of particular political players. Such criticisms should not lead us to reject applied or interdisciplinary work, nor meaning-centered approaches.

As Good explains, post-interpretive theoretical developments demand a more complex understanding of culture: “Given the emergence of practice theories and wide-ranging forms of critical analysis, it is little surprise that some formulations in this tradition now seem dated or that the very term ‘meaning-centered’ now seems best placed in quotes” (1994:56). Most contemporary applied anthropologists, regardless of their main theoretical orientation, are aware that their work contributes to certain types of
knowledge production and think carefully about how to best approach a research topic given these fundamental issues.

**Critical Medical Anthropology, Political Economy, Foucault, and Feminist Approaches**

Critical medical anthropology is perhaps more of an over-arching approach than a theory. While there is no one definition of critical medical anthropology, Morgan (1987:135) defines it as a “radical critique . . . concerned with illness as a metaphor for internalized, somaticized exploitative social relations. The foci of intellectual inquiry are the body, which absorbs and reflects social dissonance, and medical institutions, the histories of which reveal societal attempts to cope with dis-ease.” Critical medical anthropologists, drawing from political economy, Foucauldian, and feminist theory, have used this approach to challenge western epistemology and anthropologists’ roles in reproducing the power relationship inherent in western epistemology (Kincheloe and McLaren 2003).

While symbolic and interpretive theories focus heavily on the meaning-centered, ideational role of culture, political economy (PE) approaches predominantly focus on structural, macro-level forces in shaping culture. The PE of health is primarily a macro-level theory focused on the relationship between modes of production, class-based division of labor, and inequality. PE is a materialist position whereby material conditions of unequal access to wealth and power are assumed to condition social relationships (Erickson and Murphy 1998). Anthropologists using this approach tend to examine the ways in which societies group individuals (e.g. by class, gender, or ethnicity) and how power and wealth are distributed within the society. Within this framework, culture is
conceptualized as a system of objective and concrete forces, or ideologies, that reflect specific interests among members in society (Erickson and Murphy 1998). Cultural beliefs become resources that people use to “address the major social and economic contradictions affecting their lives” (Brodwin 1997:73).

Anthropologists using a PE approach draw on a historical perspective to inform their research and tend to employ dialectic or conflict models of social change in their analyses (Morgan 1987). Unlike meaning-centered approaches (which have been categorized as reformist), a conflict-based ideology is central to the PE model (and all critical theories). Here, anthropological research is used primarily to critique the “dominant reformist ideology, “to expose health inequities and domination, and to link local, national, and global entities in “webs of political influence” (Brodwin 1997:73).

PE approaches contribute to the broader research on parental acceptance of innovations (Greenough 1995a; Greenough 1995b; Obadare 2005; Turnbull 1989). Historical examinations of parental resistance to the smallpox vaccine in Victorian England reveal how mandatory immunization laws disproportionately affected the working class, who were also more likely to be harmed by vaccination (Durbach 2000; Durbach 2002; Fenner, et al. 1986). Viewed through this lens, compulsory vaccine campaigns are exposed as symbols of class oppression intended to homogenize and regulate the bodies of working class citizens (Baker 2003; Hobson-West 2007). More recent cases of vaccine resistance, such as opposition to the pertussis vaccine, have been analyzed as expressions of class-based tensions (Baker 2003). In another recent example, resistance to the oral polio vaccine among parents in Nigeria is analyzed as the result of religious and political conflicts between Islam and the West (Yahya 2006; Yahya 2007).
By examining the events unfolding in several Nigerian villages, the author ultimately questions the roles, motivations, and actions of several global and national actors who were associated with the immunization program, concluding that the 16-month vaccine standstill was ultimately a “play of political might between the international community and the federal government on one hand and the northern Muslim states on the other” (Yahya 2006:7). In this case, parental resistance to the vaccine was not understood as the outcome of individual choices or shared local meanings, but as the consequence of macro-level dynamics.

Political economy approaches are not without critics. While symbolic anthropologists are criticized for failing to account for structures, political economists are assailed for focusing too heavily on structures (Erickson and Murphy 1998). Further, many anthropologists argue that political economy approaches are too deterministic, often relegating individual actors to obscurity (Knauft 1996). When agency is discussed, it is often narrowly defined as explicitly political actions that either reinforce or resist overt types of domination (Brodwin 1997).

Critics argue that by focusing exclusively on the role of an innovation (e.g. vaccines) in advancing or diminishing the power of specific interest groups, anthropologists tend to overlook the benefits that local people might perceive from such programs (Brodwin 1997). Other anthropologists reject the PE theory as ethnocentric because of its roots in Marxist philosophy, which is premised on the assumption that “culture is the product of materialist power struggles – a uniquely Western form of analysis” (Erikson and Murphy 1998:139). The assertion that there is only one “cause of configuration between industrial capitalism, colonialism, and the post-Enlightenment
ideal of scientific progress” has caused many anthropologists to question some of the basic assumptions of the approach (Erickson and Murphy 1998:139).

Foucauldian examinations of power and discourse are another strand of analysis that can be included with the vein of critical medical anthropology. Foucault was particularly interested in the relationship between power and knowledge and the process by which some forms of knowledge become legitimate. Foucault argued that one way in which power is exerted over bodies is through particular knowledges of the body. When power is exercised onto bodies, the bodies become objects and effects of knowledge. The individual body, rather than the disease, becomes the dangerous entity (Nettleton 1988).

In the context of vaccine-preventable diseases, it is the unvaccinated body, rather than the disease, that must be controlled. Dew (1999) reveals how UN conventions, national policies, and state laws use coercive measures, through ideological, legal and financial means, to compel parents to vaccinate their children, exemplifying the way in which dissenting bodies, rather than diseases, are targeted.

While some regulations are externally-driven, Foucault argued that bio-power, or control over the body, was most effective when bodies became disciplined; that is, when regulation of the body was internalized, rather than imposed by external forces (Gaines and Davis-Floyd 2004). From this perspective, mass immunization campaigns, especially voluntary campaigns with high coverage rates, are understood as effective mechanisms of the state that function to regulate, surveil and control individual bodies. Researchers have commonly used this Foucauldian perspective to understand why so many parents routinely vaccinate their children without putting much thought into it (Brownlie and Howson 2006; Streefland, et al. 1999).
For Foucault, power and knowledge are inseparable. For example, biomedical knowledge about the body (contagion) led citizens in many European countries to accept increased state control over the regulation of individual bodies (e.g., through quarantine, vaccines, etc.). This act authorized and legitimized the expansion of state power into the domain of public health. The success of vaccination programs further legitimated biomedical knowledge about disease, while illegitimating other forms of knowledge. Through this process “the exercise of power perpetually creates knowledge and, conversely, knowledge constantly induces the effects of power . . . Power was exercised on bodies and thereby rendered them both the object and effect of knowledge” (Nettleton 1988:160).

Nations and Rebhun (1988) explored the relationship between power and knowledge to explain why oral rehydration therapy (ORT) was underutilized by parents in northeastern Brazil. The authors argued that the Brazilian biomedical institution, as embodied by physicians and nurses, created a set of rituals surrounding ORT in an attempt to mystify the treatment event. By dramatizing the rituals associated with ORT administration, by admonishing parents who used alternative treatment techniques, and by limiting the use of ORT to the clinic (rather than distributing stockpiles of unused ORT for home use), biomedical practices gained ascendancy and legitimacy over other forms of healing. New knowledge about diarrhea and dehydration was created – ORT became a biomedical entity requiring expert supervision in a clinic-setting for proper delivery. As a result, few parents felt confident that they could manage to deliver ORT to their own children. A similar situation was described in Jamaica, where aid agencies
advertised and sold ORT as a biomedical medicine, even though the ingredients were common household items that most parents had (MacCormack and Draper 1988).

While these analyses provide an alternative and challenging view of biomedicine that raises important questions about technological innovation, social justice, and competing stakeholders’ interests, it simultaneously challenges parents’ abilities to make health care decisions. The anthropologists assume that the parents would prefer to administer the ORT themselves if they had access to it, or if physicians presented it differently – or that parents would resist vaccine programs if they understood them as a disciplining discourse of control. This might be the case, or it might not. Interpreting others’ cultural beliefs and practices as mystification or false consciousness raises questions about knowledge and differences in what anthropologists and lay people can know. As Good (1994:61) explains, “it risks making actors be dupes – of a hegemonic system, in this case – even as it authorizes the perspectives of the observer over the claims of those we study.” When people’s knowledge claims are analyzed as mystification they become the subject of the anthropologist’s epistemological judgments, “with some version of a distinction between science and ideology” (Good 1994:61). The anthropologist/physician/scientist “knows better” critique once again rears its head.

As a final critique, some anthropologists also question the applicability of critical approaches to the “real” world. While critiques of biomedical, public health, and physician processes (as well as anthropology as a discipline with western-epistemological roots) provide an alternative way to view health care and the role of structures in disciplining such interactions, one also has to question how applicable these critiques are to the applied anthropologist who hopes to work within the public health system to effect
change. As Good (1994) correctly notes, approaches that are critical of biomedicine and public health exist at the same time that children die of vaccine-preventable diseases.

Feminist theories, as they relate to medical anthropology and vaccine research, have been injected into larger theoretical frameworks to approach an analysis of the medicalization of motherhood, whereby mothers face increasing pressure to make decisions regarding an expanding number of technological innovations (Malacrida 2002; Rapp 2000; Rothman 1982; Viisainen 2000). Mothers, as opposed to parents, are often the targets of health interventions, reflecting social expectations about the roles and responsibilities of the mother (Petersen and Lupton 1996). Perhaps as a result of this disproportionate focus on maternal accountability for childhood health, many mothers express feelings of responsibility, liability, and blame when making vaccine decisions on behalf of their children (Sporton and Francis 2001; Tickner, et al. 2007). These decisions are no doubt complicated by value-laden meanings and implications, thus tying them to meaning-centered approaches. Certain types of choices and the responses that those choices elicit from mothers, physicians, the state, and the public “embody both positive and negative feelings about women, motherhood, and sexuality” (Zeitlyn and Rowshan 1997:66).

The literature on the medicalization of motherhood tends to focus on differential power relationships between mothers, physicians, and the state, often through the lens of authoritative knowledge (Jordan 1997). Mothers who refuse biomedical treatments are often stigmatized or blamed for their decision (Craven 2005). For example, pharmacological treatment of Attention Deficit Disorder (ADD) is disproportionately valued by most physicians, many educators, and the state. Mothers who refuse to treat
their children with ADD drugs are often the subject of targeted interventions that portray them as non-compliant, ignorant, or irresponsible (Malacrida 2002). Women who choose unassisted births face similar stigma – women are often described as “calculating criminals”, “unnatural”, and “callous murderers” in narratives (Lupton 2003:166). While examining the meaning of motherhood, it is important not to conflate motherhood with womanhood, or to assume that all mothers experience motherhood, or decisions related to it, in the same way (Lewin 2006). One must be careful not to strip gender from other social categories that undoubtedly interact with gendered-beings – such as class, ethnicity, sexuality and religion. As several studies on mothers’ decisions regarding prenatal screening have noted, the meanings of motherhood and how expectant mothers make choices about pre-natal screening vary by class and ethnicity (Hunt, et al. 2006; Rapp 2000).

Recently, researchers have explored the intersection between medicalization and marginalization, where particular kinds of mothers, such as single mothers, teen mothers, or welfare mothers are singled out (or doubled out?) – not only because of their health care choices, but because of their sociocultural positions (Ellison 2003; Malacrida 2002; Solinger 2005). In a study of vaccine acceptance in India, researchers found that mothers in lower castes experienced significant obstacles to vaccination – forced to wait outside of a vaccination house until all of the children of higher castes had been immunized (Streefland, et al. 1999). Other studies reveal the important role that gender can play in the success and implementation of vaccine programs (Millimouno, et al. 2006; Nichter 1996c). In Bangladesh, for example, vaccine discussions occurred from behind a curtain
because male vaccinators were prohibited from having face-to-face discussions with mothers.

The normalization of feminist approaches within the larger anthropological discipline has expanded its application so that gender analyses can be incorporated into diverse theoretical frameworks (Lewin 2006). Because the analysis of gender has become so widely accepted in anthropology, many anthropologists write “gendered ethnographies,” where women’s lives are not an area of inquiry of themselves, but a lens through which broader topics are examined (Knauft 1996). While the lives and experiences of women – as mothers who are socioculturally positioned in multiple and overlapping ways – is an important component of my study, it is not in itself adequate to understand HPV vaccination decisions. As Knauft (1996) notes, the goal is to bring gender into the equation rather than to make it the equation.

Theory in the Middle: The Local Vaccine Culture Approach

“We need to know, not only what use the answer will be to someone else, but what use it will be to us. Are the questions we ask worth having answers to? This is a pragmatic view” (Herzfeld 2001:24).

Meaning-centered and critical approaches all provide important contributions to the parental vaccine acceptance literature. These approaches, which begin with assumptions about the importance of sociocultural factors in shaping individual behaviors, provide an important balance to the more individualistic HBM and TRA models. However, while the anthropological frameworks offer more holistic examinations of vaccine acceptance than are often present in the health behavior literature, they also tend to limit the role of human agency. On one extreme, the
psychological health behavior theories focus so narrowly on the individual actor that they lose sight of the larger social and cultural contexts that shape individual decisions. On the other end are the anthropological theories, which focus so widely on the role of sociocultural factors in shaping individual behavior that individuals are largely irrelevant. While anthropologists chastise public health officials for perpetuating the fallacy of the empty vessel, many anthropologists could be accused of perpetuating a similar fallacy, although in this case we could call it the fallacy of the culturally (or structurally) sinking vessel. In reality, I should note, it is unlikely that many anthropologists do perpetuate this fallacy. Rather, it exists in the meta-theorizing and grand debates that still occupy much of the discipline but not much of the work. As Knauft (2006) notes, most anthropological work “sits in the middle” – borrowing from theoretical traditions to inform specific research questions. Many of the examples that I used to illustrate one theoretical perspective could probably be used to highlight other theoretical approaches. In actual writing, there is extreme hybridization that reflects a post-post modern current in anthropology.

Knauft (2006:412) states concisely what I have found in my own review of the literature that “increasingly, theory in anthropology emerges not in itself but as a modifier of specific topics and issues to which theoretical articulations are applied, explored, and expressed.” The most useful approach that I have found for my own research, the “Local Vaccine Culture” framework, fits within this category. The approach combines strengths of the HBM and meaning-centered and critical theories to provide the flexibility to examine individual, symbolic and structural issues surrounding the HPV vaccine and parental acceptance.
This approach was largely developed by Nichter (1996c), who proposed that in order to understand vaccine acceptance a distinction needed to be made between active demand, passive acceptance, and non-acceptance. According to Nichter, active demand “entails adherence to vaccination programs by an informed public which perceives the benefits of and need for specific vaccinations” (1996c:330). Passive acceptance, on the other hand, “denotes compliance,” it is the “passive acceptance of vaccinations by a public which yields to the recommendations and social pressure, if not prodding, of health workers and community leaders” (1996c:330). Examples of passive acceptance include cases in which mothers vaccinate their children to avoid being blamed or overcharged if their children fall ill in the future (Millimouno et al. 2006).

In order to distinguish between active demand and passive acceptance, Nichter emphasizes the need to examine supply and service factors, social factors, and cultural factors that shape vaccine decisions (1996c). Therefore, Nichter argues that structural and symbolic perspectives need to be explored by examining the perspectives of parents, as well as other actors, including service providers, in the local and historical context. In addition, he argues for the need to explore cultural factors related to a specific vaccine and vaccines in general, since both affect vaccine demand (Gore, et al. 1999; Ogilvie, et al. 2007; Slomovitz, et al. 2006; Sturm, et al. 2005). Finally, he calls for a shift from exclusively focusing on “predictors of non use [of vaccinations]” to studies that also examine predictors of demand and self-regulation which “pay credence to the agency of community members” (1996c:336).

Nichter’s original framework underpins most of the recent anthropological research on parental vaccine acceptance, because his work provides the basis for the
“Local Vaccine Culture” (LVC) approach. The LVC approach was proposed by Streefland and colleagues (1999) as a more comprehensive version of Nichter’s original framework. They argued that in practice, the concepts of active demand and passive acceptance lacked sensitivity to assess actual vaccine behavior. In response, they proposed three general conceptual categories: acceptance, social demand, and non-acceptance. The authors argue that there are “gradations of acceptance” (1999:1710), pointing to cases where parents might fully vaccinate one child, partially vaccinate another, and choose not to vaccinate a third. To account for these cases, they suggest a continuum rather than a dichotomy to understand acceptance. In Nichter’s original framework, active demand results from people’s recognition of an association between the vaccine and specific therapeutic effects. Streefland and colleagues (1999) created another concept, called “social demand” to account for vaccine demand that is associated with general vaccine benefits or general trust in biomedicine. This category is helpful to describe instances in which there is a demand for a vaccine, but the demand does not relate wholly to the vaccine’s biomedically-defined therapeutic effect.

In the LVC approach, there are three modes of non-acceptance to describe the various reasons why vaccination does not occur. In one mode, mothers are willing but unable to vaccinate because of inclement weather, transportation constraints, or work requirements. In the second mode, mothers simply refuse to go to the vaccination site, which reflects resistance to the program rather than the technology itself. Provider attitudes, misinformation about vaccine availability, and concerns about side effects are

7 For instance, studies have shown that some mothers accept vaccines because they feel that the vaccine will generally improve a child’s health or prevent general illness, rather than because they associate a particular vaccine with the prevention of a specific disease.
included in this mode, although the authors mainly attribute refusals in this mode as a response to the perception that services are inadequate or malfunctioning. In Malawi and Ethiopia, for example, mothers responded that vaccinators rarely showed up to the clinics to give the injections, and in cases when they did show up, there were not any vaccines to dispense (Streefland, et al. 1999). In the third mode, mothers question the need for vaccination itself. In this mode, the challenge is directed at the technology rather than its delivery. The authors attribute cases of collective and organized resistance to this mode.

While past anthropological studies tended to emphasize either the cultural acceptability of a vaccine itself (meaning) or the delivery of a vaccine program (structural), the LVC framework allows for the exploration of both by examining them through the lens of service-delivery (Greenough 1995b). Fairhead et al. (2004:4) note the importance of exploring the interactions between parents and healthcare providers, arguing that these interfaces involve “communicative processes, creative exchanges and negotiations of knowledge and meaning which are both framed by, and in turn shape, people’s broader perspectives on the technologies, issues and agencies concerned.” The framework provides an integrated and dynamic approach to explore vaccine acceptance that connects individual practices to larger community processes, without pre-supposing the specific means through which such connections are enacted.

Though some have made minor changes to it, the LVC approach has remained popular among anthropologists conducting research in diverse parts of the world (Cassell, et al. 2006b; Fairhead, et al. 2004; Feldman-Savelsberg, et al. 2000; Kaljee, et al. 2004; Millimouno et al. (2006:1), added “significant lateness” to the category of “non-acceptance” and replaced “non-acceptance” with the word “default” to allow for cases in which mothers accept vaccines in principle, but in practice are incapable or unwilling to complete the vaccine schedule.

8 Millimouno et al. (2006:1), added “significant lateness” to the category of “non-acceptance” and replaced “non-acceptance” with the word “default” to allow for cases in which mothers accept vaccines in principle, but in practice are incapable or unwilling to complete the vaccine schedule.
Millimouno, et al. 2006; Poltorak, et al. 2004; Pool, et al. 2006; Samuelsen 2001b; Streefland, et al. 1999). The approach has primarily been used to examine vaccine acceptance in developing countries, but it has also served as a framework to examine parental acceptance of the MMR vaccine in the U.K. (Casiday, et al. 2006; Leach 2005; Poltorak, et al. 2004; Poltorak, et al. 2005). The strength of the framework (and a potential weakness) is its breadth – it allows researchers to examine the individual experiences and emotions, shared (or contested) meanings surrounding vaccination, and political and economic factors shaping vaccine policy and delivery as part of an integrated system. As a framework, the approach provides parameters through which the problem can be explored, without stifling the ability to engage in inductive theorizing. The approach has yielded complex, in-depth accounts of vaccine acceptance that encourage diverse and more nuanced theoretical understandings of vaccination behaviors and acceptance.

Incorporating elements from multiple theoretical perspectives into a coherent structure provides a dynamic, adjustable lens, which can be focused for both close-up and panoramic views of a research question. By capturing multiple levels of data, the resulting collage of information is more likely to capture the rich and complex layers of vaccine acceptance decisions than a narrowly-focused, single-theory snapshot may do.
Chapter Three – Theories of Risk

A large body of literature drawing from multiple theoretical strains attempts to explain how and why people identify, process, and respond to risks. Much of the risk literature draws extensively from psychological, cognitive, and economic theories, which tend to explain risk perceptions and decision-making from a rationalistic, individualistic orientation. More recently, however, many researchers have shifted their attention to sociocultural risk theories, suggesting an increasing consensus that social and cultural factors play a significant role in how people identify, perceive, and respond to risks. In this section, I will provide a brief overview of the theoretical schools that influence risk perception studies, along with the strengths and limitations of each perspective. I will then illustrate how our current understanding of parental risk perceptions and decision-making reflects these different strains, primarily drawing on examples from the vaccine literature. In reviews of the risk literature, authors tend to distinguish between cognitive-science approaches and sociocultural approaches (Berry 2004; Lupton 1999). I will use the same general distinction to discuss risk theories, recognizing however, that there are substantial variations within each category, as well as some overlap between categories.

Cognitive-Science Approaches to Risk

Most of the general risk literature is underpinned by a cognitive science approach (CSA). Like all approaches, the cognitive science approach is predicated on a set of
epistemological and ontological assumptions that frame the way that researchers examine and seek to answer specific research questions. Cognitive science approaches share fundamental components, including values placed on rationality, objectivity, and measurement (Lupton 1999). Within the CSA approach, risks are seen as objective hazards or threats that exist in the world (Berry 2004; Lupton 1999) that can be identified and controlled using scientific measurements and calculations (Lupton 1999). Risk, as a concept, is largely unquestioned by researchers using this approach (Lupton 1999).

The most common CSA used to understand vaccine risk perceptions and decision-making is the cognitive/learning perspective (CLP), which draws largely from psychology (Taylor-Gooby and Zinn 2006). In Chapter Two, I discussed two theories that are included within the CLP – the HBM and TRA. Rather than repeating all of the attributes of the HBM and TRA as CLPs, I will focus on other theories in this section, particularly those that study the cognitive process of risk conceptualization (as opposed to the outcome). As discussed in Chapter Two, CLPs are rational actor approaches and value-expectancy models, where a deliberate, self-maximizing assessment of the likelihood and severity of outcomes leads to behavior. Serious limitations in this approach were demonstrated when slight changes to the range of values, wording, or order of questions – factors that should be theoretically insensitive – were found to significantly alter the way that people estimated risks (Taylor-Gooby and Zinn 2006).

Rather than questioning the underlying assumption of rationality, researchers sought to understand what kept people from perceiving risks rationally. In other words, the findings led researchers to explore why these “errors” in judgment occurred. Many researchers turned their focus to the role of cognitive heuristics, or mental shortcuts that
people employ when assessing a risk, to explain seemingly irrational decisions. Several studies of parental vaccine decision-making focus on the influence of specific heuristics, such as biases of omission, availability, and control on risk perceptions and decisions (Asch, et al. 1994; Baron and Ritov 2004; Brown, et al. 2010; Gellin, et al. 2000; Meszaros, et al. 1996). Table A2 (see appendix) contains a more detailed description of each bias and how they are used to understand parental vaccination decisions. These studies emphasize the need to address specific heuristics that parents use with the goal of “completing and correcting mental models” so that parents can make “correct” vaccine decisions (Ball, et al. 1998:456; Bostrom, et al. 1994).

Studies examining risk heuristics often use hypothetical scenarios that require parents to numerically estimate an acceptable risk score based on alternative risk choices. A question might ask, “Imagine that a new HPV vaccine is developed. How safe would the vaccine have to be before you would vaccinate your daughter?” Often, parents are asked to provide a risk percentage response. Connelly and Reb (2003) provide an excellent review of studies attempting to measure parental vaccine acceptance using numeric risk scenarios. Most of the studies that were reviewed found that at least some respondents are hesitant to vaccinate when there is a significant risk involved. However, all of the reviewed studies involved one or more measurement problems that are discussed in Chapter Four.

Other researchers are more interested in understanding the specific cognitive processes that parents undergo when making risk decisions. Referred to as the mental modeling approach (MMA), this perspective is framed upon the assumption that people “develop representations of issues in their minds as part of the process of constructing
explanations” (Taylor-Gooby and Zinn 2006:399). Researchers guided by this approach tend to examine how mental models relate to risk communication, searching for “critical gaps in cognitive understanding of risk in the minds of the lay public” (2006:399). The approach could be used to examine physician and researcher mental maps as well, although it is seldom used in this regard. Ball et al. (1998:456) urge physicians to recognize their own use of heuristics, since “professional training does not preclude biases and errors in judgment.” The authors’ suggestion could equally be applied to researchers, but to my knowledge no one has attempted to explore this area, likely because the entire CLP framework is based upon the assumption that there is some real, wholly-rational way to make decisions that scientists already employ.

Some cognitive researchers argue that emotional and affective factors, as well as cognitive heuristics, are important to risk decisions. Researchers have shown that the weight (e.g., relevance) and value (e.g., positive or negative) that people ascribe to previous experiences can significantly influence their immediate risk decisions. Moreover, an individual’s mood, or what happened to the person a few minutes before a risk decision is made, can significantly influence the ultimate decision that one makes (Mellers, et al. 1998). Recently, psychometric studies have attempted to combine an affect (e.g. emotion) heuristic with other heuristics to understand how each might influence a risk decision (Lupton 1999; Taylor-Gooby and Zinn 2006; Wroe, et al. 2004). While these models vary slightly from one another, they all try to identify deficiencies in the ways that people use cognitive (and affective) heuristics, searching for “the imperfections of learning, especially in complex social situations, or the weaknesses of [lay] mental models” (Taylor-Gooby and Zinn 2006:399). While “risks” are perceived as
objective, independent phenomena, individuals’ reactions to these phenomena are seen as subjective and dependent (Lupton 1999).

A fundamental component of such frameworks is the value placed on science, which elevates the expertise and knowledge held by particular groups of people, such as physicians, researchers, and public health practitioners, whose training and perspective generally reflects a scientific understanding of risk (Berry 2004). As a consequence, when people react to a risk in a manner at odds with scientific risk assessments, their perspective is often viewed as inaccurate, invalid, and irrational. In an article examining risk comprehension, Weinstein (1999:15) acknowledges that “decisions and behaviors are not determined by knowledge alone,” noting that other factors, such as “emotions, personal values, social pressures, environmental barriers, and economic constraints” can also play a role. Despite the multitude of variables that can shape decisions, the author seems to suggest that these values are impediments to “appropriate” decision-making when he concludes that even “educated individuals do not always make wise decisions” (Weinstein 1999:15).

The belief that medical and scientific ways of knowing are (or should be) paramount to parental vaccine decisions and calculations of risk underlie much of the literature on vaccine acceptance (Allen, et al. 2010; Chan, et al. 2007; Davis, et al. 2004; Fazekas, et al. 2008). In a systematic review of HPV studies, Allen and colleagues (2010) reported that knowledge of HPV health consequences was measured in more than 45 studies, which was significantly more than any other construct. Assumptions regarding the superiority of scientific ways of knowing not only pervade the scholarly literature. A recent and widely publicized article from the Associated Press reported that
an increasing number of non-religious parents in the U.S. were using religious
exemptions to avoid vaccinating their children (LeBlanc 2007). While parents’ narratives
included a variety of reasons for claiming the exemption, the position of physicians and
public health officials was largely uniform. Dr. Paul Offit, a prominent vaccine
researcher, represented this view clearly in the article, criticizing parents’ actions as an
“irrational, fear-based decision” (LeBlanc 2007:1).

In order to correct lay perceptions, researchers and health educators often
advocate the need to educate the public about a risk, to “better inform the public and
reduce what is seen as ‘irrational’ thinking” (Leask 2002:125). Successful education
campaigns are measured by changes in public risk perceptions to conform more closely
to “expert” risk assessments (Berry 2004). The underlying assumption is that individuals
can become rational decision-makers if they are provided with sufficient scientific risk
information that is communicated in an effective manner (Crawford 2000).

Yet, if it were the case that the general public was simply ignorant of scientific
ways of knowing, then one would expect that once informed of scientific risks, the
general public would adopt behaviors more congruent with those of medical
professionals. However, as already discussed, scientific knowledge about a vaccine or
disease often has an insignificant effect on a parent’s decision to vaccinate (Alaszewski
and Horlick-Jones 2003).

In one particular study, non-vaccinating parents were presented with the type of
risk-benefit information that leads many medical and public health experts to conclude
that not vaccinating is far more risky than vaccinating. After viewing the materials, the
non-vaccinating parents became even more committed to non-vaccination, rather than
less committed (Meszaros, et al. 1996). Another study found the same effect among vaccinating parents – after viewing scientifically presented anti-vaccination materials mothers were more absolute in their acceptance of vaccines (Leask, et al. 2006). The findings suggest that parents focus on information that supports their previously held position while filtering out other information, lending support to the argument that other factors, unrelated to knowledge (e.g., trust, beliefs, moral values, etc.) play a role in these decisions.

Another problematic assumption of the CSA is that people will weigh the risks and benefits of actions to make a decision that is in their individual best interest. The assumption that parents are self-interested beings who act individually is problematic for two reasons. As discussed in Chapter Two, parents neither perceive vaccine risks as isolated actors, nor make vaccine decisions in isolation. In addition, parents are not making vaccine decisions for themselves, but for their children.

One of the major weaknesses of the CSA, and the psychometric approach in particular, is the inability to explain why some people employ different heuristic devices based on class, gender, or ethnicity, and how risks are conceptualized within shifting political, economic, and social contexts. Mary Douglas (1992:13) aptly articulates many of the problems with the underlying assumptions framing cognitive science approaches: “Warm-blooded, passionate, inherently social beings though we think we are, humans are presented in this context as hedonic calculators calmly seeking to pursue private interests. We are said to be risk-aversive, but, alas, so inefficient in handling information that we are unintentional risk-takers; basically we are fools.” Among other previously discussed
limitations, Douglas’ remark also highlights the lack of emphasis that cognitive science approaches place on the social and cultural factors that frame parental risk perception.

**Sociocultural Approaches to Risk**

Researchers using a sociocultural approach (SCA) are more interested in understanding the ways in which groups identify and react to particular risks than in identifying, measuring, or predicting the probability of a risk or its outcome (Berry 2004). The divergent focus on risk between the CSA and SCA partially relates to ontological differences underpinning the two perspectives. If risk theorists were placed along a constructionist/realist continuum, sociocultural theorists would generally fall on the social constructionist side of the continuum (although at different points), while cognitive-scientists would position themselves nearer to the realist side of the continuum (Mythen 2004; Taylor-Gooby and Zinn 2006). Sociocultural theories all share the assumption that risks can “never be fully objective or knowable outside of belief systems and moral positions: what we measure, identify and manage as risks are always constituted via pre-existing knowledge and discourses” (Lupton 1994:29). Because risks are culturally constructed, they are perceived differently among individuals who identify with particular social worlds. Risk is understood as a central “cultural and political concept by which individuals, social groups and institutions are organized, monitored, and regulated” (Lupton 1999:25). Within this framework, parental risk perceptions are not – and cannot – be limited to the individual, because they are, to some extent, products of shared meanings, experiences, and understandings about the world.
Risk society theories have become influential during the last fifteen years and generally draw on works by Ulrich Beck (1992) and Anthony Giddens (1991; 1999). Fundamental to both Giddens and Beck’s theories is the assertion that risk is a key feature of modern society that emerged through processes of modernization (Lupton 1999). Both men focus on the political aspects of risk and the processes by which risk is generated and dealt with at the “macro-structural level of society,” and both identify reflexivity as the principal response to increasing levels of uncertainty and insecurity (Lupton 1999:81). However, Beck and Giddens disagree about the relationship between risk and reflexivity. Giddens believes that a heightened degree of risk reflexivity resulted not from a quantitative increase in the number of risks that actually existed in the world, but an increase in sensitivity and focus on risk. Beck, on the other hand, sees risk reflexivity as the response to an actual quantitative increase in the number of risks to which people had to respond (Lupton 1999). Additionally, Beck sees reflexivity as rooted in distrust of expert knowledge systems, while Giddens sees reflexivity as taking place “through expert systems” and “reliant upon lay people’s trust in expertise” (Lupton 1999:82).

Beck proposes that people living in western societies are in a transitional period, where the proliferation of wealth and risk are simultaneous (Lupton 1999). With the generation of “goods” also come “bads” – or unanticipated, negative consequences that result from modernization (Taylor-Gooby and Zinn 2006). Beck argues that these unintended risks simultaneously erode “the framework of ideas and institutions
fundamental to modernity” (Taylor-Gooby and Zinn 2006:403). Reducing and managing risk has become central to political survival.

Giddens is also interested in the uncertainty characterizing people’s lives in modern western society, although compared to Beck he is more interested in the impact that cultural changes have on individual lives and the role of trust in risk mitigation (Lupton 1999; Taylor-Gooby and Zinn 2006). As societies become progressively complex, people increasingly rely on others to complete everyday activities. However, the “others” on which people must rely are abstract entities (e.g., organizations), symbolic objects (e.g., money), and “absent others” – unknown and unseen individuals whose decisions and actions affect individual lives and consequently, on whom people must rely. To rely on these “others” involves substantial trust (Casiday 2005). Trust, however, is difficult to maintain in a society where scientific knowledge production, political decision-making, and expert authority are often associated with increasing risks.

When expert systems fail, as they sometimes do, uncertainty in the system increases. As a result, “People are required to be more challenging of expert knowledges, requiring of them that they win their trust” (Lupton 1999:77). As people increasingly focus on risks, they become less confident in the abilities of expert authorities, government officials, and scientists to manage risk (Taylor-Gooby and Zinn 2006). Two patterns emerge in response to this lack of confidence. Individuals return to face-to-face relationships in an effort to re-establish trust in people whom they personally know (Lupton 1999). Additionally, individuals increasingly link trustworthiness with likeness: trust is strongest among members of the same social group (e.g. parents), while distrust
becomes more pronounced between people of different social groups (e.g., parents and providers).

Trust offers a sense of reliability or assuredness in the face of risk – providing individuals with a way to diminish concerns about possible risk; therefore, trust itself always presupposes an awareness of a risk (Lupton 1999). Giddens argues that trust is “vital to establish ontological security from infancy onwards” (Lupton 1999:78). Ontological security is conceptualized as an emotional and psychological phenomenon that provides individuals with a sense of continuity not only in their own self-identity, but in the continuity of the larger social and material world. Trust is seen as key to establishing and maintaining ontological security by offering a way to preserve confidence in the reliability of people and things. Trust can be viewed as a psychological tool that people use to deal with risks that would otherwise paralyze action or lead to feelings of engulfment, dread and anxiety. Without trust, people could not engage in the ‘leap of faith’ that is required of them in dealing with these expert knowledge systems of which they themselves have little understanding or technical knowledge of because they have not been training in them (Lupton 1999:78).

Risk society approaches have been used, though minimally, to explain some aspects of vaccine decision-making. Parents in several studies reported increased confidence in a provider’s vaccine recommendation when the provider talked about his or her own experiences making vaccination decisions as a parent. In doing so, the provider was repositioned as a parent who could recognize the individuality of each child’s health, allaying fears that providers were only concerned with population health (Brownlie and
Howson 2005; Casiday 2007). The level of distrust that people of one group (e.g., parents) feel towards people of another group (e.g., providers) varies. Findings from one study are illustrative of this point. Casiday et al. (Casiday, et al. 2006: 177) found that both parents who accepted and rejected the MMR vaccine were highly distrustful of the government, but less distrusting of providers. The authors suggest that the MMR campaign could be undermined if the government directly promoted the vaccine to parents, suggesting instead that providers take the initiative. In the latter half of this chapter I will provide a more thorough discussion of these factors.

Giddens argues that people in “risk societies” become reflexive citizens who increasingly manage their own risks. Through this conscious and reflexive process, risk becomes a fundamental feature to individual interactions and the construction of the self (Petersen 1997). As expert knowledge is questioned, people look to alternative sources of information and advice. Alternative advice can come from other parents, vaccine resistance groups, scientists with dissenting opinions, the media, and anti-vaccine medical providers. Poltorak et al. (2005:717-718) draw on the risk society approach to explain parent narratives that suggest “links between personalised approaches to immunisation, and a personalisation of responsibility . . . where distrusting the capacity of public institutions to manage technological risks, parents feel they have no one to blame but themselves”. Distrustful of expert knowledge, mothers sought information from other sources, most notably, other mothers. Through informal discussions with fellow mothers about MMR, women were introduced to other techniques and therapies – such as homeopathy, infant massage, and cranial osteopathy – that helped build their confidence to accept or reject specific health strategies (Poltorak, et al. 2005).
For citizens of a risk society, risk and risk management are central components of individual subjectivity. Themes of responsibility, accountability, and blame are central discourses that are directed at the self or at others (Lupton 2000). For example, the media portrayed the outbreaks of mad cow disease (bovine spongiform encephalopathy) as a “‘natural’ outcome of ‘unnatural’ practices” (Lupton 2000:208). In this case, the risk of mad cow disease was perceived as an external and unnatural threat and the government and beef industry were largely singled out as being responsible for creating the threat (Lupton 2000). In other cases, risks are internalized and framed as personal responsibility. This is particularly the case within medical and public health discourses where the onus is on the individual to seek care, such as vaccination (Lupton 2000). As I will discuss shortly, there are numerous ways in which vaccine risks are internalized.

There are limitations to the risk society approach. Both Beck and Giddens tend to see risk perceptions as largely rational responses to modernization – they say little about the ways that risk discourses “operate at a more latent, extra-rational level of meaning.” (Lupton 2000:210). The risk society approach also tends to paint a relatively universal portrayal of risk perceptions that can be applied to nearly all risks occurring in western societies. The theory is largely insensitive to cultural, social, and geographic variations that undoubtedly affect risk perceptions. While the risk society approach does acknowledge differences in risk conceptualization among sectors of society, the distinction is largely drawn between a public and an opposing group, such as physicians (Casiday 2007; Mythen 2004).

What is lacking, Mythen (2004:116) argues, is consideration of the “mélange of social, economic and cultural factors which underpin public perceptions of risk.”
Focusing beyond the individual requires a less compact and “messier idea of social reality than the risk society model” but such an approach may nonetheless “provide a more accurate reflection of the complex nature of public perceptions of risk” (2004:116).

**The Cultural Approach to Risk**

Douglas and Wildavsky’s *Risk and Culture* (1982) is a key work in sociocultural theories of risk. According to Wildavsky, one of the underlying assumptions of this theory is that “people construct their culture in the process of decision-making” (Selle 1991:102). He further argues that when people make choices, they “discover their preferences by deciding whether they will reaffirm, modify, or abandon their way of life” (1991:102). The choices that people make are not inconsequential; through decision-making people endlessly construct and reconstruct their culture. Shared values reinforce particular types of behaviors, which together comprise cultures or social orders (Selle 1991).

A finite number of these social orders or cultures exist and develop from two basic dimensions mapped in a grid/group model. The model is built on the assumption that there are essentially two different social organization-types that affect how people order themselves. The “group” index connotes differences between groups with high and low group ethos. The high group ethos values within-group cohesion and makes strong distinctions between “us” and “them”. The low group ethos values individuality but not group cohesion. The “grid index” refers to social constraints that are imposed on the individual. A high grid index emphasizes a greater number of cultural constraints. When these two indices are combined, there are four ideal cultures: hierarchists, egalitarians, individualists, and fatalists (Lupton 1999).
The model itself has been criticized on many levels (see Selle 1991 for an excellent critique). One of the most often cited limitations of the approach is methodological and operational – it is unclear on what basis people are categorized into particular groups or how they can move from group to group (Casiday 2007; Lupton 1999). While few anthropologists strictly adhere to the grid/group classification system, many of the approach’s underlying concepts have been influential in reshaping the way that social scientists think about risk.

The cultural risk theory focuses on risk perceptions, but at the group level, asking why people view some things and not others as risky. Wildavsky and Douglas (1982) assert that risks become risks when they threaten values associated with shared social orders. The specific weight and attention that a particular risk manifests at any given point in time have to be understood contextually, because risks are culturally constructed over time (Lentzos 2006).

Much of Wildavsky and Douglas’ (1982) work on risk developed from Douglas’ (1966) earlier work on pollution, purity, and danger. Douglas was interested in comparing non-western proscriptions (danger) against pollution with western notions of “risk”. Like “danger”, risks are not only threatening to the individual, but to the broader social order (Lupton 1999). Therefore, the concept of “risk” is used to hold individuals and institutions responsible for behaviors that do not conform to cultural expectations. Sometimes classified as a structural functionalist, Douglas is interested in understanding how systems and structures maintain social order, define boundaries, and maintain social regularities and norms (Lupton 2000).
Controversies surrounding a risk are symptoms of competing values in a society. Risk narratives often express values and meanings that go well beyond the superficial to expose underlying themes of “accountability, responsibility, liability, and blame” (Casiday 2007:1062). The anthropologist’s task is to understand how groups identify and order risks, as well as identify the symbolic basis of anxieties connected to a perceived risk. Are risks symbolically associated to fears regarding government control, the loss of personal control, the permeation of boundaries, or something else?

For example, in the late 1950s Arnold Green (1961) applied aspects of this approach to understand why town leaders resisted water fluoridation. Leaders against fluoridation often used the argument that it was toxic, however concerns regarding poison related far more to concerns about the larger social order. As Green (1961:24) explained, fluoridation became “emblematic of an ultimate aim to smother personal identity in a homogenous mass . . . [the risk of poisoning] latently labels the damage done to individual autonomy and self-esteem by a social order that is felt to be increasingly manipulative.”

In this vein, Douglas was particularly concerned with the human body. She saw the human body as a metaphor for society, capable as standing in for any type of boundary that is threatened. While Douglas was particularly interested in food taboos, vaccines can also be seen as particularly risky because they bridge the boundary between internal and external. Through vaccination, substances from the outside are injected into the body “from that which is ‘alien’ or ‘other’ to that which is ‘self’” (Lupton 2000:210). Nichter’s (1996c) analysis of vaccine programs in India reflects the ways in which the body and the vaccine come to reflect larger societal concerns. Parents associated
vaccines with Christian expansion, medical experimentation, government family planning initiatives, and western forms of technology. Nichter argues that vaccines became emblematic of foreign intervention, revealing concerns about national boundaries and conveying a sense of moral geography.

Although no authors have explicitly used a cultural risk theory in describing HPV vaccine decisions, such an approach could be used to explain how risks associated with the HPV vaccine reflect larger societal concerns related to chastity, morality, sexual abstinence and the adolescent body. For example, Waller and colleagues (2006) reported that mothers in one focus group associated the Gardasil vaccine with their children’s health and well-being, but also with declining morality. As several mothers explained, by giving children a vaccine to prevent STI’s they were essentially "teaching them ... that it's okay to be promiscuous" (1259). Some mothers did not want to consider vaccinating their daughters because the act of vaccination against HPV would serve as symbolic “acceptance of the fact that the child would one day be sexually active” (1260).

The risk society and cultural approaches differ in important ways. Douglas aims to demonstrate the continuities and similarities in risk perceptions among industrialized and non-industrialized settings, but these comparisons are incompatible within the risk society approach, which argues that risks of modernity are unique to industrialized societies. The risk society and cultural approaches also seek to explain different aspects of “risk”: Douglas is interested in understanding why certain things are perceived as risks in some groups and not others, or at some points in times and not others; Beck is interested in “how the definition of risk is a reflection on and a critique of modernity itself” (Casiday 2007:1062).
Foucault and Governmentality

A Foucauldian perspective on risk focuses on discourses of risk, particularly those conveyed and controlled by experts (e.g. public health officials, scientists, physicians). The approach provides a lens to examine the ways in which “discourses, strategies, practices and institutions” around risk bring it into being and construct it as a phenomenon (Lupton 1999:84). It is essential to analyze the discourses, strategies, practices, and institutions that create a risk because they are the means through which the ‘truths’ about a risk are defined, which then become the basis for action. From this perspective, risk is conceptualized not as a thing in itself, but as a “calculative rationality” (Lupton 1999:85).

Like Becks and Giddens, Foucault sees expert systems as central to the character of late modern subjectivity. However, Foucault does not perceive expert knowledge as a transparent means by which individuals engage in reflexivity, but rather as central to the strategy of governmentality. Through surveillance, observation, measurement, and monitoring, experts not only construct understandings of normal bodies but use these understanding to regulate them. Experts from a variety of disciplines collect and analyze information to problematize, calculate, and manage risk. In using expert knowledge to identifying problem groups in need of education or interventions, risk becomes a “moral technology” to regulate, alter, and control individual practices (Lupton 1999).

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9 Because Foucault was discussed in Chapter Two of this paper, I only briefly address this approach here.  
10 Discourse can be viewed as a “set of ideas, beliefs and practices that provide ways of representing knowledge. Discourse enables the presentation of certain forms of knowledge and precludes the construction of others” (Gabe 2004:167).
In neo-liberal states, strategies of governmentality include direct and coercive techniques, but rely even more heavily upon indirect tactics that focus on self-discipline and regulation, dependent upon individual self-regulation, whereby individuals voluntarily comply with the needs of the state. Self-regulation becomes a subtle and powerful form of governmentality (Crawford 2004; Osbourne 1997). Regulation is not primarily enacted upon passive subjects by external policing agents, but rather self-enacted by individuals who police themselves as “normalized subjects who are in pursuit of their own best interests and freedom, who are interested in self-improvement, seeking happiness and healthiness” (Lupton 1999:88).

For example, Petersen (1997) argues that one manifestation of this type of discipline can be seen in “healthism”, which posits that people have a choice in preserving their health and protecting themselves from disease. According to Crawford, health and fitness are ways in which individuals express agency and “constitute themselves in conformity with the demands of a competitive world.” (Petersen 1997:198). One’s ability to maintain a healthy body becomes a marker used both by the individual and by others to “separate those who deserve to succeed from those who will fail” (Petersen 1997:198). Individuals who fail to live healthy lifestyles are often viewed as lacking self-control; terms like ‘healthy’ and ‘unhealthy’, Petersen argues, “have become signifiers of normal and abnormal identity; of one’s moral worth” (1997:198).

Risk becomes an important tool in self-regulation when individuals begin to shape their own behaviors, practices, and beliefs in order to minimize their own risk level. The governmentality approach seeks to explain “how risks shape the way we experience our own realities” (Mythen 2004:168). Directed at the regulation of the body, risk discourses
dictate how bodies interact with other bodies and things, and contribute to the panoply of “technologies of the self” that contribute to one’s constitution of selfhood (Lupton 1999). In an attempt to become healthier or happier, to live longer, or to improve oneself in some way, individuals seek expert knowledge from institutionalized government agencies.

By controlling risk through mystifying discourses, experts have produced both the language and the data that inform broader bodies of ideas (Mythen 2004). Experts and institutions are seen as filters that sieve out information to reinforce dominant norms and invalidate alternative perspectives. Individuals are expected to follow expert advice to mitigate risk; when individuals reject expert advice or adopt alternative practices, they are often blamed for problems that result. On the other hand, when problems arise from conforming to expert advice, blame is often deflected and risk described in relative terms (expert technologies and advice reduce, rather than eliminate risk).

Several anthropologists and sociologists have used this perspective to critically examine the role of public health and health promotion in shaping risk perceptions (see Lupton 1995; Petersen and Lupton 1996). Specifically, they argue that these experts advance the notion of a reflexive subject who undertakes “self-surveillance and self-reform [as] an essential part of a ritual act that serves a disciplinary social order.” As an effect of this discipline, public health ensures that “new forms of power-knowledge move, more or less continuously, towards incorporating more of life within nets of surveillance and control” (Crawford 2000:220). To my knowledge, a Foucauldian lens has not specifically been applied to examine parental vaccine practices, though
vaccination, as a technology controlled by experts and benefiting the state, but implemented by parents, certainly lends itself to this type of analysis.

**Risk Perceptions Related to Vaccination**

As detailed above, risk theories differ substantially from one another, yet many of the risks associated with parental vaccine acceptance can be understood within multiple theoretical frameworks. Consider risks associated with a child’s immune system, for example. From a risk society perspective, some vaccine risks can be viewed as products of vaccine innovations and success. The increasing number and combinations of vaccines that children receive have led to specific fears about their effect on the immune system. From a cultural theory approach, the unique perceived vaccine risks to the child’s immune system symbolize broader conceptualizations about the incompleteness of children as human beings (Prout 2000). Using a CSA, risks associated with a child’s immune capabilities can be understood as cognitive biases that result from one of many incorrect suppositions.

The risk theories detailed above are used by researchers to explain and understand parents’ perspectives on vaccine risk, though parents themselves likely think little about these theoretical differences. In the remainder of this section I summarize the risks that parents associate with vaccination, while recognizing that these risks are filtered through particular theoretical lenses.

Many parents perceive vaccine risks associated with the child’s state of immunity and their concerns are diverse, overlapping, and often contradictory to scientific evidence. Because so many of the risks that parents associate with vaccines are contingent upon other risks and assumptions about health, illness, trust, and
immunization, it is difficult to organize these risks into discernible categories. I have arranged these risks into specific categories for heuristic purposes only and recognize that many of these risks exist simultaneously for parents.

**Freeloading, Bandwagoning, and Herd Immunity**

Issues of compulsory vaccination and opt-out clauses are intricately tied to herd immunity. One of the reasons that opt-out clauses are tolerated vis-à-vis community health is because of herd immunity, which suggests that unvaccinated individuals will be protected from disease when a critical portion of a population is vaccinated against the disease (Fine 1993). While individuals on both side of the ethical debate regarding compulsory vaccination seem to agree about the importance of herd immunity, they disagree about its ethical implications. One perspective is that herd immunity constitutes “a kind of moral hazard, allowing individuals to “free load” on others’ willingness to accept vaccination. Where high levels of immunity have been achieved, cases of adverse reactions of a vaccine, although inherently rare, may actually exceed cases of the disease against which it protects” (VHPB 2000:5). From this perspective, one might conclude that it is better to rely on the risk of others – on herd immunity – than take a chance at individual vaccination. Of course, if too many people adopt this perspective then no one benefits from herd immunity.

Freeloading or freeriding logic is sometimes used to explain why parents do not vaccinate their children. Parents who base their assumption on this supposition assume that their child will be protected against a vaccine-preventable disease as long as other children receive the vaccine. This phenomenon was noted in several parent studies (Benin, et al. 2006; Kimmel and Wolfe 2005; Meszaros, et al. 1996).
In some cases, heuristics can work in favor of vaccine acceptance. Bandwagoning refers to the tendency of parents to vaccinate their own children if they perceive that everyone else is doing it. Under this heuristic, the normative effect plays the largest role in the parental decision and little thought is put into the decision. Several studies show a strong bandwagoning effect related to vaccine acceptance (Hershey, et al. 1994; Meszaros, et al. 1996; Tickner, et al. 2007).

**Natural Immunity**

Several studies have documented parental concerns related to the “naturalness” of vaccines and their effects on the immune system and immunity. In the case of the MMR vaccine, some parents thought that their children would elicit stronger and more “natural” immune responses if the children contracted measles, mumps, or rubella naturally (Dannetun, et al. 2005; Evans and Watson 2003; McMurray, et al. 2004). In another study, some parents saw the immune system and disease-status as phenomena under God’s control – in this case, vaccines were risky because they interfered with a “natural” process (Princeton 1988; Wilson 2000).

In Ashland, Oregon, for example, one third of parents are not vaccinated. Allen (2007) notes that many of these parents ascribe to a natural, holistic view of health and see vaccination as a potentially dangerous intervention that parents unnecessarily give their children. One public health official explained the way that many parents in Ashland viewed decisions to vaccinate, “if you get your kids vaccinated it means that you are a dupe, that you haven’t done your research” (Allen 2007).
Health States and Immunization

For many parents, vaccination is not necessarily risky itself, but becomes risky in association with a child’s particular immune character. Multiple studies have shown that parents are less likely to immunize a child when the child is ill (Freed, et al. 2004; Offit, et al. 2002; Tarrant and Gregory 2003), which reflects a general perception that the child’s immune system is less able to handle, or respond to a vaccination during an illness. Some parents speak of acute illness where a child’s immune system is viewed as momentarily compromised, thus prohibiting vaccination temporarily but not indefinitely (Pruitt, et al. 1995; Taylor, et al. 2002; Tickner, et al. 2007; Wilson 2000). For other parents who perceive that their child has a chronically fragile or vulnerable immune system, vaccination might never occur. For example, parents who reported that their children suffered from asthma, allergies, digestive disorders, or recurrent ear, chest, or urinary tract infections attributed such illnesses to a weakened immune system and were therefore fearful of giving these children vaccinations (Casiday 2007; Hilton, et al. 2006b).

Parental concerns about vaccinating children while they are ill reflect deeper fears about vaccine immuno-suppression, vaccine susceptibility, vaccine overload, and immune system maturation. Some parents fear that vaccines can cause ill health – either in the short or long term, although there are many ways in which parents express this concern. Some parents worry that vaccines can compromise the immune system, thus making it vulnerable to outside infections (Freed, et al. 2004; Sporton and Francis 2001). Other parents fear that vaccines may actually cause diseases, either the diseases that the vaccines are intended to prevent or other diseases. For example, Niederhaus et al. (2001)
reported that 40 percent of parents were concerned that their children would contract chickenpox from the varicella vaccine. In a study on the meningitis vaccine, parents most feared that their children would contract meningitis from the vaccine (Timmermans, et al. 2005).

While many current vaccines consist of virus-like particles or dead viruses that cannot cause disease, the use of live-attenuated viruses has led to cases in which vaccines do cause the diseases that they are intended to prevent, most notably in the case of polio (Link 2005; Offit 2005; WHO 2007). There are also fears that vaccines can cause other diseases or conditions. Many parents associate the MMR vaccine with a risk of autism (Benin, et al. 2006; Casiday 2007; Raithatha, et al. 2003; Smailbegovic, et al. 2003; Taylor, et al. 2002), and parents have associated the DTP and hepatitis B vaccines with multiple sclerosis, autism, and other neurodevelopmental disorders (Link 2005; VHPB 2000).

Parents also express fear that vaccines will not prevent diseases. Some parents believe that their children are likely to get the vaccine-preventable disease, regardless of whether they receive an immunization, so vaccination, along with its discomfort and risks, seems unjustified. These concerns are more pronounced with particular vaccines, most notably varicella and influenza (Benin, et al. 2006), as well as pertussis and measles vaccines (Tarrant and Gregory 2003).

For many parents, the risks associated with an immunization event relate to the content and type of vaccine that is being administered. One common risk that parents associate with vaccination is vaccine or immune overload, which refers to the fear that a child’s immune system will be overwhelmed by a vaccination or series of vaccinations.
Many of the fears related to vaccine overload are associated specifically with combination vaccines and receiving more than one injection at a time (Casiday 2007; Evans, et al. 2001; Marlow, et al. 2007a; Pruitt, et al. 1995). Combination vaccines, such as DTaP and MMR, provide immunization against multiple diseases with one injection (Gregson and Edelman 2003). From a public health perspective, combination vaccines are a welcomed innovation – decreasing the number of injections and the number of clinic visits required, while increasing vaccination coverage (Chen, et al. 1995). However, parents generally perceive combination vaccines as riskier than single vaccines. While research (Black, et al. 1991; Chen, et al. 1995; Miller, et al. 2003) suggests that combination vaccines do not induce immuno-suppression – and may actually induce a heightened protective effect – many parents continue to express anxiety about combination vaccines.

Parental concerns about combination vaccines tend to relate to the immature nature of the infant or child’s immune system and beliefs about its capacities and limitations (Casiday 2007; Hilton, et al. 2006b; Miller, et al. 2003). In one U.S. study, 25 percent of parents believed that children’s immune systems would be weakened if they received too many vaccinations (Gellin, et al. 2000). In other studies, fears of vaccine overload have been a significant reason that parents either delay or refuse to vaccinate children (Bond, et al. 1998; Bostrom 1997; Niederhauser, et al. 2001; Salmon, et al. 2005). As one parent explained when voicing her concerns about the combination MMR vaccine, “the worry is putting all three in at one time, into that wee body. Individual ones for me is the way, it makes sense to not bombard it with too much chemicals all at one go” (Hilton, et al. 2006b:4324). Underlying this mother’s concern is a belief that the
child’s immune system is vulnerable, immature, and fragile. A mother from a separate study echoed this concern, explaining that receiving four shots in one study was “a lot for a tiny baby to handle. I don't necessarily think that when they're tiny is the best time to give them their shots …. I think that when they're robust and they can take it is a much better time” (Niederhauser, et al. 2001:19).

Some parents believe that combination vaccines – but not single vaccines – are unnatural, requiring an immune response that would not likely occur through natural infection. The perception of “naturalness” in this case refers to the likelihood that a child would naturally contract, and consequently elicit an immune response to multiple diseases at once. Since, for example, it is unlikely that a child would simultaneously contract measles, mumps, and rubella, these parents reason that encouraging an immune response to these three diseases is unnatural. As one mother explained, combination vaccines are like a “sudden onslaught to the body’s immune system” (Hilton, et al. 2006b:4324).

Parents also express concerns about the content of vaccines and risks associated with specific vaccine suspending fluids, preservatives, and adjuvants. For example, parents in the U.S. have expressed concerns about the safety of thimerosal-containing vaccines (TCVs), fearing that these vaccines contain dangerous levels of mercury and can cause autism (Link 2005). While multiple well-conducted, population-based studies (Heron, et al. 2004; Madsen, et al. 2003; VHPB 2000) have found no association between TCVs and autism, many parents still perceive TCVs (and the vaccines from which TCVs have since been removed) as risky. Parents also perceive more general risks associated with vaccine ingredients, as this mother’s quote suggests: “When I look at the
ingredients they’re preserved with mercury, heavy metals and formaldehyde, and DNA from other animals that would be getting into my daughter’s system doing some sort of genetic engineering with her body. I just can’t justify doing that …” (Niederhauser and Markowitz 2007:19-20).

**Risk and Disease Experience**

In the studies I reviewed, many of the risks that parents associate with vaccination relate to their past experiences. Parents often embedded risk statements within personal illness experiences and drew from their own disease history to make vaccination choices for their children. Some parents, who were never vaccinated against a disease and never developed the disease, questioned whether vaccines were necessary, and were less likely to vaccinate their children (Sporton and Francis 2001). Other parents, who had naturally contracted a disease and perceived few side-effects from it were less likely to perceive the disease as severe (Sporton and Francis 2001). In one study, parents who had naturally acquired measles immunity perceived measles as less severe and less dangerous than other parents. Similarly, parents who had experienced whooping cough perceived it as less threatening than other parents (Hilton, et al. 2006a). In another study, parents who had a child or knew someone who had a child with autism were less likely to vaccinate their children with the MMR vaccine. From their perspective, the risks of getting measles, mumps, and rubella were far less than the risks of developing autism (McMurray, et al. 2004)

Conversely, parents who knew someone who died or was seriously injured (e.g. blinded) by a vaccine-preventable disease, such as measles, were more likely to vaccinate their children and perceived vaccination as less risky than the disease (McMurray, et al.
Mothers with a history of cancer in their families were more likely to accept an HPV vaccine for their daughters than other mothers (Marlow, et al. 2007a), although these findings have been challenged in another HPV study. Dempsey et al. (2006) found that women who had experienced a past abnormal Pap smear or cervical cancer perceived HPV to be less severe, but also perceived their daughters to be at increased risk of infection and perceived an increased benefit to vaccination.

However, these women were no more likely to vaccinate their daughters than women who had not had an abnormal screening or cervical cancer. On the other hand, women who had genital warts were more likely to vaccinate their daughters, which the authors suggest is attributed to the social stigma that is associated with genital warts but not with cervical cancer or with an abnormal Pap: “Unlike cervical cancer and abnormal Pap smears, genital warts are a visually apparent condition with the potential to be recognized by the lay person as a sexually transmitted disease” (Dempsey, et al. 2006:1492).

Parents also associated their risk perceptions with previous vaccine experiences. In these cases, the risk is in the way that the vaccine is administered, not in the vaccine content itself. Parents who reported negative prior vaccine experiences, either for themselves or their children, were less likely to vaccinate their children than other parents (Tickner, et al. 2007; Wilson 2000). In one study, several mothers described experiences where providers administered the wrong vaccine to their children, leading them to doubt physician competence (Benin, et al. 2006). In other studies, the trauma associated with a vaccine experience deterred parents from immunizing their children. For example,
mothers in one study commonly used the analogies of cattle being herded, the conveyor belt effect, and “just another number” to refer to the vaccine experience (Harrington, et al. 2000:396). Many parents perceived the process as cold, insensitive, and traumatic. As one parent explained, “It’s very hard now, kind of, they just took her arm and took her leg and dump the needle in . . .” (2000:396).

**Distrust, Incompetence, and Competing Interests**

Parents often associate vaccine risks with competing interests and skepticism of physicians, pharmaceutical companies, and government motivations. In an analysis of Australian antivaccination print coverage during the 1990s, Leask and Chapman (1998) identified a recurrent theme of distrust in governmental transparency and fears of governmental conspiracies and cover-ups. In many studies, parents had concerns about physician bias, especially regarding the vaccine information that physicians provided (Dannetun, et al. 2005; Kimmel and Wolfe 2005; Raithatha, et al. 2003). Some parents questioned physician allegiance, worrying that physicians might encourage a vaccine, even if they did not think it was safe, because of economic incentives, monetary partnerships, or political positions (Benin, et al. 2006). In one study, mothers questioned whether official statistics were accurate and reliable, explaining that physicians either wanted to make measles appear to be more severe than it is (by under-reporting cases in which there are few serious complications), or rarer than it is (suggesting that doctors inflate the vaccine’s efficacy) (Hilton, et al. 2006a). Very similar fears were expressed in another study, where parents felt that physicians were too heavily influenced by governmental policies and vaccine statistics. They feared that physicians would withhold
or under-report information questioning the safety of a vaccine (Smailbegovic, et al. 2003).

Parents sometimes expressed more general distrust of the government and pharmaceutical industry (Raithatha, et al. 2003; Serpell and Green 2006). In one study, parents questioned whether the government received monetary incentives from the pharmaceutical industry for including vaccines on the schedule and were skeptical that all of the vaccines on the schedule were safe and necessary (Salmon, et al. 2005). In another study, parents questioned the safety of new vaccines, expressing fears that their children were guinea pigs of the state and pharmaceutical industry (Wilson 2000). Other parents suspected that the government over-emphasized the threat of contracting certain diseases, such as MMR, which led to a distrust of government motivations in promoting immunization (McMurray, et al. 2004).

Issues of trust appear to be a particularly important issue among African Americans, who have specifically referred to the Tuskegee Syphilis Trials when expressing hesitation about vaccines (Friedman and Shepeard 2007; Scarinci, et al. 2007; Tissot, et al. 2007). As one African American woman cautioned, when expressing fears about the HPV vaccine, “They [the government] may not be telling the full story, which, of course, we found out about syphilis, we found out about AIDS” (Friedman and Shepeard 2007:477). While mistrust of the medical community and medical interventions might well be higher among African Americans, it is important to note that other factors, such as access issues and structural disparities, might lead to lower uptake of vaccines among African Americans.
At the same time, it is worth noting that racial differences in vaccine uptake result from, are associated with, or are confounding by, other factors, such as socioeconomic status, healthcare access, and insurance coverage. For example, a U.S. study of children ages 19 to 35 months indicated significant differences in the sociodemographic characteristics of children who were underimmunized compared to those who had not received any vaccinations (Smith, et al. 2004b). Children who were underimmunized tended to be African American and to have mothers who were younger, unmarried, and had less than a college degree. These children typically lived within households near the poverty line and within the central city. On the other hand, nonimmunized children typically were white males whose mothers were married, college-educated, and living within households exceeding annual incomes of $75,000. Parents in the latter group typically abstained from vaccinating due to safety concerns and in these cases, provider recommendation had little effect on decisions.

In another study, Gellin and colleagues (2000) reported that African American and Hispanic parents, as well as those with a high school education or less, were more likely to express concerns about vaccine side effects. Due to the methodology employed in the study, it is unclear why there are educational and ethnic differences in concerns. To further complicate issues regarding trust, ethnicity, and vaccine perceptions, several studies of HPV vaccine acceptability find that some providers personally observe what they perceive to be ethnic and racial differences in HPV vaccine acceptability. Tissot and colleagues (2007), for example, conducted qualitative interviews with healthcare providers and noted that while some providers felt that African American parents were less trusting or accepting of the HPV vaccine, other providers reported that from their
own experiences, African American parents appeared to be more open and receptive to discussions of sexuality and STI prevention.

**Social Stigma as Risk**

Parents associate social risks, along with biological risks in vaccine decisions. Parents commonly associate vaccine decisions with social values related to responsibility and good parenting (Niederhauser and Markowitz 2007; Petts 2005). Many parents are concerned that providers will think that they are bad parents if they question the need for a vaccination. This fear not only affects vaccine choices, but also the scope of vaccine communication that occurs between parents and providers (Evans, et al. 2001). Some mothers felt a sense of shame after refusing a vaccine. One mother who decided not to vaccinate her child against MMR explained that when her physician learned that she was not going to have her daughter vaccinated, “she really put this huge guilt trip on me . . . So, I felt quite dejected when I came out and felt I was a bad parent” (Casiday 2007:1065). Other mothers believed that providers would treat them differently if they questioned vaccines or refused them. For example, one mother who did accept the MMR vaccine but spent substantial time researching it and discussing the choice with her provider reflected that “I’m sure they’ve got it on my file, ‘neurotic mother’” (Evans, et al. 2001:907). Another mother, who refused to vaccinate her child with the MMR vaccine explained that “They put red all over the notes, red pen, they write REFUSED in big red letters all the way across the child’s medical notes so they’ve sort of got ‘difficult parent’ in their minds” (Evans, et al. 2001:907).

Social values pertaining to vaccine decisions are not only directed at parents by physicians but also at parents by other parents. Comments made during one focus group
discussion of mothers who all vaccinated their children illustrate this point. The women in the group referred to anti-vaccination women as “burn your bra types,” “hysterical,” “new agers,” “alternative lifestylers,” “naturals,” and “go against it for rebellion’s sake” types who were “very irresponsible” and lacking “common courtesy” (Leask, et al. 2006:7241). A study of U.S. pediatricians suggests that parental vaccine decisions may not only lead to social judgments about parenting skills, but may also lead to differential access to healthcare: 28 percent of the pediatricians surveyed said that they would no longer treat children whose parents refused key vaccinations (Flanagan-Klygis, et al. 2005).

Studies also suggest that parents associate the HPV vaccine, and why one would need it, with stigma. As one woman explained, “Maybe some people will be embarrassed to go and get the shot . . . People are going to say she sleeps around and she needs the shot” (Friedman and Shepeard 2007:477). In another study, some women said that family members and partners might react poorly to knowledge that a woman wanted the vaccine. One woman explained, “My mother would really think, well, why would you really need the vaccine? You’re not really supposed to be out doing nothing like this” (Scarinci, et al. 2007:1230). Referring to many partners’ reactions, one woman said, “I can hear one of them [men] right now: so what, you’re trying to say I have something? It automatically makes them think that you’re assuming that they have something, but you’re just doing this to protect yourself” (2007:1230).

One mother’s association between vaccine choices and moral judgments went even farther: she would not vaccinate her son against tetanus because she perceived that it
was “her job to keep him out of harm” (Tickner et al. 2007:7401). As long as she was acting as a responsible mother she did not think her son was at risk of getting tetanus.

Other studies suggest that the medicalization of motherhood has consequences for mothers who refuse or delay vaccination. The stigmatization associated with failing to accept vaccine innovations is produced and reinforced not only by providers, but also by other mothers who do accept vaccines for their children (Casiday 2007; Flanagan-Klygis, et al. 2005; Leask, et al. 2006; Niederhauser and Markowitz 2007), illustrating, again, the social nature/context of vaccine decision-making.

**Risks Associated with Specific Vaccines**

Because most studies only examine parental decisions regarding a specific vaccine, there is a perception that parents are universal vaccine rejecters or accepters. However, many studies have shown that this is far from the case. Parents who are generally supportive of vaccines may choose not to immunize their children against a particular disease. As one mother explained, “I’m not actually anti-vaccines, I’m quite sort of pro-vaccines. It’s MMR in particular that I have a problem with” (Evans, et al. 2001:905-906). Specific vaccine risks can be associated with a vaccine because of its content or combination, factors associated with the disease or the child, or the relative newness of a vaccine.

Few studies have compared parental-perceived risks associated with multiple, specific vaccines, although a comparison across studies does suggest that parents perceive the risks associated with some vaccines differently from others. In one study where parents did compare risks associated with several vaccines, parents were generally supportive of all vaccines, except MMR and meningitis (Smailbegovic, et al. 2003). In
another study, however, parents perceived meningitis as the most severe and life-threatening disease to their infants and also the most important vaccine for infants to receive (Hilton, et al. 2006a).

Most of the studies conducted on parental vaccine acceptance are related to DTP and MMR vaccines, both because of their controversial histories in the U.S. and U.K respectively, and because they are combination vaccines. Hilton et al. (2006a) asked parents to describe their perceptions of several diseases associated with these vaccines and found that parents associated different risks and vulnerabilities with each disease, which influenced their perception of the need to vaccinate. Most mothers in the study recalled receiving a rubella vaccine check during their pregnancy and because of the risk to the fetus, generally perceived rubella as more severe than epidemiologists or clinicians would say that it is. While groups perceived meningitis as the most severe disease and the most important to vaccinate against, none of the parents mentioned an association between viral meningitis and mumps. Diphtheria was seen as a disease of the past – an old plague that one participant compared to the Latin language (Hilton et al. 2006a).

MMR has been perceived as the most risky vaccine among parents in many studies. Even among parents who generally support vaccination, a lack of confidence in scientific support for the vaccine’s safety is a recurrent source of fears (Raithatha, et al. 2003; Smailbegovic, et al. 2003). The risk of autism is mentioned by parents in many studies and is often considered a serious and likely risk (Andrews 2006; Bellaby 2003; Casiday, et al. 2006; Casiday 2007; Frankel and Nielsen 2003; Hilton, et al. 2007; Taylor, et al. 2002; Woo, et al. 2004).
Risks Associated with the Child’s Age

Several studies have found that parents are more likely to vaccinate their children at one age rather than another. Many parents perceive greater risks associated with vaccinating infants than older children. In a study of parental acceptance of a flu vaccine, Daley et al. (2007) reported that 20 percent of parents felt it was unsafe to administer the vaccine to infants under one year of age. In a Swedish study, 60 percent of parents would postpone the MMR vaccination until their children were at least four years of age, believing that children (and presumably their immune systems) need to mature before coping with the vaccine (Dannetun, et al. 2005). Concerns about a child’s vaccination age generally related to the infant’s immune system and its inability to cope with vaccines. However, parents had other reasons for preferring specific immunization ages.

Some parents who did not want to vaccinate their children as infants but would eventually vaccinate them explained that infants could not communicate distress and parents could not explain what was happening to the infant and why. This perspective was especially common among first-time parents (Tickner, et al. 2007). Other studies have also reported that first-time parents are significantly more likely to postpone vaccination than other parents (Dannetun, et al. 2005; Leask 2002). Parents with older children, on the other hand, felt that it was more difficult to vaccinate children when they were in pre-school because they had a greater understanding of the situation, which made parents feel a greater sense of responsibility and guilt about the vaccine experience (Tickner, et al. 2007). In a similar vein, parents from another study preferred that their children receive vaccinations at younger ages, because older children had developed a
fear of needles, screaming during the vaccination and causing the parents to feel a greater sense of guilt, distress, and embarrassment (Tarrant and Gregory 2003).

Parents not only associate vaccine decisions with the child’s age and capacities, but with their own experiences as parents and what they face at particular points in their child’s development. For example, Hilton et al. (Hilton, et al. 2006b) observed that many parents who rejected an MMR combination vaccine, opting for the single disease vaccines instead, had earlier vaccinated their children with a combination DTP vaccine. When asked about the contradiction, many parents explained that vaccine timing played a role in determining their own willingness to accept a vaccine. Several parents explained that because DTP was administered during infancy, when parents felt emotionally overwhelmed or exhausted, they were less able to fully consider the vaccine decision. As one woman explained, “I’m sure if the timing of diphtheria, tetanus, whooping cough and Hib was later like MMR, there would be a lot more discussion about it” (Hilton, et al. 2006b:4324).

Nearly all of the aforementioned studies have occurred among parents with infants and young children and relate to vaccines that are required by the time that children enter school in the U.S. It is less clear how age-of-vaccination preferences affect parental decisions for other vaccines that are not required for school enrollment. Several studies of the HPV vaccine report relationship positive correlation between child’s age and vaccine acceptability; vaccine acceptability increases as does the child’s age (Dempsey, et al. 2006; Fazekas, et al. 2008; Kahn, et al. 2003; Slomovitz, et al. 2006). From these quantitative studies, it is unclear why parents are more accepting of the vaccine with increasing age. However, results from qualitative studies, which find that
many parents are unwilling to accept an HPV vaccine until they think their children are sexually active, suggest that parents might relate vaccine-age to perceptions of their child’s sexual activity (Mays, et al. 2004).

**Gender, Sex, and Disease Transmission Route**

There is some evidence to suggest that parents consider a child’s sex when evaluating the risks associated with certain diseases and the vaccines developed to prevent them. In a study of MMR vaccine decision-making, parents of daughters were more likely to accept the vaccine than were parents of sons, an association that the authors attribute to parental knowledge that autism is four times more likely to occur in males than in females (Taylor, et al. 2002). In another study (Hilton, et al. 2006a), parents believed it was more important for daughters to be vaccinated against rubella than sons. Mothers questioned why it was necessary to vaccinate boys against a disease that they associated with pregnancy, which raised suspicions among some mothers about the goals and motivations of clinicians in vaccinating boys against rubella. Conversely, the same parents believed sons were more susceptible than daughters to mumps. Parents described mumps as a disease that only affects boys and could cause male infertility – an outcome that was often discussed through humor and jokes, which could indicate that male infertility is not seen as a particularly severe outcome (Hilton, et al. 2006a).

Diseases that can differentially threaten males’ and females’ future reproductive potential can affect the risk evaluation undertaken by parents. The modes through which diseases are primarily acquired can also factor into parents’ risk evaluations. Several studies have examined parental acceptance of vaccines for gonorrhea, Chlamydia, HIV, herpes, and Hepatitis B, which are sexually transmitted (Liddon, et al. 2005; Mays, et al. 2004).
Each study focused on predictive variables in vaccine acceptance, although the significance of associations varied in each study. Liddon and colleagues (2005) reported that parent’s sex, ethnicity, and marital status were associated with vaccine decision. Zimet et al. (2000) found significant variation in parental vaccination acceptance by recruitment site (urban versus private clinics), perceived severity of the disease, and perceived efficacy of the vaccine. In a study that compared parental acceptance of four hypothetical vaccines to prevent HIV, gonorrhea, Chlamydia, and HPV, researchers found that HPV was the least accepted of the vaccines, although reasons for the lower approval rates was unclear (Mays et al., 2004).

Several studies suggest that a disease’s route of transmission is an important factor to some parents, who associate sexually transmitted diseases with multiple meanings, including morality, self-responsibility, and self-discipline. The association between risk and morality is clearly illustrated in one father’s response to whether he would accept a hypothetical gonorrhea or HPV vaccine for his 14 year old son: “I wouldn’t be too insistent about it. Sounds to me like something a careful person . . . a responsible person wouldn’t have to worry about. Again, it’s a matter of responsibility. It’s not something you’re going to catch off a doorknob” (Mays, et al. 2004:1420). During U.S. Congressional testimony on the safety of the hepatitis B vaccine, one parent, who thought the vaccine resulted in his daughter’s death, further exemplified the moralistic nature of sexually transmitted diseases and vaccines to prevent them: “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 2006:231).
In a general study (Zimet, et al. 2005) to examine variations in acceptance by transmission route, the sexual route of transmission was not a significant factor for the overall sample of parents. However, it was a significant factor for a subset of parents (6% of the sample), who strongly opposed vaccines that prevented sexually transmitted infections. In a study of Californian parents’ intentions to vaccinate their daughters against HPV, less than 3% of parents cited moral sexual behavior concerns as a reason to refuse the vaccine (Constantine and Jerman 2007). In other studies, parents have expressed concerns that vaccinating their children against sexually transmitted infections might lead to unsafe sexual practices and a false sense of protection (Brabin, et al. 2006; Davis, et al. 2004), promiscuity (Liddon, et al. 2005), and earlier sexual debut (Brabin, et al. 2006; Davis, et al. 2004; Olshen, et al. 2005).

In a nationally representative study of Canadian parents, slightly more than one-fifth of parents had concerns that the HPV vaccine might affect their daughters’ sexual behaviors, in terms of expediting the age at which they become sexually active or encouraging daughters to practice unsafe sex or have sex with a greater number of partners (Ogilvie et al. 2007).

Prior to HPV vaccine licensure, 35 CDC-funded focus groups were conducted in order to better understand how a hypothetical HPV vaccine might be perceived and introduced to the public. The focus groups contained 314 ethnically diverse men and women from six urban and rural sites across the country. Though the authors did not specify the frequency with which concerns regarding adolescent sexuality were raised (nor the number of participants who were also parents), they noted that when asked about whether a vaccine should be administered to children, “strong concerns were voiced by
parents about giving children a false sense of security and implicitly condoning unsafe or promiscuous sexual behaviors” (Friedman and Shepeard 2007: 478).

Although HPV is also associated with cancers that affect both males and females, the vaccine was initially only available to females. Unlike other sexually transmitted diseases, which are often viewed as equally detrimental for boys and girls\textsuperscript{11}, HPV was originally marketed, manufactured, and targeted as a cervical-cancer prevention technology\textsuperscript{12}. It is likely that the strong association between HPV with cervical cancer affects the ways in which parents perceive risks for their sons and daughters (Brabin, et al. 2006; Slomovitz, et al. 2006). Moreover, because the vaccine protects against a sexually transmitted disease and sexual norms are gendered, notions of risk and gender may intersect to produce different risk perceptions (Crawford and Popp 2003; Schalet 2000).

The few studies that have included parents of sons or that specifically ask questions about the need for sons and daughters to be vaccinated suggest that there are important differences in how parents conceptualize vaccination based on the child’s sex (Brabin, et al. 2006; Lenselink, et al. 2008; Olshen, et al. 2005; Slomovitz, et al. 2006). Zimet and Rosenthal (2010) provide a comprehensive review of studies that included parental attitudes toward vaccinating boys.

\textsuperscript{11} While the symptoms and associated risks for each STI vary, to at least some extent by individual’s sex, it is likely that STI’s such as syphilis, herpes, and now HIV are seen as having significantly harmful effects regardless of sex.

\textsuperscript{12} The Gardasil vaccine is not advertised as a vaccine that protects against 90\% of genital warts, even though it does. In addition, the fact that the vaccine was only available to women originally might lead parents or the lay population to associate HPV as a disease of women. The association that the public makes between HPV and women might be even stronger for the Cervarix vaccine, which does not protect against genital warts and whose name references the cervix. I discuss the representation of the vaccine and its important to my research question more under “Goals”.

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In one of the few studies that included a qualitative component, Olshen et al. (2005) reported that while most participants believed that vaccinating boys was important to protect future partners and reduce disease transmission, at least two parents of sons did not think the vaccine should be given to boys. Unfortunately, the authors provide no narrative or explanation to contextualize the reason for these parents’ perspective. Another study of parents in Galveston, Texas found no significant differences in parent’s willingness to vaccinate sons and daughter. However, among parents of sons, a primary reason not to vaccinate related to perceived lack of direct benefit to boys (Slomovitz et al. 2006).

Other variables associated with vaccine acceptance in some studies, but not others, include parents’ comfort discussing sexuality with children (Askelson, et al. 2010; Brabin, et al. 2006; Marlow, et al. 2007a; Waller, et al. 2006). Parents’ willingness to discuss protective sexual health behaviors with daughters appears, at least in some cases, to inform HPV vaccine decisions (Brabin, et al. 2006; Marlow, et al. 2007a; Romo, et al. 2011)). Brabin and colleagues (2006) found that parents who discussed HPV-related information with their children were more likely to support vaccination. Conversely, parents who were least comfortable discussing sex with their children were least likely to anticipate having their daughters vaccinated. Marlow and colleagues (2007) reported that mothers willing to talk about cervical cancer, sexuality, STIs, or HPV with their daughters at younger ages were also more likely to express willingness to have their daughters vaccinated in general, and at earlier ages.

HPV-information sharing appears to be both content and age specific (Askelson, et al. 2010). Parents in one study, for example, felt more comfortable discussing the
cervical cancer prevention aspects of the HPV vaccine with daughters, but less comfortable discussing the relationship between the vaccine and HPV disease of STIs, especially with younger daughters (Marlow et al. 2007). The results from this study support broader findings that suggest that mothers are more likely to talk about sexual health-related issues with older children (Byers, et al. 2008; Pluhar, et al. 2008).

Fewer studies have examined adolescent perspectives regarding STI vaccines and sexual behavior. Webb and colleagues (1999) surveyed 140 primarily female, African American youth, ages 13 to 18 to understand how they would perceive a hypothetical HIV vaccine to influence their peer’s sexual behavior. More than three-quarters of youth believed that adolescents would engage in riskier sexual behavior (including decreased condom use, increased number of partners, and less selectiveness in choosing partners) if an HIV vaccine with 90% efficacy were available. In a London-based study, Forster and colleagues (2010) surveyed 162 girls between the ages of 14 and 15 attending a “high-achieving, state-funded, single-sex” secondary school. Girls were asked to rate their own intention to receive the HPV vaccine, but also asked a series of statements to assess whether they thought their parents would allow them to be vaccinated and what they thought it would mean if their parents permitted them to be vaccinated. Ten percent of girls strongly or slightly agreed that parental consent implied that they felt it was okay for their daughters to be sexually active or that girls were old enough to engaging in sexual activity (8%).

Does “Risk” Matter?

To determine how important the concept of “risk” is in parental vaccine acceptance requires consideration of what constitutes a risk. The HBM constructs of
perceived susceptibility and perceived severity are essentially risk measures. They are designed to elicit one’s self-risk appraisal. However, susceptibility and severity are measures of risk defined by public health and epidemiology. The “perceived barriers” factor can include other “risks” – such as fear of promiscuity or immune overload, but these variables are lumped with a whole host of other factors, such as economic and structural barriers, that are deliberately factored into a risk assessment.

Given the predominance of the HBM in the vaccine literature, it is no surprise that much of the literature of vaccine acceptance relates to risk perceptions. Many of the instruments that are used to explore parental vaccine acceptance begin with the assumption that “risk” is a key component in decision-making. What is unclear, however, is whether the focus on risk is a product of the instruments used to assess vaccine acceptance or because parents frame their decisions as risks. As Hobson-West (2003:279) explains, “Research into public attitudes to a technology may talk about perception of risk, simply because it has been assumed that this is the meaning of the debate to the public. In other words, research often looks for risk, and finds it, when it isn’t necessary there.” For these reasons, and because of its association with rational, probabilistic, cost-benefit measurements, the term “risk” does not necessarily describe the way that parents understand vaccine-related anxieties and concerns.

Qualitative studies that do not begin with the assumption that “risk” matters, suggest that there are many important issues, such as trust, responsibility, accountability, and the meaning of alternative health beliefs, that underlie parents’ understandings of vaccines (Hobson-West 2004). In one qualitative study on vaccine risk, mothers were asked to define, evaluate, and process vaccination decisions in their own terms, rather
than in terms dictated by a survey instrument. The results revealed that mothers have complex and multiple ways of understanding a risk, which can reproduce and/or challenge biomedical conceptions of risk. Some mothers explained that the risks that they associated with vaccines were generated through maternal instinct and intuition. From this perspective, mother’s used subjective knowledge, or knowledge from the self, to understand a risk (Rogers and Pilgrim 1995). For other mothers, risks are understood within an explanatory model that prioritizes fate over intervention.

“Given the renewed enthusiasm for the concept [of risk] it may prove tempting to build aspects of social theory on the back of risk, without empirical justification. In other words, look for risk (and find it), when it isn’t necessarily there” (Hobson-West 2003:279). While the risk appraisal is absolutely essential to scientific, medical, and public health understandings of the relative merits of vaccination, there is less evidence to suggest that parents use the same process to consider the relative merits of vaccination for their own children. In fact, studies that examine risk communication between providers and parents suggest that the relative importance of the scientifically understood risk appraisal has little relevance for most parents (Hobson-West 2003; Hunt, et al. 2006; Rapp 2000).

These findings remind us that the relative importance of risk perceptions should not be taken for granted. As previously discussed, researchers using the HBM have not convincingly demonstrated that risk perceptions can adequately account for variability in parental vaccine acceptance. The failure to demonstrate the relevance of risk perceptions relates both to theoretical assumptions (as already discussed), and to methodological issues, to which I will now turn.
Chapter Four – Methods

As illustrated in the theoretical and topical reviews presented in the previous two chapters, the HBM and TRA dominate the vaccine literature and subsequently, the methodological literature. Several primarily quantitative methods have been used in specific ways to generate most of the findings that constitute the vaccine acceptance literature. In this chapter, I review the predominant methods used in the vaccine acceptance literature, as well as other methods that can contribute to a broader, more holistic view of vaccine decision-making.

I begin the chapter with a brief definition of research methodologies that includes a set of criteria that I later use to assess the utility of given methods within the larger vaccine literature and within my own study. I then examine how various research methods have informed the structure and composition of the current vaccine acceptance literature. Based on conclusions drawn from this review, my research questions, and theoretical orientation, I conclude with an outline of the methodological strategy I employed to collect and analyze data.

Methodologies are simply a body of methods, rules, and postulates employed by a discipline (Merriam-Webster 2007). As such, they are useful tools when appropriately applied to investigate specific questions, but it is only within the context of a particular question, topic, or issue that the strengths and weaknesses of these tools can be assessed. Just as a chainsaw is a tool better suited to cutting through wood than to driving a nail
into the wall, a research method can work exceptionally well for tackling one question, while proving incredibly ineffective at addressing another. And even when methods are appropriately selected, their abilities are largely dependent on the user. Continuing the above analogy, a chainsaw can effectively slice through wood, but only if the user can operate the chainsaw. If one holds the blade rather than the handle, the chainsaw will still be effective (in lopping off a hand, for example), although not at solving the original problem (the wood is still uncut). In a less dramatic example, tools can be used more or less effectively: one might not apply correct pressure to the wood, resulting in an imperfect, albeit sliced, piece of wood. In short, methodologies are not, in and of themselves, good or bad; rather, they are more or less useful depending on the specific research question and what one hopes to learn about a given topic.

With these points in mind, I have organized each methodological section to address several points. First, I provide a brief description of a method in terms of its strengths and weaknesses. I then discuss its use in the parental vaccine acceptance literature. When applicable, I will examine how researchers from different theoretical orientations have used the method and the effects that those uses have on our understanding of the parental vaccine acceptance literature. I will conclude by proposing a methodology that fits within the Local Vaccines Culture (LVC) approach (see Chapter Two) and illustrate how this methodology will allow me to collect data that contributes to the general literature on vaccine acceptance.

Before discussing the various uses of the relevant methods, it is important to note the variability in what constitutes one method or another, both in definition and use of terms. Two examples will illustrate this point. In the first case, Gerend and colleagues
Interviews

Interviewing strategies are commonly used to understand parental vaccine acceptance, although the scope and depth of an interview, the number of people involved in the interview, and the structural constraints framing the interview vary widely (Marshall and Rossman 2006).

Survey Interviews

Following Schensul and colleagues (1999b), I define surveys as structured, primarily close-ended, instruments that are administered by a researcher in a face-to-face
interaction\textsuperscript{13}. Generally speaking, the great strength of the survey interview is that it is highly structured\textsuperscript{14} – every informant is exposed to the same stimuli (Bernard 2000). As a result, structured interviews are often more amenable to quantitative data analysis.

The survey is the most common instrument used in studies of parental vaccine acceptance. For example, 47 out of 70 (67\%) studies that I reviewed prior to developing my own methodology included a questionnaire or survey instrument. In 43 of these studies the survey was the only instrument used. Eighteen of 22 (82\%) studies on parental HPV vaccine acceptance used a survey (see Table A3 for details). These studies using survey methodology have been quite adept at revealing that immunization – a behavior that has traditionally been identified as noncomplex\textsuperscript{15} – is actually quite complex. Based on results presented in previous chapters I would argue that these studies reveal the limitations of a primarily quantitative survey instrument to find “a magic bullet” factor that can capture this complexity or produce any particularly relevant factor predicting vaccine decisions.

Several researchers who are proponents of survey methods have been especially critical of their use in the vaccine literature. The criticism largely relates to ambiguities underlying survey construction and difficulties testing hypotheses, both of which are tied to use of the HBM or hybrid –HBM models. Nearly all of the studies on parental vaccine acceptance use survey-based models to operationalize HBM or hybrid HBM models.

\textsuperscript{13} I use the term telephone survey to distinguish surveys that are still administered to someone by a researcher, though not through face-to-face interaction. Questionnaires refer to surveys that are self-administered by a respondent. While there are relative strengths and weaknesses to each of these approaches, my review treats them generally.

\textsuperscript{14} Other structured interview techniques, such as free-listing, triads, and pile sorts also share this strength.

\textsuperscript{15} Many researchers, when arguing against the use of the HBM for particular behaviors such as condom use, have argued that the HBM is only effective at explaining “simple” behaviors, citing immunization as a good example.
The way in which model factors are operationalized is no small point. If a model is intended to explain or predict behavior, then the survey items used to assess the model need to measure the factors that the model posits are important (Bernard 2000).

Unfortunately, many studies on vaccine acceptance are crippled by problems with construct validity (Brewer, et al. 2007a).

For example, the HBM posits that individual perceptions of susceptibility, severity, benefits, and barriers will affect health behavior. Because the model assumes that individual perceptions are paramount to behavioral responses, the instrument needs to frame vaccine questions to specifically probe for individual-level perceptions. In practice, however, items to assess individual risk perceptions often fail to differentiate between individual and population risk events. For example, many surveys ask the question “how serious is X disease” rather than asking “how serious would it be if you (or your daughter) got X disease?” (Brewer, et al. 2007a). If the first question is used to measure perceived individual susceptibility then there will be inferential problems in determining the locus of susceptibility (Brewer et al. 2007a). A parent might think, for example, that HPV is not generally a serious disease. However, a parent might think that HPV would be very serious if her daughter got it.

As mentioned in Chapter Two, the HBM and hybrid models assume that beliefs, perceptions, and intentions lead to actual behavior. This behavior motivation hypothesis “describes the effects of perceptions of risk on changes in behavior” (Brewer, et al. 2004:126). Specifically, the hypothesis states that individuals who currently have elevated risk perceptions will be more likely to engage in preventive behaviors in the future, which is a cause and effect hypothesis. In order to test this hypothesis, a research
design needs to include a temporal dimension – some type of longitudinal design that can measure both intentions (or perceptions) and behavior (Brewer, et al. 2004). Only one of the surveys that I reviewed (Wroe, et al. 2004) used a longitudinal research design. In my opinion, this particular weakness relates not to the method but to its application.

Granted, nearly all of the HPV vaccine acceptance studies have been necessarily limited to intentions because they were conducted prior to vaccine availability. However, a review of the larger vaccine acceptance literature contains few cases in which researchers actually test this hypothesis (Brewer, et al. 2007a; Weinstein 2007; Weinstein, et al. 2007).

Additionally, many of the surveys fail to adequately condition risk questions. As Brewer (2004) notes, risk questions need to be conditioned when researchers hypothesize that a risk perception will change one’s behavior. If a researcher expects that perceived susceptibility to a disease will motivate vaccine behavior, then questions related to susceptibility need to be conditioned on whether one does or does not get vaccinated. While this particular problem is not a concern in the HPV literature (because all studies included in my review occurred prior to FDA approval), it has been a significant problem in the larger parental vaccine acceptance literature (Brewer et al. 2004; Brewer et al. 2007a).

For example, in order to assess whether a particular factor, such as perceived likelihood of HPV infection, actually affects intention, surveys need to assess an individual’s risk perception with and without the intervention (vaccine). A survey should

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16 Benin et al. (2006) also used a longitudinal research design, but to conduct qualitative interviews that did not attempt to statistically test an association between beliefs and behaviors.
include both of the following questions about likelihood: “What is the likelihood that
your daughter will get HPV if she does not get vaccinated?” (unconditioned) and “What
is the likelihood that your daughter will get HPV if she is vaccinated?” (conditioned).
Without knowing both pieces of information, it is difficult to test whether a risk
perception, or efficacy, motivates a vaccine action (Brewer et al. 2007a).

Another methodological problem with many studies relates to the use of
unconditioned questions in cross-sectional research where parents are separated into
groups based on whether their child has or has not been vaccinated. The use of
unconditioned risk questions, while inappropriate, is common in these studies. The
answer to the question “What is the likelihood that your daughter will get cervical
cancer?” will likely be conditioned by whether the child received the vaccine or not. If
parents in the “acceptance” group rate their child’s susceptibility as lower because they
have vaccinated their child and see the vaccine as effective, then a negative association
will likely appear. However, this negative association cannot be interpreted to mean that
parents who perceive that their children are at low risk for a disease are more motivated
than other parents to vaccinate (Brewer et al. 2007a).

These construct problems are not minor issues. Rather, such errors have the
potential to completely skew results. In a meta-analysis of health behavior theories,
researchers questioned whether many studies could even be examined given their
methodological biases (Brewer et al. 2007a). While these problems stem more from
misapplication than the tenets of the method itself, they also exemplify the ease with
which entire models can be dismissed on legitimate statistical grounds.
So what about the survey method of interviewing itself? Suppose that researchers used longitudinal survey-based designs (and statistical analyses) that could actually test the model’s assumptions? How useful would survey-based research be in understanding vaccine acceptance and decision-making? The answer to this question largely depends on one’s epistemological and ontological assumptions. Many researchers, particularly those leaning more towards the relativist side of the ontological continuum, are skeptical of using structured surveys to study risk events because risks are seen as constructed.

Douglas argues that the attempt to objectify and generalize responses leads to profound limitations and inaccuracies because risks do not occur in neutral or unbiased contexts (1992). In survey-based research, people are disconnected from social networks and sociocultural contexts – the designs of many studies assume that people, not populations, carry social risk (Brehmer 1994). This is an interesting point. One of the strengths of surveys is that they can be used with large sample sizes, which allows researchers to generalize results to populations. Yet I have to agree that there is a danger in using surveys built on individual-risk theories to generalize out to populations. The result is that certain individuals, who can be grouped into particular risk categories, can be targeted for interventions. While populations do carry social risks, the effects of interventions (which are supported by this survey data), can easily lead to victim-blaming, where particular kinds of people (Douglas or Foucault could argue) become the sources of danger and targets of control.

Mythen (2004:104) argues that the survey-based design of vaccine studies “reproduces a realist understanding of risk and embodies a rationalist interpretation of human motivations.” This type of approach does not account for politicization of risk and
the importance of political issues on the meaning of a risk. The public politicizes risk and it would be inaccurate to preclude such topics from a risk analysis (Douglas 1992). This critique illustrates another main problem with quantitative survey instruments – that they cannot measure many types of information, even when developed from extensive ethnographic research. For example, in a study of mothers’ immunization practices in Haiti, Coreil and colleagues (1994) used a mixed method approach, conducting extensive ethnographic interviews and participant observation before developing a quantitative survey. From the interviews and participant observation, the researchers found that the main reasons that mothers did not get children immunized – maternal negligence, embarrassment, and shyness – could not be measured at all quantitatively, while other variables – maternal time use and previous negative clinic experience – were “incompletely assessed due to limitations in the survey design” (237). The limits of translating qualitative findings into quantitative measures raises a critical question about findings from quantitative surveys – specifically about what they can and cannot tell us. This is of special concern given that the findings from surveys are often used to develop interventions and policies, and to identify target groups. As the authors explain, “One variable which was easy to measure – knowledge of immunizations – was found to be the most significant predictor of immunization use after controlling for socioeconomic factors. While this finding is consistent with results of studies in other parts of the world, it tells us little about the relative importance of cognitive factors compared to other psychosocial variables which are difficult to measure in quantitative studies” (Coreil, et al. 1994:237).
Even though the ethnographic descriptive data led the researchers to conclude that fears of embarrassment, shyness, and maternal negligence were important predictors of immunizations, perhaps even more so than other variables, they were lost in the predictive model because they could not adequately be measured in the survey. What surveys – even ethnographically informed surveys – fail to capture then, is often the most important and interesting aspects of any phenomenon: the meaning and context behind the numbers. As I discussed in preceding chapters, many quantitative, survey-based studies on HPV suggest that X, Y, or Z group is more or less likely to accept a vaccine, but there is limited information about why parents make these decisions, especially as situated actors within a larger sociocultural milieu.

Due to the lack of consistent findings revealed through the use of surveys, and the unlikelihood that even the most carefully designed ethnographic survey would capture the type of information I hoped to explore, I opted against the use of survey-based instruments for this study.

**Qualitative Interviews**

While qualitative interviewing is a staple of most anthropological research, anthropologists have no proprietary claim to the method. Researchers in diverse disciplines use qualitative interviews, although the way that researchers design, conduct, and analyze qualitative interviews varies depending on the disciplinary lens that they apply to the method. As Warren explains, “ethnography’s lens is that of lived experience, set in an eternal present. The lens of the intensive interview is verbal – what people say and mean – but its temporal range is biographical, extending into the past and future” (2002:85).
Given the richness and depth of information potentially accessible using this method, which is typified by open-ended and less-structured questions, qualitative interviews are sometimes employed as the default method for capturing a population’s “real views” on a subject. Of course, what is “real” is open to debate and has been a matter of much philosophical, theoretical, and methodological discussion. It is well accepted among anthropologists that their own identities, positions, and roles vis-à-vis the participant will influence the types of information the participant shares and how it is communicated. Further, no individual’s responses, no matter how many interviews she completes on a topic, will encapsulate all of what she thinks and feel about an issue, event, or concept. Rather, individuals filter out information based on what they think their audience wants to know (and hear), what they (don’t) want to share, and what they think they can tell their audience. Add to this variation in the individual’s (and researcher’s) particular mood during the interview, the larger events, issues, or stresses someone experiences around the time an interview takes place, and the interview setting, and one can easily understand why the notion of a “real view” must be problematized.

Interview data, as expressed to researchers, is always partial – in the sense that it is incomplete and because it is biased. As Pool notes “these variations in expression cannot be viewed as mere deviations from some underlying “true” opinion, for there is no neutral, non-social, uninfluenced situation to provide that baseline” (Gubrium and Holstein 2002:14).

Despite the situated, contextual nature of these communications, there remains a “romantic impulse” among researchers to extract some fundamental truth or genuine voice from the interviewee. In an effort to do this, many researchers have turned to open-
ended, in-depth interviewing, which is assumed to be a better way to explore “emotional enclaves of the self” (Gubrium and Holstein 2002:11). The assumption in creating this type of research interaction is that the “true, internal voice of the subject comes through only when it is not externally screened or otherwise communicatively constrained” (Gubrium and Holstein 2002:11). The quest for authenticity, however, is a concept that has been defined and is validated by the researcher. Authenticity is an invention, a reflection of our own assumptions about the body, the self, and the way it is expressed and communicated.

As with more quantitative survey methods, recognizing the underlying assumptions and weaknesses of the method does not invalidate the method; rather, it provides boundaries that are a helpful check when designing research and interpreting findings. Again, the specific research question and the researcher’s skill and disciplinary/theoretical background mediate the usefulness of any particular method.

As an anthropologist, the lens I bring to the conduct and analysis of qualitative interviews is one of interest in meaning and context, and the connection of individuals to a broader sociocultural context. This perspective on qualitative research is partially responsible for my dissatisfaction with the current qualitative literature on parental vaccine acceptance. In health research, qualitative methods are often employed to deconstruct complex phenomena into more straightforward concepts to be included in survey questions or interventions (Pasick and Burke 2007). Most of the qualitative findings from research studies, for example, result from interview guides based on the HBM (Bond, et al. 1998; Raithatha, et al. 2003). While there is nothing inherently wrong
with crafting an interview guide on the HBM constructs, there are consequences to framing questions about vaccine acceptance based on the model.

First, conversations tend to be limited to factors that are already presumed to be important to parents, which can limit the possibility of learning about other significant factors. Second, questions, when posed as factors relevant to the HBM, tend to encourage free-listing responses rather than contextualized answers (see Olshen, et al. 2005). Finally, focusing exclusively on HBM factors limits conversations largely to the individual-level. When particular beliefs about vaccination are expressed, researchers seldom probe (or at least do not publish the data) about the meaning of those beliefs and how they are connected to larger questions.

For example, the only qualitative question included in a telephone survey on parental acceptance of a hypothetical HPV vaccine (Constantine and Jerman 2007) asked parents to explain why they rated their acceptance of the vaccine as they did (using a Likert scale). Rather than providing descriptions of the narrative, the authors grouped the items into categories, such as “health and safety,” “vaccine concerns,” and “pragmatic prevention,” which stripped any contextual attributes or meaning from the responses. Again, however, the usefulness of a tool depends largely on its purpose. If the goal of using a qualitative, open-ended question is to generate a set of items to include in a quantitative scale, then the method adequately served its function. However, if the goal is to understand the meanings, experiences, emotions, and concerns that converge to shape parental perceptions on vaccines, then the application of qualitative methods in the study was inadequate.
Individual Qualitative Interviews

Despite the limitations of interviewing and the method’s diverse application reviewed above, individual interviews\(^\text{17}\) can provide a rich source of information about a topic, experience, or way of life. Individual interviews can be more or less structured (or open-ended) and more or less in-depth (Schensul, et al. 1999b). In the vaccine literature, anthropologists have used a biographical, in-depth interview technique to elicit parent narratives.

“Child health and immunization biographies” have been applied in several anthropological studies to obtain information from parents about vaccination experiences (Fairhead, et al. 2004; Jegede 2005; Kamara 2005; Millimouno, et al. 2006; Poltorak, et al. 2004). These interviews are open-ended and in-depth, designed to “explore thinking and decision-making about vaccination in relation to other forms of health protection” for a particular child (Leach and Fairhead 2005:4). Parent biographies, rather than asking solely for beliefs or decisions specifically related to a particular vaccine, decision-point, or outcome, attempt to understand how parents access and interpret specific immunization knowledge, experiences, and events related to their own recollections and observations. Underlying this approach is an assumption that vaccine decisions are not singular, detached events, but meaningful, contextualized processes. As Poltorak et al. (2004:8) explain,

\[^{17}\text{I will use the word individual interview in this section to refer to individual interviews where at least a third of the research questions appear to be qualitative (to distinguish these from survey instruments, where there are very few or no qualitative items in an instrument). I also recognize that during an interview session, however, that multiple qualitative and quantitative instruments can be combined. For ease of discussion, however, I separate these.}\]
When parents do not vaccinate they are not necessarily merely making a statement about their scientific reading, but also to varying degrees about what they regard as valued parenthood, their responsibility to their child, the right of parents to choose, their trust in the medical establishment and their position in their trajectory of interest in the issue, how they place themselves with respect to their friends, and so on.

These biographies have, to my knowledge, only been used with parents of young children, often under three years of age. However, they can just as easily be used with parents of adolescent girls, although the types of experiences parents are likely to recall and the way that they frame these vaccine histories will vary.

Not all of the in-depth individual interviews in the vaccine literature take a necessarily biographical approach. Tarrant and Gregory’s (2003) interviews with First-Nations’ mothers in north-western Ontario produce a rich set of historically-couched narratives, although the interview guide (which they included) and researcher intentions were not specifically focused on obtaining mothers’ biographies. Unstructured (or loosely structured) interviews are an excellent tool for learning about someone’s lived experience and for understanding how people frame their own experiences (Bernard 2000).

*Semi-structured Interviews*

According to Schensul and colleagues (1999b:149), semi-structured interviews “combine the flexibility of the unstructured, open-ended interview with the directionality and agenda of the survey instrument to produce focused, qualitative, textual data at the factor level” (149). In many studies, qualitative interview questions are used within a
larger survey framework so that respondents can justify why they answered a close-ended question in one way or another (Brabin, et al. 2007; Constantine and Jerman 2007; Mays, et al. 2004). For example, Mays et al. (2004) assessed parental knowledge related to four STIs and then asked parents to rate the likelihood (using a Likert scale) that they would vaccinate their child against each disease if a vaccine was available. After parents responded, the interviewer asked parents to explain why they responded as they did. This approach is useful in identifying the multiple reasons that parents use to arrive at a particular shared response. It can also be helpful to identify problems with the validity of close-ended measurements in a survey. Semi-structured interviews can also provide material for future hypothesis testing and be useful in understanding the various terms or phrases that are used to refer to particular topics or items.

As they relate to the vaccine acceptance literature, key informant interviews, a type of semi-structured interview, have been used extensively in ethnographic studies (but in other studies as well) to interview a range of stakeholders believed to influence vaccine acceptance, including traditional healers (Fairhead, et al. 2004; Jegede 2005), health workers (Fairhead, et al. 2004; Jegede 2005; Kamara 2005; McCormick, et al. 1997; Poltorak, et al. 2004), community leaders (Millimouno, et al. 2006; Jegede 2005; Kamara 2005), religious leaders (Millimouno, et al. 2006; Jegede 2005), traditional birthing attendants and midwives (Fairhead, et al. 2004), NGO representatives (Kamara 2005); health clinic coordinators and representatives (McCormick et al. 2004), and national policy makers (Kamara 2005).
Group Interviews

Schensul and colleagues (1999a) define group interviews as any discussion that occurs between a researcher and more than one other person, regardless of whether the conversation is formal or informal, or arranged or impromptu. Group interviews have several advantages. First, they allow the researcher to obtain a large quantity of information in a short amount of time. In addition, group conversations can partially recreate the types of discourses that are likely to occur in a “natural” setting. Group interviews also provide the opportunity to examine how group members interact with one another and the subject matter (Morgan 1988). They can be useful in generating research questions for individual interviews, or to further examine themes that emerged through individual interviews. This method is especially useful for generating hypotheses because it generally requires less input and direction from the interviewer than individual interviews (Morgan 1988).

I specifically discuss the strengths and limitations of focus groups here, because they are, by far, the most common type of group interview used in vaccine studies. Focus groups were included in 17 of 70 studies that I reviewed on parental vaccine acceptance (see Table A5). While these 17 studies generally provided a clear and thorough justification regarding focus group composition (i.e. sampling), few of the studies included information regarding the role of the facilitator (or interview guide) in the group. These are important features because facilitators and guides can constrain or expand the topics of conversation. Facilitators can have more or less control in a group interview setting. A more structured interview is helpful if the researcher wants to compare data across groups or explore clearly defined issues. Most of the focus groups
to study vaccine acceptance appear to be relatively structured, which makes sense if the
goal of the group is to develop questions to use in future surveys. The focus group guide
provided by Olshen et al. (2005), for example, is relatively restrictive. Even though
parents in the groups could provide open-ended responses, the questions specifically
related to constructs in the HBM and only encouraged discussions about HPV and the
tetanus vaccine.

While increased structure yields greater control over the data generated from the
group, it also limits opportunities for generating new information and encouraging group
interaction. In less structured interviews, group interaction increases and new or
unexpected topics are more likely to emerge, but the emergent data might be less
amenable to comparison (Morgan 1988). In studies by Evans et al. (2001) and Casiday
(2007) group interviews were relatively unstructured, which led to discussions framed
around trust, responsibility, and politics, rather than (for example) the risk perceptions
probed for in studies using a more structured focus group approach.

The focus group method is a good tool for examining commonly held views and
how those views are discussed in a social situation, but the method tends only to reveal
how people who share some similar characteristic interact with one another and a topic.
This is not a problem so much as a limitation, since much of human interaction occurs
with people who we see as similar to ourselves. The method is not generally used to
understand how people from different groups (such as doctors and parents) or who have
made different decisions (vaccinate or not) interact. In the first case, issues related to
authority, respect, and power might lead some parents to feel uncomfortable expressing
their views about vaccination in front of providers. In the second example, the
environment could become charged, accusatory, and defensive if either set of parents perceives that they are being judged negatively because of their vaccine perspectives (Morgan 1988).

Like surveys and individual qualitative interviews, focus groups rely on verbal, self-reported data. This information is valuable, but also limiting. Interviewees can talk about perceptions, beliefs, attitudes, and knowledge all day long, and they can tell us how these factors relate to behavior. However, without observing actual behavior or interactions, it is difficult to know anything beyond the emic perspective.

**Participant Observation**

Participant observation (PO) is often the initial step in ethnographic research because it aids in establishing relationships, helps anthropologists understand how a system is organized (how people interact, how boundaries are defined), and provides the researcher with experiences and insights that can be incorporated into interviews (Schensul, et al. 1999a). In addition, repeated POs can reveal “patterns of etiquette, political organization and leadership, social competition and cooperation, socioeconomic status and hierarchies in practice, and other cultural patterns that are not easily addressed or about which discussions are forbidden” (Schensul, et al. 1999a:91).

In the parental vaccine acceptance literature, participant observation has been used in several studies, but mostly in developing countries (Coreil 1994; Fairhead, et al. 2004; Jegede 2005; Kamara 2005; Kishore, et al. 2003; Millimouno, et al. 2006). One ethnographic study on parental MMR vaccine acceptance in the U.K. includes clinic observations (Poltorak et al. 2004). In a U.S.-based time-motion study on provider risk communication, researchers recorded the amount of time that providers spent discussing
vaccination with parents (Davis, et al. 2004b). Silverman and colleagues (2002) also used participant observation methods to exam adult perceptions regarding influenza immunization.

PO exists along a continuum from full (or nearly full) participation to exclusive (to the extent possible) observation. There are strengths and limitations of situating oneself at any point along the PO continuum; however, I will speak directly towards issues related to less participatory, more observational strategies, because observation lends itself more easily to studies of vaccine acceptance.

Whiting and Whiting (Johnson and Sackett 1998) write that behavior observation is a time intensive method. Behavior observations take time to collect and greater time to analyze. They argue that to justify such an investment, behavior observation must be able to significantly contribute to the understanding of key research questions (though I would suggest that for any method to be justified, it should help to answer key questions). Johnson and Sackett (1998) argue that behavior observation is appropriate when the study is about behavior and when activity descriptions are helpful to understand what activities are like, who participates in activities, in what capacities, and in what contexts. Perhaps the most significant advantage of direct observation over retrospective reporting of behavior is that direct observations nearly always yield more accurate documentation of activities and behaviors than do retrospective participant recollections (Bernard 2006). In study after study, researchers found that individuals were poor reporters of prior behavior, even when those behaviors occurred the previous day (Bernard 2006).

While vaccine decisions result in specific behaviors (vaccination or not), the processes by which decisions are made are likely, in large part, cognitive in nature. At
The same time, a core underpinning of the LVC is that interactions are important components of vaccine decisions, and thus should be understood. Although the use of observation could have provided valuable information regarding the nature of parent, adolescent, and health care provider interactions and conversations, I opted against using the method due to logistical, time, and practical constraints.

As is true with any form of participant observation, one must consider the effects that observations will have on a particular exchange (Johnson and Sackett 1998). Observations characterized by little to no researcher participation can make the researcher’s presence more obvious to participants, who in turn might alter their behavior as a consequence. This is especially true in more obtrusive forms of observation, such as shadowing, where a researcher observes an individual (e.g., a physician) as they complete daily activities (LeCompte and Schensul 1999). In the case of the provider-parent-adolescent triad, and their healthcare interactions, I felt my presence would not only be quite obvious – given the average size of an examination room – but could also discourage parents or their daughters from discussing important health concerns they might have with their provider.

Because I did not feel the benefits of observations would outweigh the limitations and risks of using the method, I opted against conducting observations; as a result, I needed to obtain information about the healthcare interaction through other means. In cases where researchers cannot observe interactions, they often rely on retrospective descriptions of an exchange. This is a useful approach regardless of whether observations are conducted, because people’s recollection of events can highlight tensions, meanings, or interpretations of the exchange that were relevant to the
individual. There are, of course, limitations to relying on retrospective recollections of events, which I highlight when discussing my interview methods.

**Decision-Making Tools**

Most studies attempt to determine what factors lead parents to accept or reject a vaccine for their child. Although nearly all of the studies use the HBM or a hybrid-HBM model to predict these decisions, and most use a survey-based research design, some researchers have tried to model decisions using other methods (Sturm, et al. 2005; Zimet, et al. 2005). These include vaccine vignettes and scenarios, free-listing and pile-sorting activities, and triads. I focus only on vignettes and scenarios in this section because the other methods are seldom used within the vaccine acceptance literature (though certainly could be helpful to explore aspects of vaccine decision-making).

Vignettes and hypothetical scenarios are common methods used to assess risk perceptions and to understand how people will respond to particular situations under alternative conditions (Marshall and Rossman 2006). Researchers with diverse interests have used these methods to examine aspects of parental vaccine acceptance (see Tables A3 and A4). The critiques of these methods largely depend on their purpose, although they also share some limitations.

First, these scenarios are often used in cases where a technology (e.g., a vaccine) is not yet available. Responses to these vignettes are dependent upon a very limited understanding of a technology that is far removed from the person’s reality. Vignettes have commonly been used to examine parental acceptance of STI-related vaccines. However, in most of these studies the vaccines do not exist in reality and parents are left to imagine how they might respond to a vaccine of the future based on a very limited
amount of de-contextualized information. For example, while it is unclear what effect the marketing of Gardasil and efforts to mandate the vaccine (or its association with Vioxx, Merck, or any other host of factors) had on acceptance, it is likely that parental perceptions of the vaccine have been affected by its introduction. It is impossible to capture (or anticipate) the social and political context into which new technologies will be introduced, which dramatically limits what one can learn from these scenarios.

As I discussed in Chapter Three, hypothetical scenarios have been enormously popular in mental-modeling cognitive studies that ask parents to use numeric risk estimations to rate vaccine acceptability under various conditions. There are several important limitations to using these scenarios to calculate risk perceptions. First, the approach assumes that parents can respond to a risk scenario based solely on the facts presented, without allowing background assumptions to bias their response. Second, the approach assumes that parents can represent acceptability using a numeric scale, usually from 1 to 100. Finally, researchers assume that the risk-benefit scenarios include information that is relevant to parental decision-making (Connolly and Reb 2003). Studies designed to test these assumptions indicate that this particular method of assessing risk perception is problematic (Connolly and Reb 2003).

Context is another problem, regardless of the scenario. Even when vignettes relate to technologies or decisions that people are familiar with, they are still asked to respond to vignettes in a context far removed from the wider political and social context in which individuals make real decisions. A possible consequence is that, “under controlled conditions and outside of an everyday social context, respondents may feel compelled to make sense of risk using analytical techniques as opposed to habitual
anchors” (Mythen 2004:105). Mythen’s critique is targeted at the use of vignettes in cognitive research, where response options are limited, but the critique could also be applied more generally.

Results from these studies indicate, over and over again, that context matters. Paradoxically, the method produced findings that illustrated the limitations of the method itself. If context matters, then we need to question how useful scenarios and vignettes are in predicting or even understanding actual behavior. Findings from hypothetical scenarios are unlikely to reveal preferences or perceptions that represent real life decisions.

However, vignettes and scenarios can still provide valuable information. Garro (2004) suggests that they are especially helpful in promoting discussions related to sensitive topics (by speaking hypothetically about some other person). They can also reduce the likelihood that people will try to explain their own behaviors using “post hoc rationalizations” (Garro 1998a:325). Using hypothetical scenarios, researchers can ask people to evaluate alternative actions associated with a decision that is independent of their own past actions.

I incorporated the use of hypothetical scenarios and vignettes into parent and provider interviewers in order to delineate how perspectives or behaviors might change under different conditions and to better understand the nuances surrounding vaccine decisions. I provide a more detailed discussion of these methods when outlining my research methodology.
A Methodology for Examining HPV Acceptance

As presented earlier, conceptualizing an HPV vaccine decision as an isolated event has been challenged on multiple theoretical grounds (Baker 2007; Casiday 2007; Hobson-West 2007; Poltorak, et al. 2004). I propose that the Local Vaccines Culture approach (LVC) provides a more nuanced and holistic strategy to examine vaccine decisions within their sociocultural context. To review, the LVC approach calls for an examination of supply and demand-side factors, as well the service interface. The delivery of a vaccine program (supply-side) is affected by broader political and economic forces, and the way that macro-level processes shape the current vaccine practices generally and related to the HPV vaccine. The meanings (demand-side) ascribed to a vaccine by parents, while important, do not exist in isolation either. Rather than limiting conversations with parents to the HPV vaccine, and associated knowledge and risks, the approach requires methods that explore how parents’ vaccine practices and beliefs are associated with the wider social world. The service-delivery interface, as embodied by the pediatric practice and interactions occurring within it, is of particular interest because it is a border zone, where multiple meanings are translated, negotiated and performed.

The strength and consequential weakness of the LVC framework is its breadth in calling for the examination of the individual experiences and emotions, shared (or contested) meanings surrounding vaccination, and political and economic factors shaping vaccine policy and delivery as part of an integrated system.

By capturing these multiple levels, the resulting collage of data is more likely to capture the rich and complex layers of vaccine acceptance decisions than a narrowly-focused, single-theory snapshot may do. At the same time, producing such a complex
and organized analysis is challenging. The goals of the approach are lofty and necessitate
the use of qualitative methods that are sometimes difficult to implement, time-intensive
to analyze, and yield overwhelming quantities of data. In developing a research
methodology, I struggled to balance the requirements of the framework with practical,
economic, and time limitations. While I was unable to use specific methods that would
have provided a deeper understanding of the topic, I was able to construct a research
methodology that still allows for a deep, rich, and insightful analysis of HPV vaccine
decision-making in line with the goals of the LVC approach. In the following sections, I
describe my rationale for choosing particular research methods, sampling techniques, and
analytical strategies.

**Research Methods**

In brief, demand-side factors were explored using semi-structured, in-depth
interview methods that examined how parents situate vaccination within their larger
social worlds. Several methods contributed to an understanding of supply-side factors. I
conducted an extensive literature review on the economic, political, and structural
features of vaccine policy in order to situate the current HPV vaccine program in its
wider, historically-situated context. In addition, I conducted interviews with service
providers to elicit information about their personal approaches to vaccination, their
perceptions of parental concerns, and the meanings that they ascribe to parental vaccine
choices.

While I planned to conduct key informant interviews with health care
administrators and site managers to ascertain information about vaccine policies,
protocols, and procedures, both generally and related to the HPV vaccine, I was unable to
successfully recruit any to participate. I originally planned to use direct observations and shadowing as methods to collect information regarding the service-delivery interface. However, concerns regarding the obtrusiveness of observations and the difficulty of obtaining consent and assent from health practices, individual providers, parents, and their daughters led me to seek other ways to collect information about the patient-provider relationship. Specifically, I incorporated questions, vignettes, and scenarios into both provider and parent interviews to capture elements of the service-delivery interface.

**Semi-Structured Interviews**

I used semi-structured interviews to talk to both parents and providers. Semi-structured interviews provide most of the same openness and flexibility offered by an unstructured interview, but with the use of an interview guide that ensures that specific topics are covered. Bernard (2006) notes that semi-structured interviews are especially appropriate when participants will only be interviewed once, as was the case in this study. Additionally, semi-structured interviews work well when interacting with members of communities who are “accustomed to efficient use of their time” such as healthcare providers (Bernard 2006:212).

One of the goals of this study was to better understand the meanings of vaccination to parents – how parents frame their own stories and make connections between vaccinations, personal experiences, and larger social processes. To explore these connections, I conducted in-depth, semi-structured, one-on-one interviews with 26 parents. Within the larger semi-structured interview framework, I incorporated elements from the biographical vaccine interview approach by asking parents to recall past vaccine experiences and earlier decisions as related to specific children. I also used probes,
vaccine scenarios, and vignettes to discuss aspects of the healthcare visit, including typical provider-patient care interactions, how parents describe typical and non-typical clinic visits, if and how the structure of visits changes through time (from childhood to adolescence, for example), and how vaccination conversations occur. I also provided parents with different scenarios to understand if, when, and how they discuss specific vaccine recommendations. Other themes I explored during parent interviews included general healthcare attitudes and decision-making and general perspectives towards vaccines. Of course, a significant amount of time was spent discussing the HPV vaccine in particular, and probing themes related to sexuality, responsibility, trust, risk, and timing that emerged from these discussions.

I also conducted semi-structured in-depth interviews with 16 providers, who as primary actors in both public health and biomedical systems, are well situated to understand how larger structural, economic, and political aspects of healthcare provision and vaccine coverage relate to HPV vaccine availability, coverage, and acceptance. Providers are also key actors in the service-delivery interface; exchanges that occur between parents, providers, and youth during healthcare visits link supply- and demand-side factors and provide spaces where value conflict, consensus, and negotiation are enacted.

It is important to include providers in studies of vaccine acceptance, not only because they are part of the social/interactive experience of vaccine acceptance, but because studies have found that provider recommendations can influence parental vaccine decisions (Dempsey, et al. 2006; Dinh, et al. 2007; Esposito, et al. 2007; Rosenthal, et al. 1995). It is important to understand if, how and when providers discuss
the HPV vaccine and under what conditions they feel comfortable (and why) recommending the vaccine. It is also critical to understand how they perceive parental response to the HPV vaccine and how, if at all, this influences their own present and future interactions with parents and patients.

Finally, providers can provide aggregate-level data about parental vaccine perceptions. While parents provide the contextual richness that helps to frame and give meaning to decisions, their narratives are specific and individual. Providers’ accounts of typical parental concerns and interactions lack contextual richness, but help to situate individual narratives within what providers view as normative, typical, and generalized vaccine responses. Thus, together, parental and provider interviews provide two different lenses by which to position and make sense of Gardasil decisions.

To examine these multiple facets, I designed a semi-structured interview guide that provided a way to consistently probe specific areas, but was flexible enough to allow me to explore emergent themes. In order to understand facets of the service-delivery interface, I used scenarios and vignettes to understand how providers structure clinic visits and how procedures, protocols, and perceptions vary depending on the age of the infant, child, or adolescent and the type of visit (acute, sports physical, annual check-up, etc.). I also asked providers to describe the typical structures of clinic visits with pre-adolescents, adolescents and parents. In addition, I asked questions to elicit information about providers’ general perceptions towards vaccination and particularly vaccines for adolescents, including HPV.
Sampling Strategy and Recruitment of Research Population

The goal of my research was to understand the wide range of experiences and perspectives that come to shape the way that parents make HPV vaccine decisions for their pre-adolescent and adolescent daughters. I cast a fairly wide sampling net in an effort to include parents who already made HPV vaccine decisions for (or with) their daughters, as well as parents who have not yet made final vaccine decisions. The dearth of anthropological, qualitative and descriptive literature on this research topic suggested that a selective convenience sampling approach would be useful given the exploratory nature of the research (Schensul, et al. 1999b)

Because of the limited amount of contextualized data on HPV vaccination decisions and the overabundance of quantitative material on the subject, I felt it was important not to limit the sample population, or set pre-defined sampling quotas based on any particular demographic variable. As previously discussed, the quantitative literature on parental vaccine acceptance yields no consistent evidence to suggest that demographic variables are strong or reliable predictors of vaccine decision-making (Brabin, et al. 2006; Constantine and Jerman 2007; Davis, et al. 2004; Fazekas, et al. 2008; Friedman and Shepeard 2007; Marlow, et al. 2007a; Marlow, et al. 2007b; Moraros, et al. 2006; Olshen, et al. 2005; Riedesel, et al. 2005; Waller, et al. 2006; Zimet, et al. 2005). While no single demographic variable seems to be predictive of vaccine acceptance, parents’ own personal demographic characteristics, such as education, age (of self and daughter), ethnicity, and socioeconomic status, likely shape to some extent the way that they understand and experience vaccine decision-making. In an effort to promote diversity in
the study sample, I posted and distributed recruitment fliers in multiple locations\textsuperscript{18}, serving diverse groups of individuals; however, I did not require that a specific number of parents meeting particular demographic characteristics be sampled.

I used both passive recruitment and a snowball sampling strategy to recruit study participants; fliers were used for initial and ongoing recruitment of parents and providers, while a snowball strategy was used to recruit additional participants. Participants who learned about the study through a flier were passively recruited. Each individual needed to contact me him- or herself to learn more about the study. Parent fliers were placed in private pediatric healthcare clinics, community centers, and recreational centers throughout the Tampa Bay area (Hillsborough, Pasco, and Sarasota counties) and in central Pennsylvania (York and Cumberland counties) with permission from on-site representatives. I posted fliers in rural, suburban, and urban areas, as well in venues serving both younger and older girls, such as youth recreational facilities, libraries, and after-school program sites. Using an online phone directory, I randomly selected 100 medical provider practices in the Tampa Bay area and 20 practices in central Pennsylvania. I sent each of these practices, by mail, an envelope that contained several copies of the parent flier, several copies of the provider flier, and a summary letter explaining the purpose of my research. Providers were asked to place parent fliers in their practice waiting rooms (if desired/ permissible) and to share provider fliers with colleagues. They were also invited to participate personally in the study. Fliers targeting healthcare providers were placed in private healthcare clinics and at other sites

\textsuperscript{18} For example, I posted fliers at youth after-school program sites for underserved and/or at-risk youth, at recreational sites (e.g., YMCA), in coffee shops, libraries, convenience stores, and at clinics and healthcare practices accepting youth with public and private types of insurance
where healthcare providers congregate (e.g., workshops). In all cases, I obtained approval from recruitment sites before posting fliers; no fliers were posted in sites where prior approval was not obtained.

Snowball sampling was used as a secondary recruitment strategy, whereby interviewed participants were asked to refer other eligible participants to the study. Participants who wished to refer another person to participate in the study were given additional research fliers and contact information to share with eligible individuals.

Sample Populations: Rationale, Inclusion and Exclusion Criteria

Initially, I planned to conduct interviews with providers and parents living (or working) in the Tampa Bay area, including Hillsborough, Pinellas, and Pasco counties. There were several reasons for selecting this research population. First and foremost, as a resident of the Tampa Bay area at the time, the research population was accessible, which was key given that I hoped to conduct face-to-face individual interviews with providers and parents. I chose to include three Florida counties as part of the Florida sample because these counties represent a diverse group of individuals from urban, suburban, and rural areas (EDA 2007).

After nearly a year of data collection, I was having difficulty recruiting individuals – especially parents – to participate in the study. Nearing the end of a year, the secondary snowball sampling strategy had not led to any new participants, perhaps because many of the parents that I initially interviewed were newer to the area themselves. I decided to expand my sample to include parents and providers living (or working) in central Pennsylvania, where I was born and raised and would spend several months in which I could collect data. While splitting my sample between two
geographically distinct areas of the country required additional analysis, legwork, and state-level policy research, it also served to diversify my sample. Including participants from two distinct geographic regions of the country, however, does not itself allow for a comprehensive geographic comparison of vaccine perspectives. Even with the addition of a second research site, my sample was never intended to be random or representative, nor would the requirements that I sample to saturation likely result in sample sizes large enough to conduct any type of statistical comparisons between or across groups.

To participate in parent interviews, individuals had to be between the ages of 24 and 65 and be the parent of legal guardian of a female between the ages of 9 and 16. It is important to note that non-English speaking parents, who comprise an important segment of the U.S. population, were ineligible to participate in the study, due to my limited language skills\textsuperscript{19}, the nature of the research, and economic constraints.

Licensed healthcare providers between the ages of 18 and 65 were invited to participate in the study if the provider had contact with a pediatric population between 9 and 16 years of age and had discussions with parents or youth regarding the HPV vaccine. Because a wide range of providers discuss vaccines with parents, and because provider recommendations appear to influence parental vaccine perspectives, I attempted to recruit providers with a wide range of specialization and training. I sent fliers and research material to practices that employed medical doctors, doctors of chiropractic medicine, osteopaths, naturopaths, nurses (nurse practitioners, registered nurses, etc.), and physician’s assistants. Additionally, I sent material to practices and clinics that

\textsuperscript{19} Most notably, I did not feel that I could adequately or equally analyze interview data that were collected and transcribed by another individual, when I was solely responsible for conducting, transcribing, and analyzing all English-language interviews.
specialized in acute care (such as walk-in clinics), primary and family care, pediatric care, gynecological care, chiropractic, and naturopathic medicine.

Parent and provider interviews, on average, took between 45 minutes and two hours to complete, depending on the breadth and depth of the participant’s responses. The majority of interviews (n=37) were conducted in-person. Face-to-face interviews were conducted at participants’ homes, in participants’ offices or work place, in the researcher’s office (if preferred by the participant), or in another mutually agreed upon location that was convenient, safe and private. Due to the distance between research sites, scheduling conflicts, and weather-related cancellations, several telephone interviews (n=5) had to be conducted. In order to compensate participants for their time, I provided honorariums in the form of Target gift cards to parents ($10) and providers ($20) who initiated an interview.

Sample Size

As Schensul and colleagues (1999b:262) explain, the objective of exploratory research “is to reach the informational saturation point, which is the point at which additional data collection, including interviews and observations, produces no new information about cultural domains, subdomains, or factors.” This point, termed “sufficient redundancy” is reached when “patterns of response begin to repeat themselves and generate no new information” (261). Based on this principle, and because my goal was not to collect a statistically representative sample, I did not begin with the goal of completing a specific number of interviews. Rather, I planned to conduct interviews with parents and providers until I reached the point of sufficient redundancy.
While there was no specific number associated with achieving redundancy, most qualitative, ethnographic samples are relatively small (Schensul et al. 1999a). For example, in one study where the concept of saturation was operationalized to determine the point at which saturation occurred, researchers found that saturation occurred within the first twelve interviews and basic elements for meta-themes emerged in as few as six interviews (Guest, et al. 2006).

**Data Analysis**

Unlike quantitative analysis, which usually occurs at one point in time after all of the data are collected, qualitative analysis is an ongoing and iterative process (LeCompte and Schensul 1999). The systematic, but flexible nature of qualitative data analysis allows us to rework questions and methods as we go, to adjust our focus and sharpen our view of a problem. While statistical analysis gives us a snapshot, qualitative analysis allows us to explore other dimensions as well – to add layers and depth and nuance to contextualize findings.

I employed a data analysis strategy that consisted of several interrelated and overlapping steps that included three primary levels of analysis: item, pattern and constitutive analysis (LeCompte and Schensul 1999). Item-level analysis, which gives the “researcher analytic scaffolding on which to build” was both an initial and ongoing step in the analysis process (Charmaz 2005:517). Item-level analysis refers to the process of isolating specific elements or items from the data that are related to the research questions (LeCompte and Schensul 1999). These related items are then grouped into the same “code” or descriptive unit in order to make sense of the data (Ryan and Bernard 2000). The process of identifying items and codes was simultaneously inductive and
deductive and I drew from several code-identification procedures reviewed by LeCompte and Schensul (1999:69-70) when conducting my own item-level analysis. The process was also flexible: data could simultaneously represent elements of more than one code and the same data were sometimes re-coded more than once throughout the research process to provide “multiple readings and renderings” of a phenomenon (Charmaz 2005:517).

Once a substantial number of item-level codes had been created, I compared codes to one another to identify patterns or themes. I drew from eight methods outlined by LeCompte and Schensul (1999) to identify themes: declaration, frequency, omission, similarity, co-occurrence, corroboration, sequence, and a priori hypothesizing. While searching for similarities and patterns, I also used the process of analytic induction to search for negative or disconfirming cases to explore the variation within narratives and to highlight the nuances and multiple dimensions of experience (LeCompte and Schensul 1999).

In the constitutive (or structural) analysis phase, I began to find “consistent relationships among patterns, components, constituents, and structures” (LeCompte and Schensul 1999:177). For example, the importance of trust, vaccine timing, and responsibility were identified during this phase as important components in parental narratives. Using structural categories, I connected pattern-level themes to one another and back to the research questions in an effort to gain a more complete and nuanced understanding of the research problem. In this phase, for example, I identified connections between trust in vaccines and trust in daughters with decisions regarding vaccine timing. Finally, in the interpretive stage, I attempted to bring meaning to the data
by locating them (and my study) within the broader field of research, which I intend to do in the following chapters.

**Ethical Considerations and Participant Confidentiality**

The original research proposal and all modifications were approved by the University of South Florida Institutional Review Board. The informed consent document was written using lay language. All participants were given ample time to read the informed consent document; in addition, I verbally discussed the content of the document with participants in order to ensure that participants fully understand the document. After reading the informed consent document, participants were encouraged to ask questions about the scope and/or breadth of the project, specific risks or benefits of participating, and information in the document that they did not understand or about which they wanted more information or had concerns. Participants who had reviewed the document, discussed it with me, asked relevant questions, and were judged to be capable of providing informed consent and willing to participate in the study were asked to sign the informed consent document.

Participants were interviewed only once. Interviews were conducted at participants’ homes, in participants’ offices or work place, in the researcher’s office (if preferred by the participant), or in another mutually agreed upon location. Every effort was made to accommodate the participant to find a safe and private location to conduct the interview. In order to ensure confidentiality, all locations had to provide a reasonable amount of privacy. Whenever possible, interviews were conducted in-person. However, due to the distance between research sites, participants’ limited availability, inclement
weather, and economic constraints, five of the 42 interviews had to be conducted over the telephone. In cases where a face-to-face interview was not possible, an initial telephone call was used to discuss the research and to verbally review the informed consent documents; participants who were still interested in participating then received, via postal mail, a copy of the informed consent document, a Target gift card (a $20 honorarium for providers and a $10 honorarium for parents), and return envelope and postage. After receiving and reviewing the packet of information, a second phone call was set up to discuss, in detail, the informed consent document and answer any questions that potential participants might have had regarding the study or their participation within it. Participants who still wanted to participate sent the signed informed consent document back to me, along with receipt that they received the incentive, and upon receiving this information, I contacted participants to arrange a time to conduct the interview.

Snowball sampling was only used to recruit participants within groups (e.g., parents to recruit other parents or providers to recruit other providers). I did not ask providers for any direct referrals of patients to avoid exerting undue pressure on parents to participate. All electronic data (digital audio recordings of interviews, transcribed interviews, and other data-related files) have been (and continue to be) stored on a password-protected computer that is not part of a larger computer network. Hardcopy data (field notes, informed consent documents) are stored in a locked office on the USF campus. Post-interview, all audio-recorded data were saved in a digital format on a password protected computer and erased from the audio-recording device. Typed

For example, one face-to-face interview in Pennsylvania had to be cancelled due to a blizzard; due to the parent’s work schedule, it was impossible to reschedule the interview before I had to return to Florida. Therefore, we agreed to conduct the interview by phone.
transcriptions of the interviews, as well as coding and analysis files, are also stored on a password protected computer.

Parents discussed their own vaccination choices and perspectives about a vaccine that is delivered to their daughters. Therefore, it was possible that through these discussion parents could provide information that could directly identify their daughters and other individuals, such as spouses, grandparents, or healthcare providers, who might be mentioned in relation to vaccine decision-making. Providers sometimes discussed information that could lead to their own or their colleagues’ identification. In order to protect the confidentiality and privacy of all individuals who were either directly or indirectly discussed during the course of an interview, I removed all information that I felt might lead to the identification of individuals.

To ensure further protection of parent and provider confidentiality, I have assigned all participants pseudonyms. In many cases, I use pseudonyms to identify which parents and providers express specific ideas. In some cases, however, I felt that including a participant’s pseudonym with some quoted material could potentially lead to his or her identification, especially were someone to examine all of his or her quoted material collectively. I do not use parent’s names when they are describing specific information about their children that could lead to their identification and I refrained from including specific information about some disorders due to their rarity. I also avoid using provider names in association with quoted material that might lead their colleagues or clients to identify who they are or where they work, especially because some of the information that they shared with me was critical of their clients. I have used my best
judgment in attempting to protect confidentiality while providing the reader with a sense of participant profiles.
Chapter Five – Setting and Participants

National and State-Level Vaccine Coverage and State Laws

Each state has its own laws specifying which vaccines are mandated for school entry, in what dosages, and at what ages or grades. Vaccine-related policies and requirements are not straightforward, but often politically charged issues for states, as exemplified by recent presidential debates, in which Michelle Bachmann questioned Rick Perry’s previous efforts as the governor of Texas to mandate the HPV for school entry. Similarly, each state defines the conditions under which a child attending public schools can be exempt from vaccinations. Finally, the ways in which states contribute to and use federal vaccine funds through VFC, Medicaid, and 317 differ, which will be discussed below. In this section, I briefly discuss Florida and Pennsylvania vaccine-related laws.

To attend public schools in Pennsylvania or Florida, children must have proof of diphtheria, tetanus, poliomyelitis, measles, rubella, mumps, hepatitis B, and chickenpox vaccines (or proof of immunity) (Florida 2008; Pennsylvania 2011). In addition to early childhood vaccines, students entering the seventh grade must receive a vaccine against tetanus and diphtheria toxoid and acellular pertussis (TdaP). In both states, students may also require a chickenpox booster vaccine for seventh grade (Florida 2011). In Pennsylvania, children entering the seventh grade are also required to receive the meningococcal conjugate vaccine (MCV), though this law was enacted in 2010 (Pennsylvania 2010), after I completed interviews with parents. In addition to state required vaccines, children ages 11 and 12 are also eligible to receive a series of catch-up
vaccines, including Hep A and B, polio, and MMR, as well as the annual flu vaccine (CDC 2011b).

Both Pennsylvania and Florida allow for medical exemptions. In both states, parents submit a form signed by a physician or the physician’s designee stating that the immunization(s) may be detrimental to the child’s health. Both Pennsylvania and Florida law also permit religious exemptions, but Pennsylvania’s definition of a religious exemption is more expansive than Florida law. In Pennsylvania, an exemption can be granted “if the parent, guardian or emancipated child objects in writing to the immunization on religious grounds or on the basis of a strong moral or ethical conviction similar to a religious belief” (PA §23.84, 2008). In Florida, parents can request a religious exemption by filling out a form issued by the county health department. The parent submits a signed form that states in writing that a religious conflict exists. Under Florida law, exemptions for personal or philosophical reasons are not permitted (Florida 2008).

At the national level, American Indian or Alaska Native (AIAN) girls were most likely (64.8%) to have received at least one dose of HPV vaccine, followed by Hispanic (56.2%), Asian, non-Hispanic (50.1%), and Black, non-Hispanic (48.9%) girls. Initiation rates were lowest among White, non-Hispanic girls (NIST 2010a). However, a different trend characterized three dose vaccine completion rates. Asian, non-Hispanic (86%) and White, non-Hispanic (74.7%) girls were most likely to complete the series, followed by girls identifying as Black, non-Hispanic (65.4%) or of American Indian or Alaska Native (64%) descent. Rates of series completion were lowest among Hispanic girls at 56.1 percent (NIST 2010a). In Pennsylvania, 2010 indicators reveal that Black, non-Hispanic girls (ages 13 to 17) were most likely to have initiated the series (63.6%), followed by
Hispanic (54.5%) girls. Only half of White girls (50.2%) initiated the series (NIST 2010a). However, White, non-Hispanic girls who initiated the series were more likely (87.4%) than non-Hispanic Black girls (65.4%) to complete the series (no data existed for other race/ethnicity completion rates) (NIST 2010a). In Florida, 2009 data comparing rates of one-dose coverage were slightly higher among Latina/Hispanic girls (40%) than Whites (38%); data were unavailable for coverage rates among African Americans (NIST 2009).

National statistics indicate that a slightly greater percentage of girls below the poverty line have had at least one dose of HPV vaccine. Approximately 52 percent of girls below the poverty line began the series, compared to 48 percent of other girls. However, girls at or above the poverty line (73.2%) were more likely to complete the series than other girls (57.3%) (NIST 2010b; NIST 2010c; NIST 2010d). State-level indicators for HPV coverage by poverty level were unavailable in Florida; however in Pennsylvania girls living below the poverty line were more likely to both initiate (57.8% vs. 50.4%) and complete (86.8% vs. 82.9%) the HPV series (NIST 2010).

Although national and Pennsylvania state indicators suggest that girls below the poverty line are more likely to at least begin the HPV series, it is unclear whether Florida patterns are similar. The 2010 national average is based on information collected from eleven states and the District of Columbia; it is unclear what types of differences are appearing in other states (NIST 2010d). Moreover, and as will be discussed in greater detail below, structural differences in state-level management of its CHIP, Medicaid and VFC programs can lead to differential uptake rates even among girls enrolled in or eligible for these services. For example, a comparison of HPV vaccine uptake in Texas
between 2006 and 2008 revealed lower rates among girls enrolled in Medicaid and CHIP programs, compared to those with private insurance (Staras, et al. 2010). Moreover, uptake was higher among girls enrolled in Medicaid, as opposed to CHIP, programs (Staras, et al. 2010a)

HPV vaccine coverage among 13 to 17 year old girls is higher in Pennsylvania than in Florida. Based on results from the 2010 National Immunization Teen Survey, 41 percent of girls in Florida have received at least one dose of HPV (either Gardasil or Cervarix), compared to 52 percent of Pennsylvanian girls (NIST 2010e). A greater proportion of Pennsylvanian girls had received three or more HPV vaccine doses as well (42% compared to 25%). Pennsylvania’s HPV vaccine rates are above and Florida’s rates below the national average. Pennsylvania has the 19th highest initial vaccine rate and the 9th highest 3-dose completion rate in the country (NIST 2010e). Florida has the 12th lowest uptake rate and 7th lowest 3-dose completion rate in the country (CDC 2011c).

Many factors likely contribute to variations in HPV vaccine coverage; one factor is vaccine availability. Providers surveyed in several studies report that vaccine reimbursement is a significant barrier to vaccination (Boodman 2007; Freed, et al. 2008; Keating, et al. 2008; Kelley 2010) and there appears to be regional variations in vaccine availability. In a national survey of family and pediatric physicians, 89 percent of respondents in the northeast administered the vaccine in their office, compared to only 79 percent of providers in southern states (Daley, et al. 2010a). The cost of a single Gardasil vaccine averages $120; a complete series costs an average of $360 (Kaiser 2008). While the cost of the vaccine is the highest of any recommended vaccine currently on the
market, its status as an ACIP-recommended vaccine (the vaccine approval and recommendation process is discussed thoroughly in the following chapter) guarantees that Gardasil is available for low or no cost through Medicaid and Vaccines for Children (VFC) programs (KFF 2008). It is significant that the vaccine is covered through VFC and Medicaid programs given that nearly a quarter (23%) of girls ages 9 to 18 are publically insured and 13 percent have no insurance. Although the majority of girls are privately insured (63%), it is unclear exactly what percentage of private plans currently cover Gardasil vaccination (Kaiser 2008).

While many girls have private insurance, they still might be underinsured. Underinsured children, defined as those who have “commercial (private) health insurance but the coverage does not include vaccines, whose insurance covers only selected vaccines (VFC-eligible for non-covered vaccines only), or whose insurance caps vaccine coverage at a certain amount” can receive VFC vaccines only through Federally Qualified Community Health or Rural Health Centers (CDC 2011c). While there are ways in which underinsured girls can obtain the Gardasil vaccine at low or no cost, factors such as awareness of eligibility and site location can potentially limit access to these centers.

For example, the number of community and rural health centers in the five counties sampled in this study varied. In Hillsborough County, there are 14 federally qualified community health clinics (FACHC 2011). There are seven community health clinics located in Pinellas County and three operating in Pasco County (FACHC 2011). Cumberland County has one community health center, while York County contains four
Of the five counties included in this study, Hillsborough County is the only one that contains federally qualified rural health centers (RAC 2011).

In Florida, approximately 18 percent of girls under age 19 are uninsured, while an estimated 7 percent of girls in Pennsylvania lack any type of health insurance. These girls can also receive Gardasil at low or no cost through the Vaccines for Children Fund (VFC) (KFF 2011). Data from 2008 and 2009 indicate that approximately 30 percent of children in Florida (29%) and Pennsylvania (30%) are insured through Medicaid or other public programs, specifically the Children’s Health Insurance Program (CHIP) (KFF 2011).

The Children’s Health Insurance Program (CHIP) was created to expand insurance coverage and services to underinsured families (Kaiser 2008). At the federal level, CHIP is administered by the U.S. Department of Health and Human Services, which provides matching funds to states for health insurance to families and children. Individual states are responsible for implementing the program and have some degree of flexibility in deciding how to administer CHIP. CHIP programs can take one of three overarching forms. States can create CHIP programs that are completely independent from state Medicaid programs, they can use CHIP funds to expand Medicaid programs, or they can take a combined approach where some funds are used to expand Medicaid programs while others are funneled into an independent program (Kaiser 2008).

The structure of each state’s CHIP program affects a child’s eligibility to receive vaccines through the VFC program. Children who are enrolled in a separate CHIP program are not eligible for vaccines through the VFC because they are considered to have insurance coverage and have access to ACIP-recommended vaccines through their...
CHIP insurance program. Pennsylvania has a CHIP program completely separate from Medicaid, while Florida uses a combined approach. In Pennsylvania, children enrolled in the CHIP program can receive ACIP-recommended vaccines, such as Gardasil, as part of their program benefits, but are not eligible to receive the same vaccines through the VFC program. Children enrolled in Medicaid expansion CHIP programs, on the other hand, are Medicaid eligible, and therefore entitled to VFC program benefits. Though families can obtain free or low cost vaccines through CHIP, Medicaid, and VFC, program types affect aspects of service-delivery (e.g., locations from which vaccines can be obtained) and provider reimbursement.

The structure of Florida’s combined program offers a good example of the ways in which insurance coverage can affect vaccine uptake. Through the combined CHIP and Medicaid programs in Florida, children are enrolled in one of six programs. Enrollment options depend on the specific needs of the child and county of residence. In a two-year Florida study of HPV vaccine uptake among girls (ages 11 to 17) enrolled in these programs, researchers found that HPV vaccine uptake varied by Medicaid program type and by length of enrollment (Staras, et al. 2010b).

While a significant percentage of Pennsylvanian and Floridian children can or do receive vaccines through federally and state-sponsored programs (due to CHIP/Medicaid coverage and/or being uninsured), they are underrepresented in this study sample. All 15 of the parents interviewed from Pennsylvania had private insurance plans that covered all childhood vaccines. In the Florida sample, two of 11 parents had children covered under Medicaid/CHIP programs and two parents currently had no insurance.
County-Level Demographics

Approximately two and a half million people reside in Hillsborough, Pasco, and Pinellas counties. Hillsborough County is the largest and most ethnically diverse of the three counties (1,229,226; 71% White, 17% Black, and 25% Hispanic). Pinellas County is slightly smaller, has an older population, and is less ethnically diverse (916,542; 82% White, 10% Black, 8% Hispanic). Pasco County is the smallest of the three counties, largely rural, and predominantly White (464,697; 88% White, 5% Black, 12% Hispanic). These three counties include urban, suburban, and rural areas as well as linguistic, ethnic, and income diversity.

The population sampled from central Pennsylvania is smaller and more homogenous in comparison. Collectively, less than 700,000 people reside in Cumberland and York counties and the majority of residents are White (91% in Cumberland County; 86% in York County). While York County does include a large metropolitan area, none of the providers or parents who participated in this study lived or worked in this region of the county.

Provider Characteristics

Sixteen healthcare providers participated in this study. Eleven of the providers worked in Florida and five worked in Pennsylvania. The five Pennsylvania providers included two school nurses, two pediatricians (one MD and one DO), and one family nurse practitioner. While the sample of healthcare providers from Pennsylvania is small, the population in the sample area is also relatively small. The nurse practitioner and physicians worked in three practices that see more than 35,000 children in the area.
Florida providers included eight nurse practitioners, two pediatricians, and one chiropractor.

Providers in both sites worked in a variety of healthcare settings and several (n=7) worked in more than one setting, providing them with comparative insights regarding differences in vaccine uptake and perceptions. Nine providers worked in physician-owned practices: seven in pediatric practices, one in a family practice, and one in an OB/GYN practice. Four providers worked in university affiliated, publically funded teaching clinics. Two providers worked in non-profit family planning and STI clinics, two in private retail clinics, and two in public and private elementary, middle, or high school settings. The chiropractor worked in chiropractor-owned office. The OB/GYN office was the only setting in which Medicaid or other publically-funded insurance was not accepted. Most providers worked in settings where both public and private insurance were accepted, though some settings dealt primarily with privately insured patients (n=2), and others primarily with Medicaid insured or uninsured clients (n=5).

With the exception of the chiropractor, all providers were female. The gender-bias is surprising given that slightly more than half of research fliers were sent to male healthcare providers. In two cases, male providers who received the fliers passed them on to females in their practices, who contacted me to be interviewed. I asked several of the providers with whom I spoke why they thought male providers had not volunteered to participate. Four providers speculated that males were simply less enthusiastic about a vaccine that was targeted to and benefited females. One pediatrician said, “I think female practitioners are more sensitive to the topic, and therefore more willing to invest time to talk about it.” Another provider, whose male colleague passed the flier onto her,
reflected, “I almost feel like they don’t really want to touch it yet. Because they don’t – I don’t know, maybe they don’t understand it as much or they don’t sympathize as much. I know people – my friends have HPV. I know about it.”

It is possible that males were more likely to pass fliers along to female colleagues, not because they were disinterested in women’s health, HPV, or the Gardasil vaccine, but because they knew some of their female associates were more passionate about the topic. One pediatrician explained how she came to learn about the study: “[The flier] was sent to the president of our office, who is male. And he said, ‘We received this, is anyone interested in doing this?’ And he kind of [said to me], ‘I think this would be good for you, you’re really interested in this.’ And I was like, ‘Yeah, I’ll do it.’”.

It is also possible that males were less likely to participate because they felt they had limited experience regarding the topic, or that female providers would have greater breadth of experience to draw from concerning vaccine interactions. Several providers noted that in their healthcare setting, female providers saw the majority of pre-adolescent and adolescent females, while male providers tended to work with most of the young males.

Providers also thought that broader gender differences might explain the absence of participation among males. One pediatrician thought that even if males participated in the study, they would not (presumably unlike females) represent the general male provider: “The males that are interested in doing it are not going to be your typical male population anyway.” A nurse practitioner was not at all surprised that men had not responded to research fliers, explaining, “I think most guys have a good bit of ADD. They just don’t sit down and do anything that’s not going to immediately benefit them.
Men just tend to be a little more selfish (laughs).” She went on to speculate that women, as nurturers, are more likely to take time to help others. “I think it’s the nature of the beast. Women tend to like to be helpful to other people.”

It is unfortunate that the chiropractor is the only male perspective presented here, especially given that chiropractors’ typical vaccine discussions, interactions, and roles differ markedly from those of medical doctors and nurse practitioners, regardless of gender. The absence of male perspectives is especially disappointing because studies suggest that there are some gender differences in HPV-vaccine approaches. Daley and colleagues (2010) reported that in a national sample of family providers, female physicians (95%) were more likely than male physicians (83%) to report giving Gardasil in their offices.

Several of the female providers in this study also suspected that men viewed the vaccine differently. As one pediatrician reflected, “you wonder if [male providers] just feel uncomfortable. You wonder what they’re saying to patients.” Two providers thought male providers would be less likely to push the vaccine, especially to parents of younger girls. One provider thought the males with whom she worked would spend less time discussing or promoting the vaccine with parents or young women. She said, “They’ll just slap a pamphlet in front of them and say, ‘I think this is a good thing. Here’s the information. Read it and let me know if you want it.’ In my experience, that’s been the guys I’ve worked with.” Two pediatricians suspected that they pushed Gardasil more heavily than their male counterparts and wondered how different their approaches were. Another provider knew that males in her office were not routinely initiating Gardasil conversations with younger girls, “They’ve told me at meetings with our reps
and they’ve told me themselves that they sometimes don’t even bring it up to the 11 year olds. They don’t even mention it. . . I’d love to hear a man’s take on it and if it’s different from my take.”

I present the reflections of these few female providers not to suggest that male providers are selfish, disinterested, or unlikely to recommend the vaccine, but to point out some of the gender differences female providers perceive in male/female practice and attitudes towards Gardasil. If differences exist in the ways that male and female providers approach the vaccine – as is likely – it is critical to use caution when interpreting the results of this study. The small sample of providers already precludes wide generalization of findings, as does the analytic techniques employed, but the lack of male voices certainly restricts any generalized interpretations that might be made even further.

All of the healthcare providers in this study were generally supportive of vaccination. However, the pediatricians tended to be more staunchly pro-vaccine, making blanket statements in support of vaccination, while nurse practitioners were more likely to convey overall support for vaccination but express specific concerns or ambivalence towards certain vaccines. The differences in nurse (n=11) and physician (n=4) perspectives towards vaccines are discussed throughout the dissertation, although it is important to stress that variation in physician and provider vaccine perspectives may be the result of sampling-bias. For example, while two physicians I interviewed described their colleagues as pro-vaccine, both providers also noted that compared to their colleagues they were the most supportive of vaccines, and the least likely to allow parents
to split\textsuperscript{21} vaccines. These two physicians were also the most likely to initiate vaccine conversations with every parent at every visit, regardless of previous vaccine refusals. One of the physicians thought that while all of the other physicians in her practice were “very pro HPV vaccine” she was not “sure that everyone is as forceful about it” as she is. The other physician admitted that she was the most enthusiastic supporter of all vaccines, especially Gardasil, in her practice. Of the difference in her own and colleagues stance towards Gardasil she said, “I’m the only woman in the practice, so I think I’m a little bit more for it than the men are. They’re a little bit more cautious because it’s a new vaccine.”

**Parent Population**

In total, 26 parents completed interviews. Parent characteristics are presented in Table 1 below. The majority of parents (n=22, 85%) who participated were mothers. Slightly more than half of parents (n=15, 58%) resided in central Pennsylvania, while the remainder (n=11, 42%) lived in the Tampa Bay area.

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parent Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 36</td>
<td>1</td>
<td>8%</td>
</tr>
<tr>
<td>36-40</td>
<td>6</td>
<td>23%</td>
</tr>
<tr>
<td>41-45</td>
<td>5</td>
<td>19%</td>
</tr>
<tr>
<td>46-50</td>
<td>10</td>
<td>38%</td>
</tr>
<tr>
<td>Over 50</td>
<td>4</td>
<td>15%</td>
</tr>
<tr>
<td><strong>Parent Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>22</td>
<td>85%</td>
</tr>
<tr>
<td>Male</td>
<td>4</td>
<td>15%</td>
</tr>
</tbody>
</table>

\textsuperscript{21} In common usage, vaccine splitting can refer to two different practices: choosing to administer each component of combination vaccines separately (e.g., vaccinating a child against measles on one visit, and mumps on another) or to having children vaccinated, but at times that diverge from those recommended on the CDC Recommended Vaccine Schedule (Sears 2009).
<table>
<thead>
<tr>
<th><strong>Residence</strong></th>
<th>Florida</th>
<th>11</th>
<th>42%</th>
<th>Pennsylvania</th>
<th>15</th>
<th>58%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Employment</strong></td>
<td>Full-time</td>
<td>16</td>
<td>62%</td>
<td>Part-time</td>
<td>6</td>
<td>23%</td>
</tr>
<tr>
<td></td>
<td>Household</td>
<td>4</td>
<td>15%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td>Under $50,000</td>
<td>4</td>
<td>15%</td>
<td>$50,000-$99,999</td>
<td>8</td>
<td>31%</td>
</tr>
<tr>
<td></td>
<td>$100,000-$149,999</td>
<td>10</td>
<td>38%</td>
<td>$150,000+</td>
<td>3</td>
<td>12%</td>
</tr>
<tr>
<td></td>
<td>Prefer not to answer</td>
<td>1</td>
<td>4%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td>White/Caucasian</td>
<td>21</td>
<td>81%</td>
<td>Black/African</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td></td>
<td>American</td>
<td>1</td>
<td>4%</td>
<td>Hispanic/Latino</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td></td>
<td>Mixed</td>
<td>2</td>
<td>8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Religion</strong></td>
<td>Christian</td>
<td>20</td>
<td>76%</td>
<td>Jewish</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td></td>
<td>Spiritual</td>
<td>2</td>
<td>8%</td>
<td>None</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td><strong># of Children</strong></td>
<td>1</td>
<td>7</td>
<td>27%</td>
<td>2</td>
<td>8</td>
<td>31%</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>7</td>
<td>27%</td>
<td>4</td>
<td>3</td>
<td>12%</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>1</td>
<td>8%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong># of Daughters</strong></td>
<td>1</td>
<td>17</td>
<td>65%</td>
<td>2</td>
<td>4</td>
<td>15%</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>5</td>
<td>20%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong># of Sons</strong></td>
<td>0</td>
<td>10</td>
<td>38%</td>
<td>1</td>
<td>13</td>
<td>50%</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>2</td>
<td>8%</td>
<td>3</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>1</td>
<td>4%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Daughters’ Ages</strong></td>
<td>&lt;9</td>
<td>2</td>
<td>8%</td>
<td>9</td>
<td>4</td>
<td>15%</td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>1</td>
<td>5%</td>
<td>11</td>
<td>6</td>
<td>23%</td>
</tr>
<tr>
<td></td>
<td>12</td>
<td>3</td>
<td>12%</td>
<td>13</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td></td>
<td>14</td>
<td>7</td>
<td>27%</td>
<td>15</td>
<td>7</td>
<td>27%</td>
</tr>
<tr>
<td></td>
<td>16</td>
<td>6</td>
<td>23%</td>
<td>≥17</td>
<td>3</td>
<td>12%</td>
</tr>
<tr>
<td><strong>HPV Vaccine Decision (for all daughters ages 9-17)</strong></td>
<td>All girls vaccinated</td>
<td>14</td>
<td>54%</td>
<td>None vaccinated</td>
<td>2</td>
<td>8%</td>
</tr>
<tr>
<td></td>
<td>Deferring</td>
<td>7</td>
<td>27%</td>
<td>decision/Undecided</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Decision varied by daughter</td>
<td>3</td>
<td>12%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The sampling strategy used to obtain interviews differed by state. In both states, initial participants were recruited passively using study research fliers. The goal was then to use a snowball sampling strategy to recruit eligible friends, family, and colleagues of participants. As discussed in the previous chapter, I chose to include Pennsylvania as a study site after experiencing low parent response in the Tampa area. With one exception, all of the parents that I interviewed in Florida were passively recruited. On the other hand, the majority of parents with whom I spoke in Pennsylvania were recruited using a snowball method.

The different strategies are important to note. As an effect of the heavy reliance on snowball sampling used to recruit parents in Pennsylvania, there is more homogeneity in parents’ socioeconomic and occupational attributes. The demographic profiles of Florida parents are more diverse because parents were not recruited by friends or colleagues. I also bring up differences in sampling strategy to highlight the importance of social cohesiveness and participant-researcher rapport when conducting research. In Florida, the parents with whom I spoke were strangers, willing to take a few hours out of their lives to speak with me. These parents were likely less likely to feel comfortable encouraging their friends to do the same, especially for a stranger. In Pennsylvania, on the other hand, parents were more willing to contact their friends to participate in the study because even if they did not know me personally, they knew of me (e.g., that I was born and raised in the area, that I had attended a local high school, etc.).

The majority of parents (n=21, 81%) self-reported as White. Three parents (12%) identified themselves as mixed race/ethnicity, one parent (4%) as African American/Black, and one parent (4%) as Latino. Sixty-two percent (n=16) of parents
worked full time, 23 percent (n=6) had part time positions, and 15 percent (n=4) took care of the household. Fifteen percent of parents (n=4, 15%) reported a household income of fewer than $50,000 per year, a third (n=8, 31%) between $50,000 and $100,000 annually, and half (n=13, 50%) reported household incomes of $100,000 or more. Three quarters of parents (n=20, 76%) identified themselves as Christian, one as Jewish, two as spiritual, and one as having no religious or spiritual affiliation. Most parents had between one and three children (n=22, 85%). All parents had at least one daughter between the ages of 9 and 16. Approximately one third of parents had only one daughter (n=17, 65%); the remaining parents had either two or three daughters. More than half of the parents interviewed also had at least one son (n=16, 62%). Most parents (n=22) had private health insurance plans that covered their daughters. The children of two parents were Medicaid-insured, and two parents did not have any type of health insurance coverage.

Few Americans completely abstain from vaccinating their children. It is much more common that parents resist specific vaccines, especially those which are not required for school attendance. The vaccine practices reported by parents in this study mirror those seen in the wider population, providing us with an opportunity to understand how ‘typical’ parents view vaccines. All of the parents I interviewed were generally supportive of vaccination. With the exception of one mother, who refused to have her children vaccinated against chicken pox, all parents reported that their children had received vaccines required for school entry. Two parents home schooled their children. One was home schooling because she did not want to have her children vaccinated against chicken pox. The other mother’s children had received all school-required
vaccines, but were home-schooled for other reasons. One couple waited until their eldest daughter was five to give her all school-mandated vaccines, but followed the normal vaccine schedule with their subsequent three children. As discussed in the analysis, vaccine practices for chicken pox, flu, hepatitis A, and HPV were more variable.

**Participant Quotes**

Brackets used within participant quotes indicate that originally quoted material was altered. When phrases or words are contained within brackets, I have altered the actual quote either to protect the identity of an individual (for example changing an actual name in a quote to [my daughter]) or to improve the flow of narrative. No substitutions were made that, in my estimation, altered the meaning of the quote. Italics are used to indicate that a participant stressed a certain syllable, word, or phrase when speaking. Parentheses are used to note when participants whispered, laughed, gesticulated, or used other non-verbal cues to express an idea.

Bernard (2006:505) argues that while “there is a case to be made for recording people’s statements verbatim,” there is often no such case to justify reporting those statements verbatim. While I transcribed participant’s narratives verbatim, the quotes used throughout the dissertation have been lightly edited to flow more seamlessly. Bernard argues that editing out the run-ons, false starts, pauses, fillers, (e.g., “um”, “uh”, “you know”, “like”) is not only acceptable practice, but advisable, when one is not doing a linguistic, conversation, or narrative analysis. In Bernard’s estimation, “unexpurgated speech is terrible to read [. . .] If you don’t edit that stuff, you’ll bore your readers to death” (505). I agree. I removed unnecessary fillers, pauses, false starts, and run-ons in an effort to create a more fluid text that highlights the importance of participant’s actual
ideas, rather than their stutters or filler syllables. No speech was edited or removed from quoted material that I deemed to alter or significantly contribute to the conveyed meaning.
Chapter Six – Context

In organizing the analysis of the data collected for this dissertation, I move from distal to proximate factors related to Gardasil vaccine decisions. Distal factors include an analysis of institutions, bodies, and legislation. Distal factors also include what Giddens (Cassell 1993) refers to as experts systems of knowledge, abstract entities such as biomedicine and science that are removed from and beyond identifiable individuals.

I have chosen to begin the analysis chapters with a discussion of structural factors associated with vaccination. Aside from being an important consideration, as outlined in the Local Vaccines Culture approach, there are strong epistemological reasons for beginning with this discussion because these factors constrain, limit, and shape other factors, such as the ways in which parents approach the vaccine or how providers choose to discuss it. Different evaluations of vaccines and the diverging pathways that lead to these assessments can be attributed to differences in the ontological status of processes, factors, etc.; for instance, the differences in the creation of vaccine-related legislation with the formation of a parent’s thoughts about vaccine risk. In many cases, these things can be said to operate at different temporal scales, and take place within different entities and between different actors (FDA board meeting vs. provider/parent interface vs. spousal discussion) resulting in and reproducing social processes that pertain to different ontological realms. Certainly it is true that parents’ ideas about sexuality, for example, exist concurrently with legislation and pedagogical strategies for training health
professionals, but ultimately the difference in scale—the social manifestation and emergence of each of these processes—will respond to different units of a larger social system. A careful study of the steps involved in parents’ decisions concerning the vaccine needs to attend to the fact that the behavior under study is situated within a larger system, and that this system is comprised of different levels (pertaining to temporal and spatial scales), actors and interfaces.

I begin the structural analysis with a historical review of salient developments in vaccine development, legislation and vaccine adoption and resistance. I then present the processes leading up to and defining the availability of Gardasil to the public in 2006. In the following chapter I shift the analytical lens from examining legislative factors towards an examination of pedagogical models of health care delivery and factors relevant to the provision of vaccines. Using nurse practitioner narratives that differentiate their own nursing model of care from the medical model of care, I hope to avoid an atomistic discussion of vaccine delivery. Instead, I present these differences in care models in an attempt to immerse provider interactions within a larger conceptual system and in a larger system of practice.

Moving towards a discussion of proximate factors, I then discuss sources of HPV knowledge, trust relationships, perception of risks and benefits related to Gardasil, HPV and daughters’ sexuality. To frame an analysis according to distal and proximate ends entails a center. I have chosen to define this center through interconnectivity, humanness, sociality, and tangible relationships; that is, as a psychological and socio-culturally bounded individual, in this case, the parent. I try to illustrate, throughout this analysis, how interconnectedness threads its way along the distal-proximate continuum. In human
form, such interconnections between distal and proximate entities reveal themselves through the parent/provider interface, and through parents’ narratives about their daughters. Healthcare providers encapsulate “contradictory” manifestations; they have faces, they have kids of their own, they interface with parents and children. They care for their individual patients (thus are not quite public health officials), and they are also intimately associated with expert knowledge systems (science, biomedicine), institutional entities (government regulatory bodies, public health system), and industries (e.g., insurance, pharmaceutical) which parents may not necessarily trust. In essence, the interactions with providers act as the distal-proximate interface, in which abstract entities, and processes of temporal scope that far supersede those usually associated with an individual, emerge and gain saliency in people’s lives.

Provider narratives, perception, and behaviors flow throughout the different sections of this analysis. The provider embodies a Janus-faced dual-dimensionality, capable of providing two different, but related perspectives on vaccination. Providers can be seen as key experts, who can speak to typical parental vaccine perspectives as opposed to the singular, though contextualized perspective of parents themselves. In this way, providers present aggregate information on parental concerns, parental decisions, and typical interactions. At the same time, providers through their interfaces and interactions with public health, pharmaceutical, insurance, biomedical, and scientific communities, offer an alternative lens through which parent vaccine decisions can be framed.

In the final sections of the analysis, I specifically examine the patient-provider interaction as a situated event, from both parent and provider perspectives. I highlight some of the challenges, tensions, and opportunities that arise through interactions and that
emerge from different perspectives on the constitution of knowledge, conceptualizations of risk, and trust relationships.

**The Legal, Economic, and Political Vaccine Landscape**

HPV vaccine decisions cannot be understood without first examining the historical, political, and cultural vaccine landscape. Many of the tensions surrounding the HPV vaccine apply broadly to all vaccines, and stem, at least partially, from historical events and developments. Moreover, many parental concerns regarding vaccine use cannot be understood outside of vaccine policies and laws that limit the ways in which parents can conceive of vaccines themselves. The information presented in this section provides necessary contextualization in understanding the findings that emerge of this research project.

While parents have some decision-making power when it comes to vaccinating their children against diseases, other stakeholders shape the landscape in which parental vaccine decisions are made. In order to understand why specific themes gain saliency in contemporary HPV vaccine discussions, one must first situate vaccines, and vaccine campaigns, within their historical and sociocultural context. At both the federal and state level, the U.S. government plays a pivotal role not only in approving and monitoring the safety of vaccines, but in assuring that new vaccines are developed, current vaccines are manufactured, and available vaccines are administered to the public. Political decisions regarding compulsory vaccination laws, vaccine funding, and school exemptions are shaped by epidemiological factors and public opinion regarding vaccine safety and the rights of individuals and the state to guarantee individual and collective well-being.
Vaccine financing, federal regulations and oversight, and litigation influence which companies will engage in vaccine manufacturing, which diseases will be targeted for vaccine development, and how much vaccines will cost. Insurance reimbursement influences whether private physicians carry vaccines. The ease with which vaccine waivers (for school entry) can be sought and whether vaccines are covered by insurance will factor into parental economic decisions. All of these factors will affect, either directly or indirectly, parental choices.

In this chapter, I provide an historical overview of vaccination in the United States, focusing on the roles that public opinion, vaccine safety, economics, and legislation have played in shaping the current vaccine landscape. I then describe the processes by which vaccines are approved and recommended for general use. Finally, I discuss the legal, economic, and social issues surrounding the approval and recommendation of the Gardasil vaccine in 2006.

**Historical Overview**

Government involvement in the dissemination and regulation of vaccines can be traced to the turn of the nineteenth century with initial federal efforts to improve smallpox vaccine accessibility. In 1801, President Thomas Jefferson and several hundred of his friends and their families became some of the first individuals in the U.S. to be vaccinated against smallpox (Hodge and Gostin 2002). A year later, Jefferson attempted to transport vaccines to the southern states, while also increasing their overall availability. Despite his efforts, vaccination largely remained a technology of the elite. Among the working class and poor, safety concerns and accessibility issues generally led to low uptake (Hodge and Gostin, 2002). Thus, while the vaccine could protect individuals from
contracting smallpox, it did little to curb the larger epidemic, especially among the working class. In 1813, the U.S. Congress passed a bill to encourage vaccination, which gave President James Madison authority to appoint an agency to oversee the safe distribution of the vaccine throughout the country. Though well intended, the bill had little effect given the fragmented and uncoordinated healthcare system and lack of transportation (Hodge and Gostin, 2002).

While the federal government attempted to promote voluntary vaccination, compulsory immunization efforts were underway in individual states. Unlike many countries, where compulsory vaccination is enforced and regulated at the federal level, in the U.S. individual states control vaccination policies (Tobey 1926). In the United States, regional outbreaks of disease became the catalyst for introducing state vaccine legislation. In 1809, Massachusetts became the first state to legislate vaccination requirements and other states followed suit (Tobey 1926), but as an increasing number of states adopted mandatory immunization policies, resistance to vaccination also mounted.

Colgrove (2010) argues that mounting vaccine resistance can be in part understood as a response to broader public health initiatives developed in the latter half of the nineteenth century. During the period, a flurry of legislative activity resulted in the passage of an increasing number of laws directed at protecting public health through the regulation of industrial practices, quarantine, isolation, vaccination, and sanitation. The new regulations forced both individuals and commercial entities to modify their behaviors and people did not respond well to what they perceived as government’s increasingly regulatory role. The public was especially resistant to vaccine regulations
because while most public health laws prohibit an individual from engaging in a specific activity, vaccination requires an individual to submit to a bodily invasive procedure.

While resistance to larger public health regulation and government control did little to help the case of compulsory vaccination, Colgrove (2010) suggests that vaccination laws ultimately became victims of their own success. As rates of smallpox declined generationally, people no longer witnessed the devastating effects of the disease. In the face of expanding regulatory public health measures, people saw vaccination less as a necessity and more as another example of governmental control. Vaccine laws were challenged and while the courts often upheld the constitutionality of compulsory vaccination campaigns, especially for school entry, the court of public opinion was a different matter. Sensitive to the sentiments of constituents leery of public health regulation, and in response to anti-vaccination activists, many legislators were persuaded to repeal compulsory vaccine laws. During this period, vaccine opponents were instrumental in repealing compulsory vaccination laws in eight states (Wolfe and Sharp 2002).

Questions regarding the constitutionality of compulsory vaccination were put to rest in the 1905 Supreme Court Ruling of *Jacobson v. Commonwealth of Massachusetts*, 197 U.S. 11 (Court 1905). The impetus for the case began in 1902 when the city of Cambridge, Massachusetts passed a statute mandating that all city residents who had not been infected with “natural” smallpox be vaccinated, or re-vaccinated (if vaccinated before March 1897) to protect against an outbreak (Court 1905). The city argued that vaccination was a matter of public health and safety, and moreover, that because the vaccine was offered free of charge and required of everyone, it was not putting undue
burden on any individual (Court 1905). Henning Jacobson, a resident of the town, refused to be vaccinated and was consequently prosecuted. In a seven to two ruling, the Court sided with the state. Justice Henson wrote in the decision:

The liberty secured by the Constitution of the United States does not import an absolute right in each person to be at all times, and in all circumstances wholly freed from restraint, nor is it an element in such liberty that one person, or a minority of persons residing in any community and enjoying the benefits of its local government, should have power to dominate the majority when supported in their action by the authority of the State (1905:1).

By 1905, eleven states had adopted compulsory vaccination policies and thirteen states had specific laws for excluding unvaccinated children from attending public schools\(^\text{22}\) (Hodge and Gostin 2002). Despite court rulings in support of compulsory smallpox vaccination, compulsory vaccine laws were rarely enforced. In the early twentieth century, three new vaccines became available, but states were in no rush to mandate their use. Legislators were weary of the political fallouts and the public was weary of governmental interference and vaccine safety. The problems associated with early vaccines helped to explain, at least partially, why many people were distrustful of government public health initiatives and compulsory vaccination programs (Sturm, et al. 2005; Wolfe and Sharp 2002). Unsanitary vaccination techniques leading to disease outbreaks throughout Europe were not lost on the American public. In England, for

\(^{22}\) Compulsory vaccination policies existed in Connecticut, Georgia, Kentucky, Maryland, Massachusetts, Mississippi, North Carolina, Pennsylvania, South Carolina, West Virginia, and Wyoming. School-exclusion policies existed in California, Georgia, Iowa, Maine, Massachusetts, New Hampshire, New Jersey, New York, Oregon, Pennsylvania, Rhode Island, South Dakota, and Virginia.
example, most working class individuals had to obtain the smallpox vaccine at public vaccination stations where one syringe was used to inoculate many children. By using the same needle to vaccinate multiple people, other disease, especially erysipelas, syphilis, and hepatitis B were spread (Fenner, et al. 1986). Similar cases led to a jaundice epidemic among factory workers in Germany and a syphilis outbreak among children in Italy (Fenner, et al. 1986).

In the United States, tragedies in Kentucky and New Jersey heightened public fears regarding the safety of vaccines. By the turn of the century a diphtheria vaccine manufactured by many private and public companies was being widely administered to U.S. children (Offit 2005). The vaccine was manufactured by injecting the diphtheria toxin into horses and then extracting the serum to inject into children. In 1901, during the St. Louis diphtheria outbreak, a five year old girl who had received the vaccine died of tetanus. Thirteen more children died of tetanus soon after receiving the diphtheria vaccine. All of the vaccines involved in the deaths were traced to one batch of serum produced by the St. Louis city health department. A subsequent investigation revealed that one of the horses used to obtain the serum was infected with tetanus (Offit 2005). In Camden, New Jersey a similar disaster occurred – nine children died of tetanus following vaccination for smallpox (Offit 2005).

As a result of the St. Louis deaths and in an effort to address public concerns about the safety of drug manufacturing, Congress enacted the Biological Control Act on July 2, 1902 (Colgrove 2005; Offit 2005). The bill gave the U.S. Public Health Service the authority to regulate “any virus, therapeutic serum, toxin, antitoxin, or analogous product applicable to the prevention and cure of disease of man” (Offit 2005:59).
Government regulation of vaccine safety led to a general unwillingness to acknowledge vaccine-related injuries (Colgrove 2005; Offit 2005). The government, especially the U.S. Public Health Service, had a vested interest in reducing the number of vaccine-related injuries since any increase in injuries would reflect poorly on the agency. Practitioners were also less likely to attribute diseases to vaccination, perhaps reflecting their own confidence in the new regulatory requirements. Often when disease did develop following vaccination, officials blamed the infection on poor hygiene. As such, blame was shifted from vaccine manufacturers, physicians, or regulatory agencies, onto the individuals who were vaccinated (Colgrove 2005). In deflecting blame from themselves to individuals in an attempt to preserve public trust in vaccine safety, government agencies and healthcare providers paradoxically caused many individuals to distrust not only vaccines, but those that regulate and administer them. Thus, governmental oversight of vaccine production gave some Americans a sense of security, while heightening others’ fear and distrust not only of vaccines, but of government as well.

Over the next few decades, vaccine-related fear would intensify for several reasons, including epidemiological disease shifts, pharmaceutical company expansion, the growth of preventive healthcare, and government reform. One shift in vaccine perception resulted from shifts in the epidemiology of smallpox disease. In 1907, the milder form of smallpox, variola minor, appeared in the U.S. Variola minor shared many of the same symptoms with variola major, but the disease left fewer scars and was associated with a much lower case fatality rate (Colgrove 2005). Within twenty years it had surpassed the more virulent strain as the most common form of smallpox in the
country. As more people developed the less virulent form of smallpox, the public perceived fewer risks associated with developing smallpox and public resistance to the vaccine increased (Colgrove 2005). Similarly, as the fatalities associated with smallpox declined, the public became more critical of fatalities and adverse effects associated with the vaccine.

Pharmaceutical companies were also expanding during the early part of the twentieth century, forming partnerships with universities, the medical community, and pharmacies, employing large staffs of scientists to research and develop products (Colgrove 2005). By 1910 the term *vaccine*, which originally referred exclusively to smallpox inoculation, was applied to a broader host of diseases (Colgrove 2005). Companies developed vaccines against diseases such as cholera, typhoid, and plague. New developments were met both with excitement and anxiety. Media sources devoted widespread coverage to vaccine development and there was a general sense of hope that vaccines would contribute to an improvement in overall health (Colgrove 2005). Yet vaccine developments also elicited concern. Anti-vaccination groups worried that the development of new vaccines would lead to an increasing number of compulsory vaccinations – something that many anti-vaccinationists vehemently opposed, not only because of perceived infringement on individual rights, but because of the unknown side effects associated with vaccines (Colgrove 2005).

Broader social changes during this period, particularly related to health, also influenced vaccine policy and public opinion. Many individuals perceived the increasing number of social workers, visiting nurses, and educators employed within the private and public sectors as a threat to family privacy (Colgrove 2005). After 1910, new workers’
compensation programs led many employers to require employee physical examinations. At the same time, life insurance companies started requiring physical examinations of policyholders (Colgrove 2005). These changes represented a new focus on preventive care, which previously had not been a significant component of healthcare. In an effort to deliver preventive care, healthy individuals needed to see physicians; earlier perceived as experts of sickness, physicians were now also experts in health. The increasing role of physicians, nurses, and social workers in everyday life made many Americans uncomfortable. When health reforms permeated the school system, parents feared that the government and physicians were usurping parents’ rights (Colgrove 2005).

The establishment of the federal Children’s Bureau exacerbated concerns in 1912. In an effort to control tuberculosis, the Bureau “distributed millions of health education pamphlets aimed at teaching scientifically based methods of child rearing to mothers around the country,” (Colgrove 2005:172). Many people interpreted the educational materials as the government’s attempt to control how mothers parented their children. Protests over state control culminated with the 1920 Sheppard-Towner Act, which emerged as a “lightning rod for criticism” (Colgrove 2005:173). To opponents of burgeoning state medicine programs, the Sheppard-Towner Act was a definite act of state control, representing “the creeping expansion of a distant, centralized government, a trend that was especially threatening amid the postwar backlash against socialism” (Colgrove 2005:173).

23 The reforms also affected public school inspections, which originally related only to infectious disease control. In the early 1900s, however, the inspections were expanded to include screenings for chronic or hidden conditions. The expanding role that physicians played, especially in child health, sparked concerns over parental rights. Opponents of such measures argued that physicians and schools were slowly and covertly “removing children from the control of their parents” (Colgrove, 2005, p. 172).
In 1921, a member of Congress described the fears felt by many Americans:

“Government supervision of mothers; Government care and maintenance of infants; Government control of education; Government control of training for vocations; Government regulation of employment, the hours, the holiday, wages, accident insurance and all.” (Colgrove 2005:173). To this litany of fears, the anti-vaccinationists added vaccination as a form of government control. The process of medicalization and the emphasis on preventive care continued through the 1920s led to changes in anti-vaccination arguments, which now asserted that vaccination, as well as larger healthcare reform, were part of a “well-laid plan to medically enslave the nation” (Colgrove, 2005:172).

The emergence of polio tempered public reactions to health based social reforms. In the summer of 1916, the first major U.S. polio outbreak struck New York City (Offit 2005). At that time, it was the largest polio epidemic ever recorded, paralyzing 9,000 and killing 2,400 (Offit 2005). While polio undoubtedly caused widespread pain and suffering, it paled in comparison to the toll of the 1918 influenza epidemic, which killed 675,000 Americans. To put it in perspective, more Americans were killed in this one epidemic than in World War I, World War II, and the Vietnam War combined (Offit 2005). While polio caused fewer deaths than other U.S. epidemics, its effects on the American psyche were far more profound. Those who contracted paralytic polio and survived rarely recovered fully; it did not help that most of polio’s victims were young children. As Offit (2005:9) explains, “The sight of small children trying to use withered arms or struggling to walk with crutches or lying helplessly in breathing machines (called iron lungs) was a constant, crushing reminder of the infection.”
The devastating effects of polio prompted government and private support for polio vaccine research. By 1935 two researchers, Maurice Brodie and John Kolmer, had independently developed two different polio vaccines. Both of the vaccines were produced using pulverized spinal cord fluid from monkeys that had been infected with polio, but the processes varied slightly. With the hope of protecting their children from polio, parents enrolled their children to participate in vaccine trials (Offit 2005). Kolmer’s vaccine was administered to ten thousand children in 36 states and Canada. The study had no control group which made it difficult to estimate the vaccine’s efficacy, but the vaccine caused paralysis in ten children and the deaths of five others. When pressed about the association between his vaccine and the deaths, Kolmer denied any association, which led to public anger and likely increased public fear and distrust of vaccination (Offit 2005). Brodie conducted his own study in North Carolina, Virginia, and California, but with a control group. The vaccine was shown to be 88% effective: 5 of the 4,500 children without the vaccine developed polio compared to 1 in 7,000 vaccinated children. However, there were still risks associated with vaccination. One vaccinated child died four days after receiving the inoculation and two infants developed polio within two weeks of their first vaccination. The price for the public was too high and both Kolmer and Brodie were vilified. Both had trouble finding work for the remainder of their careers and their fate led to a significant decline in polio vaccine research, both in terms of researchers and funding interests.

Eventually, however, funds and public interest for a polio vaccine reappeared. As polio exacted higher annual tolls, the public became increasingly desperate for an answer. In 1943, there were 10,000 U.S. cases of polio. In 1948 the annual total jumped to
27,000. By 1952 fear of polio, more than polio itself paralyzed the nation. One U.S.
national poll reported that Americans feared polio second only to the atomic bomb (Offit
2005). During the preceding years, physician Jonas Salk had been working to perfect a
polio vaccine. In the spring of 1953, Salk vaccinated himself, his wife, and his three
children with an inactive form of the polio virus suspended in a mineral oil adjuvant.
While Salk clearly had confidence in the vaccine, the National Foundation for Infant
Paralysis (NFIP) (Dimes 2011)\textsuperscript{24} was concerned with the mineral oil adjuvant. Joseph
Bell, an epidemiologist at the National Institutes of Health, was hired by the NFIP to
design the test of Salk’s vaccine. Bell resisted the adjuvant, arguing that mineral water
occasionally caused pain at the injection sight and “running abscesses” (Offit 2005:39).
The restriction against mineral water was more than minor – the adjuvant was extremely
important in stimulating a prolonged immune response\textsuperscript{25}. Finding a suitable replacement
was not a simple proposition. By the time that Salk was told he would need to find
another adjuvant the prospect of a vaccine had already been leaked to the press and Salk
found himself under tremendous pressure to produce a vaccine for large scale trials\textsuperscript{26}.

As Salk struggled to find a new vaccine, Parke-Davis, the pharmaceutical
company originally set to manufacture the vaccine, pulled out. Salk’s lack of
comprehensive production protocol made Parke-Davis nervous. Without a manufacturer,

\textsuperscript{24}The National Foundation for Infant Paralysis was founded by President Franklin D. Roosevelt in 1938
with the goal of eradicating polio in the United States. The name was later changed to the March of Dimes
Foundation (Dimes 2011).
\textsuperscript{25}Offit (2005) discusses the vaccine development process in great detail. The intense public pressure,
coupled with Salk’s inability to use his mineral oil adjuvant (which appeared to work very well but caused
side effects) and his choice in polio virus strain (an extremely virulent form) all contributed to the Cutter
laboratory crisis that followed.
\textsuperscript{26}The description of the field trial and results are all paraphrased from Offit (2005). Direct quotes are cited
specifically throughout the text.
the NFIP turned to other companies with an enticing proposition: The NFIP would buy 27 million doses of the vaccine at a cost of 9 million dollars after the vaccine was publicly available. The pharmaceutical companies would have to pay for all costs of trial vaccination. Even if the vaccine did not work and could not be sold, the NFIP would still pay the company. As Offit (2005:45) explains, the NFIP had “taken the risk out of vaccine research and development”. Four companies agreed to produce the vaccine. Removing the economic risk of research and development led to widespread interest in the vaccine industry. In later years, a different type of risk would drive most of the pharmaceutical companies out of the vaccine industry.

In 1954 Salk got permission to test his vaccine on U.S. children. It is worth describing the magnitude of the field trial as well as the public response because it might be the only time in recent U.S. history that a vaccination trial or vaccine has held so much hope or captured so much interest from the American public. Beginning in April of 1954, and supported by the NFIP for Infant Paralysis, the community field trial remains to this day, “the largest, most comprehensive test of a medical product ever performed: twenty thousand physicians and health officers, forty thousand registered nurses, fourteen thousand school principals, fifty thousand teachers, and two hundred thousand citizens in forty-four states volunteered to participate” (Offit 2005:52). The trial also included an astounding 1.8 million children who received one of three treatments.

Thomas Francis was charged with the monumental responsibility of analyzing the trial data, which included an enormous amount of data (1.8 million children’s worth!). The task is even more awe-inspiring when one recalls that Francis had no high-tech computers and statistical software to aid in the analysis. Francis not only had to analyze
an enormous data set – he had to do it as the country held a collective breath. The public desire for a vaccine was overwhelming. A May 31, 1954 Gallup poll exemplified the public interest: More Americans knew about the polio vaccine trials than knew the President’s full name (Dwight David Eisenhower), likely because more Americans had “participated in the funding, development, and testing of the polio vaccine than had participated in the nomination and election of the president” (Offit 2005:54).

On April 8, 1955, Francis completed his report and on April 12th he presented the results to the public. Normally, the results of scientific trials would be announced at scientific conferences among peers, but the polio announcement was different. Francis walked into a conference room filled with 150 press, radio, and television reporters and 16 television and news reels. Fifty-four thousand physicians packed cinemas and movie houses around the country to witness the announcement. Francis reported that by the end of the trial, 16 children had died of polio, none of whom had received the polio vaccine. Thirty-six children developed severe (iron lung) polio, but only two of these children had received the vaccine. Children without the vaccine were 3.3 times more likely to be paralyzed from polio than those who were vaccinated. The vaccine was safe and effective.

It is difficult for those of us who did not experience the polio epidemic to appreciate the effect that the announcement had on the American public. Offit (2005:55) describes the moment:

Inside the auditorium Francis finished to restrained applause. Outside the auditorium Americans tearfully and joyfully embraced the results. By the time Thomas Francis stepped down, church bells were ringing across the country,
factories were observing moments of silence, synagogues and churches were holding prayer meetings, and parents and teachers were weeping.

By the following year, Salk’s inactive polio vaccine (IPV) was mass distributed to children around the country. Until this period, childhood immunization was relatively inexpensive – children only received widespread vaccination against DTP and smallpox (Hinman, et al. 2006). In order to mass produce the vaccine and ensure that all children could access the vaccine, the government contributed federal funds. In 1955 and 1956, Congress appropriated federal funds to ensure that all children could receive the IPV (Hinman, et al. 2006). While the appropriations undoubtedly assured that many children received the vaccination, the IPV coverage was unequal and incomplete (Hinman, et al. 2006). To address these inequities, the Vaccination Assistance Act (Section 317 of the Public Health Service Act) was passed in 1962 (Orenstein, et al. 2005). The main purpose of Section 317 was to use federal money to provide state and local health departments with grants to support comprehensive immunization. The government negotiated prices for vaccines with manufacturers and was able to obtain the vaccines for significantly less than the private sector (Orenstein, et al. 2005). Few people suspected that government vaccine coverage and price negotiations would significantly affect vaccines shortages forty years later (a topic to which I will return shortly).

Shortly after the polio vaccine was released for general use, problems began to develop. On April 25, 1955, an infant with paralytic poliomyelitis was admitted to a California hospital, just nine days after receiving the vaccine (Offit 2005). Five more cases were reported to the California Health Department in the next few days. All five individuals became ill several days after receiving the vaccination and they all suffered
from localized vaccination site paralysis (Link 2005). The Public Health Service traced all six cases back to a set of vaccines distributed by Cutter Laboratories and asked Cutter to recall all of its vaccines that had already hit the market. Cutter complied, but too late. Two weeks after the first six cases were reported, another larger wave of polio cases emerged. This time, however, the cases could be traced through household contacts and social networks. An additional 454 children were infected and it was soon discovered that the polio vaccine, which was supposed to contain an inactivated virus, actually contained a live virus. Changes were made to the vaccine inactivation process and the vaccine was made safe (Offit 2005). While most of the public quickly forgot about the incident, anti-vaccination groups have not, and continue to refer to it as the man-made polio epidemic (Offit 2005).

The next major vaccine events did not unfold for two decades. The DTP vaccine was a combination vaccine that provided protection against three diseases: diphtheria, tetanus, and pertussis (Baker and Katz 2004). Today, the same three diseases are prevented using the DTaP vaccine. The difference in the two vaccines relates to pertussis. The DTP vaccine was made from the whole-cell pertussis bacteria (rather than a subunit), while the DTaP vaccine uses acellular pertussis. Unlike its whole-cell counterpart, DTaP only contains a few detoxified components of the cell that elicit immunity (NVIC 2011).

Beginning in the early 1970s, fears started to emerge about the DTP vaccine and its association to neurological impairments. The scare led to the emergence of vaccine litigation in the U.S. While there was a “lack of true epidemiologic, pathologic, or physiologic evidence linking specific vaccines to specific adverse outcomes” associated
with the DTP vaccine, the legal system nevertheless became the engine through which claims were assessed and damages awarded (Freed, et al. 1996). It is interesting to note that today, after thirty years of studying the effects of whole-cell pertussis, scientists still cannot agree on the validity of DTP allegations (Ball, et al. 2001; Geier and Geier 2002; Geier and Geier 2003; Pichichero, et al. 2002).

Regardless of the scientific validity of the claims, the economic costs (and for some, gains) of vaccine litigation were substantial. In 1978, the average amount sought per claim was $10 million. By 1984 the number jumped to $46 million and by the following year “the total amount sought through litigation was $3.162 billion, an amount more than 30 times greater than the market value of all DTP vaccine sold in the private sector that year” (Freed, et al. 1996:1870). This new market for vaccine litigation attracted lawyers. With the lawyers came countless advertisements that portrayed the dangers of vaccination.

Litigation caused more than economic consequences. The 1970s litigation cases against vaccine manufacturers led many manufacturers to leave the industry, thus causing vaccine shortages. Between 1974 and 1986 the number of DPT manufacturers dropped from seven to two; oral polio manufacturers went from three to one; and manufacturers of the measles vaccine declined from six to one (Link 2005). The media covered the DTP shortage, but focused on the vaccine’s alleged side effects rather than the possible public health consequences of reduced vaccination coverage (Freed, et al. 1996). Many Americans also viewed the shortage suspiciously. The arguments of one attorney illustrate how the DTP vaccine and the larger vaccine industry were portrayed at the time:

27 See Reyes v. Wyeth Laboratories (Link, 2005).
“alleged DTP shortage is a ploy by drug manufacturers to avoid paying damages for a product that the companies knew was less safe than they led the public to believe” (Freed, et al. 1996:1871).

Litigation not only caused some companies to leave the business, it caused those who remained in the business to proceed with caution. This precautionary principle was evident in 1976, when the government recommended a massive immunization program against a severe swine flu epidemic that epidemiologists predicted (Link 2005). The immunization recommendation became integral to the presidential election, receiving widespread attention and creating a public panic. The vaccine manufacturers were “under tremendous pressure to create a vaccine ‘yesterday’” (Link 2005:35). Insurance companies refused to provide liability coverage for the vaccine manufacturers and the manufacturers in turn refused to distribute any vaccine without insurance liability coverage.

In 1986, in an effort to relieve the economic risks placed on manufacturers, Congress approved the National Childhood Vaccine Injury Act (NCVIA), which established the National Vaccine Program, as well as the National Vaccine Injury Compensation Program (VICP) (Malone and Hinman 2003). The main purpose of the VICP was to provide no-fault insurance funds as a compensation source for “actual vaccine-related injuries” (Freed, et al. 1996:1871). For each vaccine, the Program established a list of conditions eligible for compensation. Many of the conditions that were listed on the table of vaccine associated conditions had never been scientifically tested – inclusion was based on litigation settlements, public fear, and unsubstantiated claims of associations, not science. In the eyes of many researchers and vaccine
advocates, including conditions on the Table that were not scientifically substantiated reproduced and reinforced public distrust and fear of vaccines\(^{28}\) (Orenstein, et al. 2005). Further, “in a legal sense, the vaccine injury Table legitimized a condition not grounded in scientific data” (Freed, et al. 1996:1871).

While it minimized manufacturers’ risks, the VICP does not absolve manufacturers from all liability or potential risk. If an individual believes that a vaccine caused an injury, he must file a claim through the VICP. After going through the VICP process, a plaintiff may either accept the decision and possible compensation offered through the VICP, or reject the decision and take the case to the tort system. If a plaintiff accepts the VICP offer he is prohibited from suing the manufacturer or vaccine provider. In this regard, the VICP does offer some manufacturer protection, but only if the plaintiff settles with the VICP. Further, the VICP legislation does not prohibit individuals from seeking compensation for pain and suffering through the tort system, which can result in substantial economic settlements (Orenstein, et al. 2005)

The VICP offered federal liability to manufacturers, but liability came at a price. If the VICP was going to accept economic risks associated with vaccine production and dissemination, then it was also in the government’s best interest to ensure that manufacturers were subject to stringent vaccination manufacturing standards. The FDA is charged with enforcing these standards (Orenstein, et al. 2005). Facilities that manufacture vaccines must comply with current Good Manufacturing Practices (cGMP). The FDA is responsible for cGMP oversight and the cGMP standards require controls

\(^{28}\) For example, one clause associated with the DTP vaccine stated that the vaccine “may result in permanent impairment” (Freed et al., 1996).
involving the production plant, the equipment, and all procedures involved in vaccine manufacture (Orenstein, et al. 2005). The FDA also approves the labeling for vaccines and has the authority to recall vaccines if there are safety or efficacy concerns.

Stricter FDA requirements for facilities caused vaccine manufacturing to decrease (Jacobson, et al. 2006a). The cost of bringing facilities up to new codes was not economically beneficial to many companies, causing several to leave the pediatric vaccine business. As one example, Warner Lambert (now Pfizer) ceased production of the influenza vaccine, Fluogen, due to financial losses and regulatory constraints. Warner Lambert sold the factory to King Pharmaceuticals, who subsequently ceased production altogether when it determined that bringing the factory up to governmental codes would be too costly (Stern and Markel 2005).

FDA requirements also oversee pre-marketing regulations, which include extensive clinical trials to measure the safety and efficacy of drugs. These requirements have led, in part, to waning vaccine research and development (Riddiough and Willems 1980). While these regulations undoubtedly help in protecting the public’s health, they also contribute to pharmaceutical disinterest in vaccine development because complying with pre-marketing regulations can be incredibly time consuming and costly. In 2000, it was estimated to cost between $110 million to $802 million dollars to bring a new drug to licensure (Orenstein, et al. 2005). A review of five vaccines, conducted by the NVAC, found that it took between 2 and 21 years from Phase I trials to licensure (Orenstein, et al. 2005). Without measurable economic gains it is easy to understand why the

28The cGMP standards include measures of safety and quality for each stage of vaccine production: “protein content, viral infectivity, bacterial contamination, and endotoxin content” (Orenstein, et al. 2005:603).
pharmaceutical companies, which are profit driven, have largely fled the vaccine business.

The decrease in pharmaceutical interest in the vaccine industry is directly associated with federal regulatory policies, public fear and litigation, and recent vaccine shortages. Over the past few decades, many companies have abandoned the vaccine business to pursue research and development in the chronic disease field. Unlike the chronic disease industry, the vaccine industry is not economically lucrative. Many companies believe that the cost of complying with vaccine regulations outweighs the economic benefit of vaccine production (Stern and Markel 2005).

The exodus from vaccine research and development occurred gradually, not only as a result of the VICP, but also due to changes in vaccine financing and public fears of autism. In the early 1990s, a number of pharmaceutical companies were still involved in vaccine development, and the cost of vaccines was increasing dramatically. The increasing prices primarily resulted from new vaccination developments that required expensive technologies and procedures (Hinman, et al. 2006). Rising vaccination costs led many families who normally sought treatment with private providers to seek free immunizations from the health department (Hinman, et al. 2006). The subsequent fragmentation of health care provision allowed some children to slip through the cracks, contributing to a measles upsurge between 1989 and 1991 (Hinman, et al. 2006). After investigating the epidemic, the CDC found that more than half of the children who developed measles had not been immunized, despite that many of them had previously seen a health care provider (Hinman, et al. 2006).
In response to the epidemic and rising vaccine costs, Congress passed the Omnibus Budget Reconciliation Act (OBRA) in 1993, creating the Vaccines for Children (VFC) Program. Unlike Section 317, the VFC is an entitlement program that guarantees vaccines free of charge to children who are on Medicaid, uninsured, or who are American Indians or Alaska Natives (Orenstein, et al. 2005). Children who have health insurance that does not cover immunizations can also receive free vaccines through Federally Qualified Health Centers or Rural Health Clinics.

While the VFC ensured that more children would have access to recommended childhood vaccines, it also further discouraged companies from manufacturing vaccines. More companies might have been willing to update facilities and adhere to stricter FDA requirements (described above) if the pediatric vaccine industry was more lucrative. The decline in the pediatric vaccine business is at least in part due to the creation of the Vaccines for Children Program. The program led the federal government to buy over half of all pediatric vaccines that are administered in the country. Given their prominence in the market, the government has successfully negotiated the prices of these vaccines and is able to obtain them for significantly lower prices than can private sector distributors (Jacobson, et al. 2006b). For example, in 2005 it cost $792.27 for a child to receive all of her recommended vaccines (from birth through school entry) from the private sector. In the public sector, the same vaccines cost $517.12 (Hinman, et al. 2006). As a result of the negotiated prices, the profit margins for drug companies plummeted. Many pharmaceutical companies did not see economic benefit in pediatric vaccine distribution and the drug shortage cycle continued.
Recent public concerns about the safety of vaccines did little to encourage pharmaceutical companies to remain in the vaccine industry. Interestingly, many current vaccine fears are largely the result not of manufacturer errors, but of a series of decisions made by the FDA, CDC, and AAP. In 1997 the FDA, in compliance with the FDA Modernization Act, began to compile a comprehensive list of all drugs and foods that contained “intentionally introduced mercury,” with the goal of eliminating any that could potentially lead to harmful exposure levels (VHPB 2000:7). The results were presented at an FDA meeting in 1999. During the meeting, members “recognized that some infants could be exposed, as a result of vaccination . . . to cumulative mercury levels that exceeded one of the three existing federal guidelines on exposure to (methyl)mercury” (VHPB 2000:7). The FDA recommended that the hepatitis B vaccination schedule for infants be modified to delay vaccination until a thimerosal-free vaccine was available (VHPB 2000). More detailed and conservative guidelines were subsequently published by the AAP and CDC, increasing public fears about the dangers of thimerosal.

Until this point, thimerosal had been one of the most widely used vaccine preservatives since the 1930s without any known toxicity (Link 2005). The preservative was so popular and used in so many vaccines because of its excellent antibacterial properties (Link 2005). What was curious and controversial about the FDA recommendation, and subsequent recommendations by the AAP and CDC, was that thimerosal did not contain methylmercury, but ethylmercury. The FDA was trying to

30 Some researchers argue that thimerosal might have been safe when children received fewer vaccines, but became toxic as children received a greater diversity of vaccines, many of which contained thimerosal. There is no scientific evidence to support the position, but it’s worth exploring.
reduce levels of a completely different type of mercury, methylmercury. The two types of mercury have differential effects on the body and different toxicity levels. Using methylmercury guidelines to ban a product containing ethylmercury was not scientifically supported (Link 2005).

In addition, there had been no reports of any harmful effects caused by exposure to mercury at the levels contained in the vaccine (VHPB 2000). Scientific studies do not support an association either. One review of 14 published studies on the association between thimerosal-containing vaccines (TCV) and neurodevelopmental disorders (NDD) concluded that no statistically significant association existed between the two. The reviewers argued that the four studies that found an association, all by the same authors, utilized overlapping datasets that were methodologically flawed and therefore impossible to validly interpret (Parker, et al. 2004). Another prospective cohort study of 14,541 English children found no association between TCVs and NDD (Heron, et al. 2004). Researchers in Denmark examined rates of autism diagnosed among children in the country from 1971 to 2000. The authors found no increase in autism rates during the years when thimerosal-containing vaccines were used (up to 1990). Moreover, the researchers found that autism rates increased from 1991 to 2000, after thimerosal had been removed from the DTP vaccine (Madsen, et al. 2003).

Was it appropriate for the FDA, CDC, and APA to revise vaccination guidelines to ensure that children did not receive thimerosal-containing vaccines? Some researchers argued that the change was appropriate even though there was no scientific evidence to support it, because it would allay public fears about the safety of vaccines. Supporters of this view argued that the general public would not distinguish between the different types
of mercury and their effects and that media would likely exacerbate fears by reporting that childhood vaccines contained mercury without qualifying the statement, thereby leading to mass concern among parents. Opponents of the decision argued that removing thimerosol from vaccines only served to confirm and fuel public fears that vaccines are unsafe. If there was not anything dangerous about the drug then why would the government remove it from the market? Regardless of whether the ban was appropriate, the event emphasizes the role that public fear has on vaccine regulations and recommendations. The outcry regarding the vaccine, and the changes required to respond to public concerns, also help to illustrate why pharmaceutical companies continued to reassess the economic viability of vaccine development. According to the Institute of Medicine, there are currently only four major vaccine manufacturers worldwide, and only two in the U.S. (Medicine 2001).

Vaccine Approvals, Recommendations, and Funding

FDA Process to Approve a Vaccine

In this section I present a brief overview of the processes through which vaccines are approved, recommended and funded. Noting this is important because many of the public’s concerns surrounding vaccines revolve around these three processes. The FDA’s Center for Biologics Evaluation and Research (CBER) regulates vaccine research, approval, and monitoring in the U.S. An Investigational New Drug (IND) application must be submitted to CBER when a sponsor wants to conduct clinical trials on a vaccine. The IND application includes specific information about the vaccine, how it is manufactured, tests for quality control, vaccine safety, proof of immunogenicity in animal testing, and the proposed clinical study protocol for testing in humans (FDA
If approved, the sponsor can begin to conduct pre-licensure vaccine clinical trials, which typically are carried out in three phases. In Phase 1 trials, a small number of closely monitored subjects are recruited to test the safety and immunogenicity of the vaccine. Phase 2 studies commence to determine the dose-ranging for the vaccine; these studies can include hundreds of subjects. In the final pre-licensure phase, thousands of subjects are typically enrolled to “provide critical documentation of effectiveness and important additional safety data required for licensing” (FDA 2011).

A Biologics License Application (BLA) can be submitted if the vaccine successfully advances through the three pre-licensure phases. The BLA includes efficacy and safety data from the pre-licensure studies that will enable the FDA reviewer team to assess the risks and benefits of the vaccine in order to approve or oppose it. During this stage of the review process, manufacturer facilities and the actual vaccine production process for the vaccine under review are inspected (FDA 2011).

After the FDA has reviewed the BLA, the sponsor and the FDA present findings to the Vaccines and Related Biological Products Advisory Committee (VRBPAC). This non-FDA expert committee comprised of scientists, physicians, biostatisticians, and a consumer representative, advises the FDA regarding the safety and efficacy of the vaccine for the proposed indications. Generally, the FDA follows the recommendation of the VRBPAC. For a vaccine to be approved, it must also have sufficient, detailed labeling so that health care providers can properly use the vaccine, assess the vaccine’s risk and benefits, and administer it to the public (FDA 2011).

After a vaccine is licensed, the FDA continues to oversee the production process to monitor safety. Periodic facility inspections and monitoring of the product and
production must continuously occur throughout the duration of vaccine licensure. The vaccine manufacturer must also provide the FDA with results from their own safety, potency, and purity tests for each vaccine lot, and must provide, if requested, samples from each vaccine lot for FDA testing (FDA 2011).

Despite the three phases of pre-licensure human trials, the potential adverse of a vaccine cannot be fully anticipated until after the vaccine had been administered to the general population. Thus, many vaccines undergo Phase 4 studies, which are formal studies on a vaccine that occur after it is on the market. Aside from these studies, the government relies upon the Vaccine Adverse Event Reporting System (VAERS) to identify potential vaccine safety issues post-licensure.

**The CDC Vaccine Schedule**

The Childhood and Adolescent Immunization Schedule is maintained by the CDC. Whether a vaccine is included on the Schedule, and the designation it receives, plays a critical role in determining which vaccines will be widely manufactured, which will be covered by federal insurance programs, and often, which will be covered by private plans and mandated for school entry. The vaccines that are included in the schedule, the dosing, and the timeliness of dosing are updated annually and the vaccines included on the Schedule are approved by the Advisory Committee on Immunization Practices (ACIP), the American Academy of Pediatrics, and the American Academy of Family Physicians (CDC 2011b).

The role of the ACIP is particularly important in determining which vaccines appear on the Schedule, and in what form, because the CDC almost always follows the ACIP’s recommendations. The ACIP is a committee including 15 experts from
immunization related fields; the experts are selected by the Secretary of the Department of Health and Human Services “to provide advice and guidance to the Secretary, the Assistant Secretary, the Assistant Secretary for Health, and the CDC on the most effective means to prevent vaccine-preventable diseases” (CDC 2011a).

Pharmaceutical companies, specific vaccine advocates, and health practitioners have a vested interest in ensuring that vaccines are recommended. The Immunization Schedule is so important because it is federally issued and used by states, insurance companies, schools, and parents to make important vaccination decisions. States do not mandate any vaccines that are not listed on the vaccine Schedule. In addition, insurance companies usually base coverage on the schedule and are less likely to cover vaccines that are not included on the schedule. Finally, Section 317 (federal grants extending vaccine coverage for children who don’t qualify for VFC programs) and VFC funds only cover vaccines that are included on the schedule (Hinman and NVIP 2005; Smith 2010).

Over the past decades the specific diseases covered on the schedule have changed, as have the vaccines’ compositions (e.g., whole cell versus acellular pertussis), the number of doses, and the age at which immunization occur. In 1983, DTP, oral poliovirus (OPV), and MMR were the only vaccines listed on the schedule (Tempte 2007). In 1991, the ACIP added *Haemophilus influenzae* type B vaccination (Philadelphia 2011). By 1994, the ACIP included universal Hepatitis B vaccination of infants on the Schedule, along with the DTaP version diphtheria, pertussis, tetanus shot. By 2002 the varicella, rotavirus, pneumococcal, hepatitis A, and inactive polio vaccines were added (Philadelphia 2011). The 2007 Schedule includes twelve vaccines that are recommended for infants and children up to eighteen years of age (CDC 2007). The vaccines prevent
fifteen viruses: hepatitis B, rotavirus, diphtheria, tetanus, pertussis, *Haemophilus influenza* type b, pneumococcal, measles, mumps, rubella, inactive poliovirus, varicella, hepatitis A, meningococcal, and human papillomavirus (CDC 2007). Ensuring that vaccines remain on the Schedule might actually have the largest impact on actual vaccination practices, given the Schedule’s structuring power.

**Gardasil Development and Approval**

The events leading to the initial approval of the Gardasil vaccine and its later dissemination are worth discussing in detail given the focus of this dissertation. As Williams and colleagues (2008:817) argue, pharmaceuticals “develop lives or biographies of their own; trajectories shaped at every stage or phase by politics.” Gardasil’s pharmaceutical development, testing, and approval as a vaccine (initially) targeting females highlight the gender and sexual politics of the vaccine (Casper and Carpenter 2008; Williams, et al. 2008). An examination of Gardasil’s history helps to explain why an expensive vaccine with relatively low public health benefit is targeted to (all) young girls and covered by private and public insurance plans. Ultimately, political decisions following the approval of Gardasil, which were highly publicized and controversial, led to questions regarding stakeholder motives, vaccine safety, and vaccine need.

Pharmaceutical companies like Merck play an increasingly important role in medical decision-making processes through, among other things, the sophisticated use of carefully constructed direct-to-consumer advertising (Williams, et al. 2008). For instance, the behind-the-scenes work that Merck undertook prior to Gardasil approval helped to largely frame Gardasil as a desexualized cancer vaccine. Understanding the work carried out by Merck prior to the launch of the vaccine also explains why,
compared to technologies such as Plan-B emergency contraception, there was relatively little initial resistance to the vaccine, despite its introduction during the conservative Bush-era. In sum, the story behind Gardasil’s debut has largely shaped the public’s response to it and has had long-lasting and far-reaching effects, influencing the ways that both providers and parents view the vaccine several years after its launch.

**Research and Testing**

The Gardasil vaccine is the result of three decades of research and clinical trials (Rothman and Rothman 2009). Researchers first identified HPV infections to cellular changes in the cervix and linked HPV-16 to pathogenesis of cervical cancer (Rothman and Rothman 2009). In subsequent studies, other types of HPV were found to have a causal role in the development of anogenital and cervical cancers. In the early 1990s, independent researchers discovered that “empty virus cells” could be created without HPV DNA encoding, providing the technological possibility to develop a preventive vaccine (Herskovits 2007). Merck licensed the technology to make the DNA-free virus shells in 1995 (Herskovits 2007). The technological and scientific discoveries regarding HPV were the impetus for vaccine development and in 2002, results found that women who received a vaccine against HPV-16 remained free of “persistent infection” throughout the 17 month study. As their end point, investigators used persistent HPV infection as a “reasonable surrogate” for cervical cancer due to both “ethical and scientific” concerns (Rothman and Rothman 2009:782).

Based on promising results from the 2002 study, Merck developed a quadrivalent vaccine designed to protect against two high-risk strains – HPV-16 and HPV-18, and two low-risk strains (HPV-6 and HPV-11) linked with genital warts. The vaccine, when
tested on 12,167 females ages 15 to 26 years old, protected against persistent HPV infection among those who had not been previously infected. Although the publication concluded that “widespread immunization of female children and adolescents may result in a substantial decrease in HPV-16—related and HPV-18—related cervical disease, including cervical cancer” (Rothman and Rothman 2009:782), responses from the wider scientific community regarding the promise of an HPV vaccine were more cautious. Studies on the cost-effectiveness of the vaccine questioned whether it was prudent use of public health resources. Others challenged the claim that reducing incident cases of some HPV types would actually lead to a decrease in cervical cancer rates (Aronowitz 2010). Related to this were concerns that targeting the two most prevalent oncogenic strains (HPV-16 and HPV-18) could create opportunities for less successful but more virulent strains of HPV to reproduce (Aronowitz 2010). To these concerns, others added that research regarding the duration of effectiveness or possible long-term adverse effects on natural immunity were lacking.

Though concerns were – and continue to be – raised about the long-term consequences of an HPV vaccine, the promise of a vaccine against cancer generally was regarded with excitement and hope among women’s health advocates, public health practitioners, medical providers, and the lay community. The unknown was whether public concerns about the sexually transmitted nature of HPV would dampen public support for the vaccine.

**Preparing for FDA Approval Process**

Rothman and Rothman (2009) argue that Merck’s experience with a hepatitis B vaccine largely influenced the way it approached the Gardasil vaccine. In 1982,
approximately 4,000 American contracted liver diseases related to hepatitis B and 800 died from hepatitis B-related liver cancer. Merck neither tried to convince the ACIP that most Americans were at risk for developing hepatitis B, nor that the vaccine was an anticancer product. When Merck originally requested approval for the HBV vaccine, it agreed with the ACIP recommendation that the vaccine be narrowly targeted to include healthcare workers who might have contact with blood or other bodily fluids, men who have sex with men, IV drug users, prisoners and staff in custodial institutions, and pregnant women in high-risk groups. Merck did not attempt to argue (as it would later do with Gardasil) that because hepatitis B infections can lead to cirrhosis and liver cancer, that all groups should be vaccinated; nor did it argue, as it later would, that HBV vaccine was a cancer-preventing vaccine.

When the HBV vaccine originally became available, high-risk users did not get vaccinated and rates of hepatitis B did not decline. One reason that high-risks users were not vaccinated related to the lack of government subsidization. As one analyst explained, “Services for junkies and gay men were not a popular line item” (Rothman and Rothman 2009:782). Disappointed in low HBV vaccine uptake, the ACIP recommended universal HBV vaccination for infants in 1991 with the goal of preventing the disease “before the humans who carried it had a chance to make the behavioral choices that spread it” (Rothman and Rothman 2009:782). The recommendation was endorsed both the American Academy of Pediatrics and the American Academy of Family Physicians. Despite the recommendations, only two-thirds of pediatricians and one-third of family doctors thought universal vaccination was a good idea and only half of pediatricians and a quarter of family physicians routinely recommended the vaccine. Providers in small
practices were not stocking the vaccine due to issues with insurance reimbursement and high upfront costs, while many parents were against giving their children another vaccine. Two years later, in 1994, when Congress enacted the Vaccines for Children Program, HBV vaccine coverage sky-rocketed. By 2002, 90% of children under three years of age had received the vaccine (Rothman and Rothman 2009).

Merck’s experience with the HBV-vaccine led to important insights about the importance of dissociating the vaccine from high-risk behaviors or populations, gaining professional medical association support, and securing government reimbursements and mandates. To successfully frame the Gardasil vaccine and win political, provider, and public support for it, Merck not only relied on past experience, but also on its role as a titan in the pharmaceutical industry. Merck had the experience and funds to frame and aggressively promote its drug, as well as the connections, name recognition, and resources to lobby conservative politicians and organizations prior to the review process to minimize controversies regarding transmission (Epstein and Huff 2010; Rothman and Rothman 2009).

When Merck presented the HBV vaccine for FDA approval, it did not attempt to frame it as a cancer prevention vaccine; with Gardasil, cancer was at the forefront of vaccine framing. Years before the FDA would approve Gardasil, during the commencement of vaccine safety and efficacy trials, both Merck and the FDA agreed that Gardasil would primarily be developed as a cancer-prevention technology. Dr. Eliav Barr, the Senior Director of Vaccines/Biological Clinical Research for Merck recalled that “at the inception of the program, Merck and the FDA met and agreed that the primary basis for licensure was to—was based on the demonstration of the prophylactic
efficacy of Gardasil, to show that Gardasil is efficacious in preventing HPV 16 and 18 and related cervical cancer” (Thompson 2010:121).

In 2001, Merck’s clinical research team analyzed efficacy data from an interim analysis of the HPV-16 component: the vaccine had 100 percent efficacy. Based on these promising results, Merck hired consultants to “start thinking about the policy issues surrounding Gardasil” (Herskovits 2007). Merck’s Executive Director of Medical Affairs, Rick Haupt, explained that in 2001 he saw HPV “predominantly as an education challenge” (Herskovits 2007). In thinking of how to approach the vaccine, he remarked, “what drives the standard of care for providers is what their professional society recommends.”

Merck sought to gain the support of professional medical associations (PMAs), including the American College of Obstetricians and Gynecologists, the American Society for Colposcopy and Cervical Pathology, the Society of Gynecologic Oncologists, and the American College Health Association by providing them with funding. Rothman and Rothman (2009) provide a thorough analysis of the funding provided to each of these PMAs, how funds were used to gain professional support for the vaccine and raise awareness about the dangers of cervical cancer, and the ethics of these relationships. Here, it is sufficient to say that using Merck money and training, members of PMAs provided direct training through workshops, speaker’s bureaus, awareness campaigns, and webcasts about the vaccine and cervical cancer to well more than 11,000 healthcare professionals (Rothman and Rothman 2009). With Merck funding, an HPV vaccine toolkit was distributed to clinicians to aid them in discussing the vaccine with parents and young women, and e-mail and postal letter templates about the vaccine were given to
clinicians to distribute to college-aged women. Rothman and Rothman (2009) questioned whether the materials presented to healthcare providers using Merck funds were balanced. Pointing to an ACHA webcast, they also challenge the disclosure policies of PMAs. Five of eleven presenters and program committee members who organized or spoke at an ACHA-funded webcast, “HPV Vaccine Update”, offered for CME credit to members failed to disclose that they had received expense reimbursements or had participated in the Merck speaker’s bureau. ACHA only requested that members disclose their relationship with Merck, stating that “it remains for the participants to determine whether the faculty’s outside interests may reflect a possible bias” (Rothman and Rothman 2009:785).

By framing the Gardasil vaccine in a highly biomedicalized and desexualized way, Merck avoided some of the problems that manufacturers of other reproductive technologies (such as Plan B) faced when trying to win conservative support and FDA approval. That Merck side-stepped many potential issues regarding sexual transmission is perhaps even more significant given the highly conservative political climate. As Epstein and Huff (2010:213) explain,

In repeated cases involving sexuality policy, powerful actors within key federal government agencies privileged a Christian Right moral agenda over the mainstream scientific consensus. More precisely, right-wing activists both inside and outside government sought to influence federal policies by deploying a scientific counter expertise that aligns with conservative Christian values, using the idiom of science to call into question the conventional scientific wisdom.
Epstein and Huff (2010) argue that Gardasil was able to fare better than other reproductive technologies or efforts at the time, such as condom efficacy and Plan B, both because of drug attributes and manufacturer strategies. Long before Gardasil was licensed, Merck met with women’s health advocates to discuss vaccine framing and how to disassociate HPV as a sexually transmitted infection from cervical cancer prevention (Epstein and Huff 2010). Merck also met with leading conservative groups to address any concerns they might raise prior to approval. In particular, there were concerns among some experts that religious conservatives would oppose offering a vaccine to adolescents that would prevent a sexually transmitted infection (Globerson 2007). Referred to by some as the “promiscuity vaccine”, some religious conservatives did indeed fear that adolescents who received the vaccine would be more likely to engage in sexual activities, or engage in those activities with a great number of partners (Colgrove 2010). By and large, however, fears of conservative opposition to the vaccine were overblown. Prior to and during the approval process, conservative groups were largely in support of a vaccine to prevent cancer.

Conservative leaders’ support of the vaccine can be attributed both to Merck’s pre-licensure efforts to frame Gardasil as a cancer-preventing vaccine and to public lack of awareness of HPV. Public fear regarding cancer might have made the vaccine more difficult for conservative groups to oppose. In evaluating why so many conservative organizations supported a vaccine to prevent a sexually transmitted infection, one women’s health advocate reasoned that they “clearly made a strategic [decision] that coming out against a vaccine that could save women from getting cancer was not a place that they wanted to be. So they pinned their position on this idea that it shouldn’t be
forced on anyone and that parents should always have the decision-making authority” (Epstein and Huff 2010:216-217).

The public’s general lack of knowledge regarding the connection between sex and HPV also helped the manufacturer sidestep many issues associated with promiscuity, morality, and reproduction. In fact, the lack of knowledge regarding what HPV was or how it was transmitted initially made it difficult for conservative groups to oppose the vaccine based on promiscuity fears. Bush-era federal health advisory committee member and former Focus on the Family consultant, physician and public health trained Reginald Finger appeared to be the quintessential far-right spokesperson. On his personal webpage, for example, Finger writes, “in everything I do, I seek to put Jesus Christ and His Kingdom first” (Epstein and Huff 2010:215). Finger determined that an HPV vaccine was unlikely to encourage sexual promiscuity because few teens understood what HPV was or how it was transmitted. He concluded that “for disinhibition to be a factor inhibition has to be a factor. And nobody really has evidence to show that fear of HPV is an inhibition factor for teenagers. Certainly, HPV is not HIV and neither is it pregnancy” (Epstein and Huff 2010:216).

While many conservative groups were generally supportive of Gardasil, there were dissenting opinions. Two groups, the Concerned Women of America and the Family Research Council initially opposed the vaccine, largely due to concerns that the vaccine would promote promiscuity. By the time vaccine hearings commenced, however, the groups were largely on board (Epstein and Huff 2010). Epstein and Huff (2010) suggest that the groups softened their positions in light of practical considerations and continual reminders that girls who practiced abstinence until marriage could still
become infected by future spouses or by force. In a prepared statement for the ACIP, the Family Research Council’s policy analyst stressed the importance of abstinence, but then conceded, “we also recognize that HPV infection can result from sexual abuse or assault, and that a person may marry someone still carrying the virus. These provide strong reasons why even someone practicing abstinence and fidelity may benefit from HPV vaccines” (Epstein and Huff 2010: 219).

The FDA Approval Process and State Legislative Activities

In December 2005, Merck & Co. requested that the FDA conduct a priority review of the Gardasil vaccine. Merck’s previous efforts to control vaccine framing and win support of key groups on both sides of the political spectrum might help to explain the relative lack of opposition to the vaccine during the approval process. Unlike the FDA and CDC hearings for Plan B, which were highly political and marred in controversy, the Gardasil hearings were relatively uneventful. Individuals who had attended hearings for Plan B and Gardasil commented on the general lack of resistance to the vaccine (Colgrove 2010; Epstein and Huff 2010).

Amy Allina, director of the National Women’s Health Network, who attended the hearings, noted a desire on all sides to frame Gardasil as a cancer-preventing vaccine rather than a vaccine to prevent a sexually transmitted infection. “The level of tension was just much lower, there wasn’t a feeling that there was something very controversial or contentious being discussed. It was much more what you’d see at another advisory committee meeting where you’re just talking about a major medical breakthrough. Everyone was aware that there was this undercurrent of discomfort with talking about anything that has to do with sex, which we have in this country, but by focusing on the
cancer prevention instead of on the HPV as a sexually transmitted infection, the company managed to shift the conversation a little bit” (Epstein and Huff 2010: 219).

In May 2006, an FDA scientific advisory committee voted unanimously (13-0) that Gardasil was a safe and effective vaccine to administer to girls ages 9 to 26 years of age. Discussions about age recommendations for Gardasil commenced two-and-a-half years prior to licensure. Members of the Advisory Committee on Immunization Practice’s (ACIP) HPV Working Group began examining a “huge amount of material” on the virus and vaccine in order to make an age recommendation. While the vaccine was approved for females ages 9 to 26, the ACIP ultimately followed the advice of its HPV Working Group, recommending routine vaccination for girls between 11 and 12 years of age with catch-up vaccination among girls ages 13 to 18 (CDC 2007).

The decision to target 11 and 12 year old girls was based on several factors: first, at this age girls are also targeted to receive other federally recommended vaccines, including the meningitis vaccine, the hepatitis A vaccine, and boosters for chicken pox and tetanus/diphtheria/pertussis (Herskovits 2007). Moreover, parents take their children for wellness checks less often during the pre-adolescent and adolescent years; offering a vaccine during this stage encourages more frequent visits. As Dr. Janet Gilsford, Chair of the HPV Working Group explained, “We decided to focus on 11 and 12 year olds because there’s a strong movement afoot to establish adolescent visits [to the doctor] at a time of life when people aren’t going to the physician for routine care” (Herskovits 2007). Secondly, since sexual contact is the primary mode of HPV transmission and the vaccine is most beneficial when administered before sexual onset begins, it is important to vaccinate individuals before sexual debut (Pollack, et al. 2007; SAM 2006; Siddiqui
Finally, research has indicated that the immunologic responses to the HPV vaccine (as well as other vaccines) is higher among pre-pubescent than post-pubescent individuals (Stanley, et al. 2006).

The CDC and ACIP decision to designate Gardasil as a recommended vaccine was crucial because the designation ensured that federal funds would be provided to states to ensure that low-income children have access to recommended vaccines. Moreover, because most insurance providers’ reimbursement policies are based on ACIP/CDC recommendations, designation as a recommended vaccine more or less guaranteed that most major insurance providers would cover the vaccine (Fisher and Brundage 2009). Even more than other vaccines, public and private payment for Gardasil was critical due to its high cost: completion of the three-dose series, on average, costs $360. Within five months of ACIPs decision to recommend Gardasil, the CDC had added Gardasil to its Vaccines for Children Contract, thus ensuring that qualified girls between the ages of 9 and 18 would be able to receive it (Herskovits 2007). In the subsequent months, the private sector followed suit. Ninety-five percent of plans added Gardasil to their formularies (Herskovits 2007).

Post-licensure, conservative groups largely remained supportive of the vaccine (Colgrove 2010). The shift in support occurred when individual states attempted to mandate Gardasil for school entry. In September 2006, approximately three months after FDA approval, the first bill to mandate HPV vaccination was introduced in Michigan (Colgrove 2010). Beverly Hammerstrom, the state legislator who introduced the bill, was also a member of Women in Government (WIG), an advocacy organization comprised of legislators who supported bills focused on advancing women’s issues (Colgrove 2010).
A key priority among WIG legislators was to advance HPV-related legislation to increase funding, education, and in some states, vaccine mandates. WIG supporters argued that all girls and women, regardless of ability to pay, should have access to preventive technologies to protect against cervical cancer (Fisher and Brundage 2009). Fundamental to meeting this goal, they argued, was mandating that all middle school aged girls receive the vaccine, although parents could choose to opt-out of the program. In the coming months, more than 30 states would initiate some form of legislation to mandate the Gardasil vaccine. As legislation efforts increased, so did the controversy surrounding the vaccine.

Members of the religious right expressed outrage that states would require young girls to be vaccinated against a sexually transmitted disease (Herskovits 2007). A representative of Focus on the Family explained her organization’s opposition to the mandate, “We are an organization that supports parental rights . . . We believe that parents are the medical decision-makers for their children” (Epstein and Huff 2010:220). Conservative groups argued that the mandate was another case of “‘big government’ trampling the rights of the individual” (220) – a perspective that many people of a libertarian persuasion found compelling.

Debates surrounding the vaccine mandate not only exposed long-standing tensions regarding governmental and parental control, but tensions concerning the role of the pharmaceutical industry in shaping public health policy, and the independence (or lack thereof), between government agencies, politicians, and the pharmaceutical industry. Attention surrounding political efforts to legislate HPV and cervical cancer prevention, education, and screening also led to a more critical view of the vaccine itself. Many
parents, worried about the newness of the vaccine and the unknown long-term risks and side effects, opposed the school mandate (Herskovits 2007). Some members of the public health and medical community agreed, arguing that there were still too many unknowns to mandate the vaccine (Fisher and Brundage 2009). Some healthcare professionals and public health advocates worried that mandating a new vaccine – especially one that was meant to prevent a sexually transmitted disease – would undermine the already diminishing public trust in immunization programs.

The controversy surrounding HPV vaccine mandates reached its climax on February 2, 2007. Texas governor, Rick Perry – “a conservative Christian and opponent of abortion rights and stem cell research”– issued an executive order mandating that all girls entering the sixth grade be vaccinated against HPV (Globerson 2007:75). Normally, vaccine mandates are enacted through a legislative process or by public health officials who are granted rule-making authority. Justifying the unusual move, Governor Perry compared the Gardasil vaccine to the polio vaccine, arguing that by reducing rates of cervical cancer, the vaccine would ultimately save women’s lives, and – for the state of Texas – money (Globerson 2007). Governor Perry’s decision to bypass the legislative process generated a firestorm of controversy, both in the conservative state of Texas, and nationwide. Perry’s motives for bypassing legislative procedure were questioned and it was soon discovered that Perry’s former chief of staff was also a Merck lobbyist. During the same period, the press released reports that Merck has made significant financial contributions to Women In Government (Colgrove 2010). In response to public outrage and negative publicity, Merck ceased lobbying efforts to achieve state mandates and the Texas legislature passed a bill to prohibit any HPV school mandate (Colgrove 2010). The
decree raised the level of resistance to the vaccine, and also questions regarding the relationship between legislators and the pharmaceutical industry.

As Colgrove (2010:5) explains, “The revelation of this aggressive lobbying was a public relations debacle for Merck”. Added to concerns about Merck’s lobbying tactics were questions regarding its business ethics and drugs’ safety. Merck was already the target of negative publicity in light of accusations that it withheld and concealed risks associated with use of its pain medication Vioxx. Moreover, as the result of Vioxx-related civil litigation, Merck was forced to pay billions of dollars in damages, which led to the joke that HPV stood for “Help Pay for Vioxx” (Colgrove 2010). While criticism of Gardasil’s hefty price tag was not new, it intensified in the wake of reports that Merck had made donations to Women in Government.

Though experts had raised concerns about vaccine need and cost before licensure, events post-licensure drew the attention of a larger group of critics. At an average cost of $360, Gardasil cost significantly more than other common childhood vaccines. Some people wanted to know whether the benefits of the vaccine were worth the costs. In advertising Gardasil, Merck highlighted the vaccine as a cancer-prevention technology, but it did not mention how many women develop cervical cancer or what types of women were most at risk for HPV-related disease. In one of a series of critical reviews of the Gardasil vaccine published by the Center for Media and Democracy, Judith Siers-Poisson (2008) questioned whether public funding or universal immunization was necessary given that Gardasil only protects women from some strains of HPV that can cause cervical cancer, and moreover, when all cases of cervical cancer account for a relatively low mortality rate and small disease burden. She argued that cervical cancer does not
“even crack the top ten fatal cancers for women,” then provided comparisons of the number of lives claimed from all cancers, heart disease, and Vioxx: “cancer of all types combined kills more than 500,000 people in the United States each year, while heart disease claims more than two million lives. An estimated 27,000 to 55,000 people have died just from taking Merck's Vioxx.”

**Gardasil Marketing and Advertising**

As previously discussed, Merck sought advice from women’s health advocates, consultants, and organizations on both sides of the political spectrum prior to seeking vaccine licensure. These conversations, along with lessons learned from the HBV-vaccine, led Merck to adopt a highly medicalized and desexualized advertising campaign that emphasized the vaccine’s cancer-preventing benefits. Even the name “Gardasil” was carefully considered. Until the advent of Gardasil, vaccines were named after their creators or the diseases that they prevented. Gardasil was the first vaccine to be identified by its trade name, which was created to elicit a connection between the vaccine and its ability to “guard” – not against HPV, but cervical cancer (Rothman and Rothman 2009).

From 2001, Merck recognized that HPV and cervical cancer awareness were low within the population. To successfully market the vaccine, education had to focus on the association between HPV infection and cervical cancer, rather than the connection between HPV infection and genital warts, for example, or any other association that would link HPV as a sexually transmitted infection (Mamo, et al. 2010). Fortunately for Merck, it appeared that few Americans knew much of anything about HPV. The results of a Merck-funded study of HPV awareness, completed prior to advertising Gardasil,
found that only five percent of women and girls surveyed knew of a connection between HPV and cervical cancer (Herskovits 2007).

Merck wanted women and girls to have a strong association between HPV infection and cervical cancer before Gardasil became available. In order to heighten awareness of the connection, Merck launched a massive non-branded disease awareness campaign on September 30, 2005, several months before obtaining FDA approval for Gardasil. Merck partnered with DDB advertising agency and Edelman public relations firm on both its branded and unbranded marketing campaign (Herskovitz 2010). The non-branded DTC media campaign focused on awareness and came in various forms from “Tell Someone”, “Make the Connection”, and “Make the Commitment” (Mamo, et al. 2010). The first campaign, “Make the Connection” aimed to increase public awareness regarding the connection between HPV infection and cervical cancer. Beaded bracelets were used along with the “Make the Connection” advertisements to raise awareness. Merck funded events throughout the country where celebrities wore “Make the Connection” bracelets to promote cervical cancer awareness and girls could order kits from the Internet that included materials to make bracelets and educational materials (Herskovits 2007). The kits were so successful that Merck ran out.

In the second phase of the unbranded campaign, girls and women were encouraged to “Tell Someone” about the connection between HPV and cervical cancer. According to Bev Lybrand, Vice President and General Manager for Gardasil, the “Tell Someone” campaign tapped into “women’s natural inclination” to talk and share

31 Ads aired during the “Tell Someone” campaign can be accessed through the following links: 
http://www.youtube.com/watch?v=4yV7SpHOcrw
Elizabeth Rohm: http://www.youtube.com/watch?v=OMbvhug7CGU&feature=related
information (Herskovits 2007). Actresses looked directly at the viewer and encouraged women to talk about the connection between HPV and cervical cancer and share information with mothers, daughters, sisters, friends, and peers. Girls could share information with others online, choosing from a selection of e-cards that included the question “Did you know that cervical cancer is caused by certain types of a common virus?” (Herskovits 2007). Mothers were targeted through “Make the Commitment” advertising which encouraged women to pledge to talk their daughters’ healthcare providers about the risk of cervical cancer (Mamo, et al. 2010).

The unbranded campaigns were intended to play on cancer fears and on themes of empowerment and protection. Lybrand explained, “Of course everyone understands cancer and is scared of cancer,” but “we learned early on that moms really wanted to protect their daughters—that protective insight is important. For young women, they want to empower themselves to take control of their own destiny” (Herskovits 2007). Messages of female empowerment and parental responsibility continued to be salient themes within the branded advertisements.

After gaining FDA approval, Merck began its “One Less” marketing campaign. Television commercials include an ethnically diverse group of girls who are individually, or in groups, engaging in a variety of activities, including jump roping, dancing, skateboarding, playing basketball, and playing the drums (Aronowitz 2010; Braun and Phoun 2010; Mamo, et al. 2010). Speaking directly to the camera, while engaging in

32 One-Less and I Chose ads can be viewed through the links below:
One-Less: http://www.youtube.com/watch?v=hl8x3KR75fA
One-Less: http://www.youtube.com/watch?v=15JkOBm3IU&feature=related
I Chose: http://www.youtube.com/watch?v=ZHUamYN9H9c&feature=related
I Chose: http://www.youtube.com/watch?v=ehvxbEOgNEM&feature=related
activities, girls say, “I want to be one less . . . one less statistic” (Aronowitz 2010:20). In another commercial, girls confidently shout, “I want to be one less, one less!” An adult woman, presumably a mother, then appears on screen and explains that “Gardasil is the only vaccine that may help protect you against the four types of HPV that may cause 70% of cervical cancer”. Side effects are then discussed by another, older woman (Aronowitz 2010; Mamo, et al. 2010). Print advertisements for Gardasil, appearing around the same time, focused on evading risk, rather than becoming one less cancer statistic. Advertisements read, “She won’t have to tell him she had HPV . . . because she doesn’t.” (Aronowitz 2010:21).

In 2008 television spots, the words “I chose” are central to messaging. A group of mothers say, one after the other, “I chose to get my daughter vaccinated” while young women announce, “I chose to get vaccinated.” The spots include the tagline “You have the power to choose” (Chesler and Kessler 2010). Fisher and Brundage (2009) draw comparisons between the “one less” advertisements and the public awareness campaigns created by the American Cancer Society in the 1950s. In both campaigns, the emphasis has been placed on the individual’s role in preventing cervical cancer and by reducing “false modesty” (Fisher and Brundage 2009:255). The Merck “One Less” campaigns encourage both girls themselves and their mothers to avoid becoming a statistic by talking to their providers about the vaccine. While the argument has been made that such advertising “suggests the main obstacle to eliminating cervical cancer is ‘unjustified prudishness’” (Fisher and Brundage 2009:255), a counter argument could be made that the intentional decision to avoid using the words “genital warts” – rather discussing them as “other HPV related diseases” is an effort to deny or deflect focus on the relationship
between HPV and sexual transmission. Gardasil advertising has been examined by several researchers (Braun and Phoun 2010; Fisher and Brundage 2009; Mamo, et al. 2010) who point to the lack of sexual related information in the advertisements. For example, males are never depicted in advertisements, despite the fact that most females contract HPV through heterosexual contact. Advertisements repeatedly mention cervical warts, but genital warts are referred to as “other HPV-related diseases”, despite the fact that the vaccine protects against two strains of HPV that cause 90% of genital warts.

**Chapter Six Summary**

In summarizing this chapter, it is important to remember that opposition and support to vaccines is not static, but rather changes through time. It is important to understand general vaccine trends, while not obscuring the heterogeneity involved with each vaccine. Hope in technology, perhaps best exemplified in Jonas Salk’s polio vaccine, is countered by risks associated with technology. It is worth reiterating that the following analysis has to be understood as necessarily being greatly influenced by the trends discussed in this chapter; throughout the remaining chapters I refer to events described here to contextualize parent and provider perspectives. Expert, parental, and lay perceptions do not emerge out of thin air, but stem from specific historical contexts.
Chapter Seven – Structural Factors in the Provision of Vaccines

In the following chapter, I describe how structural factors, including vaccine cost, administration fees, billing, and reimbursement formularies shape providers’ views towards and practices regarding Gardasil. Specifically, I discuss providers’ knowledge and awareness of the economics of vaccination for their practices, highlighting how structural factors can affect which practices carry Gardasil, when they administer it, and to whom. I also describe the role that patient vaccine costs and insurance coverage had, or will have, on parents’ Gardasil choices, as well as the perceived role that insurance coverage and cost have on other parents’ vaccine decisions.

Practice Level Costs and Considerations

The information presented in this section is based on comments made by a few physicians and nurse practitioners who spoke about the economics of vaccination. Providers who discussed the profitability of vaccines had varying perspectives, which might relate to differences in their patient populations, office types, and strategies for procuring vaccines (Zimet 2009). In the first section of the chapter, I rely more heavily (but not exclusively) on the perspectives of one nurse practitioner, Ann, whose professional responsibilities include addressing the economics of vaccination. Along with clinical responsibilities, Ann consulted with health clinics, private practices, and other health care institutions to develop more streamlined and cost-effective strategies to provide vaccinations. Drawing from her own experiences working with clinics and
practices, she was particularly helpful in explaining some nuances of vaccine cost and reimbursement.

Most of the providers I spoke with were not sure whether vaccines were profitable for their practice. This lack of knowledge was not surprising to Ann, who felt that most providers knew very little about the economics of their business.

I mean a smart provider these days, even in a solo or small group practice, they separate themselves from [the business-side of the practice]. They have someone that tells a patient, “No, we can’t see you because you don’t have insurance, or your co-pay today is X, Y, or Z.” The provider doesn’t want to get into that because it taints that consulting relationship.

Providers offered information about the economics of vaccination for their practices, but usually began with the caveat that they were fairly far-removed from the business-side of healthcare provision. Many providers (both MDs and NPs), regardless of whether they were aware of practice economics or not, stressed that the business-side of healthcare was not an aspect of health provision they wanted to be involved in. Moreover, several providers expressed discomfort with any suggestion that profitability factor into treatment decisions; a few providers specifically cited examples in which they had prescribed or withheld treatments knowing that in so doing, they would be costing the practice money.

Providers, in other words, made a point of separating their own treatment decisions from economic concerns. Jane, a nurse practitioner in Pennsylvania, provided a typical response to questions regarding the profitability of vaccines:
I do think we make money on vaccines but I don’t do money. So I really don’t know. I’m one of those old idealistic people who thinks that she can just give the right care and not care what it costs. So I’m not into making money for the office. When they [office managers] come and say ‘We need you to do this, this, and this because it really makes us a lot of money’ I just ignore them because I do what I think people need and I won’t give a Gardasil because it makes money for the office. But I think it probably does.”

Ann described some of the challenges one of her clinics faces when purchasing vaccine doses: “We don’t buy [Gardasil] in bulk, we don’t get the lowest rate for purchasing Gardasil and last year the lowest rate for the real bulk purchases was like $150 per dose. But we couldn’t even buy it for that. We were buying it for like $160 or $165 a dose.” Ann explained, “Most people charge at least $10 to $20 [as an administration fee]. I think in our student health services we usually only charge about $7. The health department has a really low administration fee too, but a lot of private providers really tack on administration, record keeping expenses and stuff like that.”

Ann went on to clarify that it is possible to get better deals on the vaccines, but doing so is often time intensive and requires legwork and resourcefulness on the part of the practice. She recalled that the director of one student health center became so frustrated with the high cost of the Gardasil vaccine that she confronted a Merck representative at a professional meeting. Ann noted that while the representative was helpful, it required a lot of effort on the director’s part to find ways to make the vaccine affordable.

While few providers knew how much their practice charged as an administrative fee for vaccination, several providers did justify the use of a fee. Jane, who was emphatic
about her disinterest in profit-driven healthcare, also felt that a practice should not lose money on vaccines. For this reason she felt administrative fees were justified, given the guesswork involved in ordering vaccines, their limited lifespan, and the costs associated with storing them properly. “It’s fair that we charge significantly more than the vaccine costs because our overhead costs are high and sometimes, if you get them in individual doses they’re more expensive. And if you get them in big bottles they expire and you may throw out some of the stuff; so you have to give enough of it so that it’s cost effective.”

Although lack of sufficient reimbursement can lead some practices to decline stocking all or specific vaccines in office (Keating et al. 2008), only one provider in this study worked at an office that did not stock the Gardasil vaccine. Patients who wanted the vaccine were written scripts, picked up the vaccine at a local pharmacy, and then returned to the practice to have it administered.

In some cases, providers had to turn down parent requests for single-component vaccines, not because of any clinical resistance to administering three separate vaccines, but due to the high economic cost. Several providers mentioned that many parents request separate vaccines in place of combination vaccines, such as the combined MMR (measles, mumps, and rubella) and DTaP (diphtheria, tetanus, and pertussis) vaccines. Nina, a pediatrician working in Pennsylvania, noted that while she had no clinical reason to oppose administering separate component vaccines, the cost of doing so was prohibitive. In reference to administering measles, mumps, and rubella as three separate components, she explained, “We looked into this. I think it was like a thousand dollars. It
was astronomical to get *just* a case of measles [vaccine] for however many come in a box. But it was an astronomical amount and so, no, we’re not going to do that.”

Insurance reimbursement concerns sometimes altered if and when providers would administer vaccines. Sophia, a Florida nurse practitioner, told me that she rarely gives children vaccines during sick visits because more than half of her clients are on Medicaid and the office is prohibited from billing Medicaid for sick and well-care treatments on the same visit. Sophia described the policy as frustrating and recognized that the policy not only resulted in many missed vaccine opportunities, but also burdened parents, who had to make return visits to vaccinate their children. When I asked her if she knew why the policy existed, she replied, “I don’t know. We’ve [she and the other providers] brought that up at office meetings and with our billing and coding person and she said, that’s the rule, that’s what you got to do”. Despite the fact that Medicaid would not reimburse the office for vaccines administered during acute-care visits, the providers sometimes gave the vaccines anyway. “Nine times out of ten your hands are tied. Sometimes we fudge, sometimes we’ll do things and just don’t get paid for it.”

Economic concerns can also affect who administers vaccines. Only two providers (one NP and one MD) regularly administered vaccines themselves and only one parent said that her provider generally administered vaccines to her child. For the most part, vaccines are administered by nursing staff or medical assistants. When I asked Elizabeth, a Florida pediatrician, why she did not administer vaccines herself, she responded that it was not a time (thus, cost) efficient strategy: “It’s actually built in time purposes because drawing up the vaccine, recording it, and then administering it can take up to 10 minutes.
so it’s not efficient in the office to have the doctor doing that part because while the nurse is occupied with that I’ll go see the next patient."

Only one healthcare professional reported that in her practice, physicians routinely administered vaccines, largely because it reduces medical errors and because parents like it. The pediatrician explained that at first, she did not feel trained to administer vaccines. “I’m used to it now. It takes more time and it’s actually not a good business proposition because a doctor’s hour is worth more than a nurse’s hour in pay – we spend a lot of time pulling up the vaccines and giving the vaccines, where we could be seeing more patients. But at the same time, the parents love it.”

In her explanation, the pediatrician argued that having nurses administer vaccines would be more profitable. However, the reason that her colleagues opted to give vaccines themselves can also be seen as profitable if parents interpret the practice as unique and indicative of extra care and attention. By keeping parents happy, the practice develops a loyal, satisfied clientele.

Just as they felt ill-equipped to talk about vaccine reimbursements, few providers felt confident speaking to the profitability of vaccination. Sophia was confident that her practice did not make money on vaccines. Upon further reflection, she suspected that they sometimes actually lost money in an effort to cover all of their patients. “We have lost [money] sometimes because if we didn’t have enough of a VFC dose in, we’ve actually borrowed shots from our private ones that are out of the boss’ pocket to give to our other kids. So in that case, yeah, we’ve lost money on them.”

On the other hand, Elizabeth thought that for her practice, the HPV vaccine “definitely has been a money maker.” She attributed profitability to the newness of the
vaccine, arguing that over the short-term, all new vaccines generated income for the practice. “Usually the first year it’s pretty lucrative. After that it’s more of a break even thing. So it doesn’t tend to be a long standing money maker.” Nina, also thought that her practice profited from vaccines. She attributed profitability to the size of the practice, good vaccine management, and their ability to sell unused vaccines to other smaller practices. Janet, another pediatrician practicing in Pennsylvania, didn’t know exactly how profitable vaccines were for her practice, but she knew that her practice generated at least some income from administering vaccines, a feat she attributed to their support staff, who are responsible for ensuring proper billing, purchasing, and management of vaccines.

We have a clinical office manager and it’s her job to order the vaccines and figure out the best way to get them covered. So many practices have no profit margins on their vaccines. But if you order them correctly and you bill for them correctly, then they get covered by insurance and you do have a fair amount of profit margin on your vaccines. Our practice is not losing money on vaccines, we’re making it. But it’s not a huge amount.

**Patient-Level Costs and Considerations: Insurance Coverage and Patient Access**

The cost of Gardasil was not a significant factor in most parents’ vaccine decisions. Of the 17 parents who had already had at least one daughter vaccinated with Gardasil, only six checked to see if it was covered by insurance before beginning the series. Four of the six parents who first checked to see if the vaccine was covered were privately insured and two were using Medicaid. All of these parents, including the two
mothers on Medicaid, would still have had their daughters vaccinated if the vaccine were not covered by insurance, but three of them (one on Medicaid and two privately insured) might have waited to begin the series for financial reasons. As a mother of three explained, “I probably would have put it off if I had to pay out of pocket simply because I live on one income and $360 is kind of tough for just a shot. I mean yes, obviously I thought it was a good idea and I probably would have somehow, probably later down the road, figured out how to come up with the money to get it for them.” The other mother thought she might have spent more time researching the vaccine and making sure it was a sound economic investment, but still would have had it done.

The remaining parents had their daughters vaccinated without confirming coverage, generally because they assumed their plans would cover it. After telling these parents how much an average three-dose series cost, I asked if they would have rethought the vaccine decision if their insurance companies had not paid for it. Most parents believed said that they still would have had their daughters vaccinated. Several parents explained that you could not put a price tag on a child’s health. From their perspective, parents do – and pay – whatever it takes to protect their children. As one father said,

No, it was not really a consideration. I mean it probably should be, but I think it doesn’t matter if I have to pay that out of my pocket. I’ve made the decision. You’ll see that as a parent, once you’ve – whatever it takes. Give them a kidney, that’s no big deal. When do we start? I mean, seriously. You just have to – that was not even a part of the decision-making equation.”

It is worth noting that many parents in this study were financially secure and likely had fewer economic concerns than many parents. Only one mother would have rethought the
vaccine had it not been covered, explaining, “I think working as a normal consumer, I think I would have delayed and looked into it and asked, okay, is this something that is really necessary? What all does this really show? And what will it really help?”

Of the 9 parents who had not vaccinated any child, two were uninsured and the rest were privately insured. Insurance coverage was not a consideration for the two mothers who were not planning to vaccinate their daughters at any point in the future, though one of these two women was uninsured. Six of the seven parents who would likely vaccinate in the future, but had not yet made a definitive vaccine decision, were covered privately. Though none of these parents knew if their insurance companies would cover the vaccine, lack of coverage would not be reason enough for them to decline vaccination. Two of these parents thought that they might postpone the decision if the vaccine were not covered. One father noted that it would cost over $1,000 to have all three of his daughters vaccinated without assistance, which would likely require that his daughters begin the series at different points to make it financially viable. Despite the financial burden, paying out-of-pocket would not be a “show stopper.” The other mother thought she might delay the decision to maximize the amount of “useful” coverage her daughter received from the vaccination. If a booster would eventually be necessary, she wanted to ensure that she didn’t pay for “wasted” years of protection when her daughter wasn’t nearing sexual activity. She would likely delay the vaccination until a year before she thought her daughter was sexually active to get the most active protection from the vaccine.

Though economics did not factor into any parent’s ultimate vaccine decision (aside from timing for a few parents), a number of parents (n=8) perceived that cost likely
explained why *other* parents did not get their own children vaccinated. However, only one woman could think of particular individuals whom she thought would be unlikely to vaccinate due to economic issues and lack of insurance.

Providers had mixed responses regarding the role that vaccine cost played in vaccine decisions. A few providers (n=3) mentioned that cost was a concern when the vaccine originally came out and fewer insurance plans were covering it; however, most providers did not believe that cost was a significant issue for most parents of pre-adolescent and adolescent daughters (ages 9-17). One pediatrician said that “It’s very rare – almost unheard of that insurance is the reason *not* to give it.”

Perceptions that cost is a not a general issue likely are in part related to the populations with whom providers interact. Most providers who worked in offices where most parents had private healthcare coverage or were wealthy enough to pay out-of-pocket did not encounter too many parents who declined the vaccine for financial reasons. However, providers who worked in offices where they saw a larger proportion of parents without insurance were more likely to say that cost could potentially be an issue, but more so in terms of access and convenience (recall that uninsured and underinsured girls are eligible for low cost or free vaccines, but must obtain them through VFC-participating clinics, and in the case of underinsured girls, through federally qualified community or rural health centers).

One nurse practitioner working in Florida noted that a significant portion of her clients were covered by Medicaid or uninsured. While she thought that parents of Medicaid enrolled children most readily accepted recommended vaccines for their children, she noticed more variability in vaccine acceptance among uninsured parents. At
the clinic in which she works, uninsured parents can get the vaccine through the VFC program and are only required to pay a $10 out-of-pocket fee to cover administrative costs. Despite the relatively low cost of the vaccine, Sophia said some parents still did not feel they could afford it. She advised these parents to go the local health department, where they could get the shot for free (i.e., without an administrative fee), but some people rejected this suggestion, saying, “‘I’m not going to go down there and wait three hours for a shot.’ That’s usually the excuse. ‘I don’t want to go, it takes too long to get anything done down there’”. Another provider in Pennsylvania also noted that when cost was an issue, it had less to do with the ability to obtain the vaccine for free, and more to do with the inconvenience and stigma associated with getting it for free. She explained, “[Cost is] not really a problem [for] younger girls, since they can go to [. . .] a state health department immunization clinic. But even if they need to sometimes they won’t, they have their own ideas about the State system, etc.”

Often times, parents were simply unaware of governmental assistance programs that provide vaccination at low or no cost. One Pennsylvania school nurse believed that insurance coverage and access, as much as cost itself, were primary reasons children did not receive all of their vaccines. With the economic crisis, she noted that more parents were losing jobs and insurance coverage and were unaware of governmental programs to help them receive vaccines. Once parents were informed of opportunities to receive vaccines, they generally took advantage of them. Another school nurse recalled an experience when the only reason a girl had not been vaccinated was because her parents did not realize there were programs in place to assist families in need: “I ran into a
student last year whose father’s insurance company wasn’t paying for the [Gardasil] vaccine [ . . .] and then I told him about the free program and he got it.”

More providers (n=5) described cost as a significant barrier to women in their twenties. Laura, a nurse practitioner in Florida, observed that “The ones who tend not to get it are girls that are out in the college age – maybe in the early 20s – and they’re thinking about it but then maybe their insurance doesn’t cover it.” For parents who had delayed the decision due to concerns about vaccine safety and newness or their daughters’ sexual maturity, insurance coverage sometimes became the decisive factor compelling parents to vaccinate their daughters. As part of her Gardasil conversation with parents and older adolescents, Jane generally stressed that “you are going to end up not having it paid for if they don’t get this soon,” noting that this frame generally compelled parents to initiate the series. Another provider highly encouraged parents to initiate the series by their daughters’ seventeenth birthday. When parents expressed ambivalence about whether they should vaccinate their daughters, she would say,

Look. If you’re wondering just because of time, if you don’t give it by the time she’s 18, it might not be covered. And it’s [more than] 300 dollars. And then usually – [parents say,] “Okay, give it! (laughs). Let’s squeeze it in before the 18th birthday.” So sometimes insurance works favorably for us; it really tips the scales.

As these cases illustrate, when economic concerns are an issue, providers can play an important role in helping parents find alternative means to obtain the vaccine, but doing so requires that providers have a thorough understanding of available resources to their patients. Providers, however, often admitted that they knew little about the
insurance and payment side of vaccine administration. This might be one reason why some providers were unaware of potential resources for their patients. For example, one Florida nurse practitioner did not think that Gardasil was covered under VFC “because if it was it would bankrupt the whole system.” Yet, Gardasil is covered by the VFC (CDC 2011c). Another Florida provider seemed to be unaware of some of the options available to uninsured, underinsured, and Medicaid-participating patients. She perceived cost to be a major barrier to Medicaid and uninsured parents:

> I think most [private] insurance companies are paying for it. Our public health, the Medicaid is not paying for it. And in our community, a huge percentage of the population definitely is not going to be able to afford to do it and will not vaccinate if it’s not paid for. And the uninsured – I think most of the uninsured are not going to be able to afford it and are not going to be interested.

However, as discussed previously, all children through age 18 who are Medicaid eligible, uninsured, American Indian or Alaska Native, or underinsured are eligible to receive vaccines, including Gardasil, through the Vaccines for Children Fund.

Ann recounted an experience where one of her nursing students was working in a pediatric office and had to educate the provider about vaccine coverage: “A young woman came in who was 17 and the student was recommending Gardasil and the provider there that ran the practice had not thought of VFC for her, and of course she would qualify for free Gardasil, which is hugely expensive.”

**Vaccine Uptake: Education as a Marker of Class**

Education is not necessarily itself a structural factor, but because clinicians discuss education as a proxy for, or marker of social-class differences, I chose to include
the discussion here. Providers sometimes pointed to the interrelated variables of education level, income level, and insurance coverage as predictors of vaccine resistant among parents. Several providers (n=5) felt that well-educated, middle and upper-class parents were more resistant to vaccines. Janet, a pediatrician who worked in a large pediatric practice serving a largely White, middle and upper-class population, compared these parent’s reactions to Gardasil with the responses she received from parents when she was in residency and the vaccine had just become available. During her residency she primarily served a low-income, less educated, minority population; despite the newness of the vaccine, she reported that during her residency she encountered far fewer parents resistant to the vaccine. She primarily attributed the variation to patient education. Her previous population consisted primarily of poor, younger, minority populations. She recalled, “We gave the Gardasil at 9 [years of age] and hardly anybody refused it, because of the population. You probably know this – the lower educated population refuses vaccines a lot less. They kind of just do whatever the doctor tells them to do.”

One nurse practitioner, who also thought resistance was more pronounced among well-educated parents, drew from differences she observed at her previous low-resource setting and in her current retail setting, Jessica explained, “I think the vast majority of parents who oppose vaccines are highly educated. They have access to information to make a choice. And the internet has only fueled the fire.” To Jessica, it made sense that well-educated parents would seek perspectives and information from multiple sources because they had the knowledge, time, and opportunity to do so. She also thought that parents with less education might be less aware of options to abstain from vaccinating, or
processes by which exemptions could be obtained. Jessica saw this as an educational issue, but more so, an economic issue: “I also think [well educated parents] are more willing to fight. For instance if the child can’t get into school unless they’ve had all these vaccines, parents in the housing projects may not have the means or resources, or even the wherewithal to tackle that battle.”

The settings in which vaccines are offered to parents in these populations might also discourage them from postponing from vaccine decisions due to access issues, time constraints, and convenience. Jessica noted that in some low resource settings, you will often see the well-child checks and the vaccine-checks tied in with WIC vouchers, so there’s a give and take here. It’s like, alright I’m going to get my WIC vouchers and my food here and I got to take my kid in so that they can get their vaccines. I mean you just don’t have that in the private insurance, high resource settings.

Several providers (n=4) thought that most resisters they treated were privately insured. One physician said it was uncommon for her to encounter vaccine resistors, but then added, “This is a public clinic and most abstainers go private. Most of my kids are on Medicaid but I do get some [private insurance] too.” She believed that in her own clinic, the mothers who resisted Gardasil or expressed concerns about it were the privately-insured “women in a higher social class”.

While providers attribute vaccine resistance to education and access issues, providers also felt that parents receiving free or low cost vaccines through federal and state-funded programs viewed medical technology differently from parents who were privately insured. Parents who were offered vaccines through public programs saw
medical technologies as expensive, protective technologies that they should accept if given the opportunity. Sophia explained, “Most of our Medicaid and VFC recipients say ‘Yes, whatever it is they need, whatever is out there, give them everything’. It probably is more of the private insurance patients, or parents, that are a bit more hesitant.”

Interestingly, several parents (n=3) also considered vaccine resistance to be a class-based phenomena, not related to differences in education level, but the result of an inflated sense of entitlement. They tended to see it as a privileged position adopted by some middle and upper class Americans who, concerned about the health risks of vaccines, rely on others to incur risks to protect their own children. One father perceived middle class parents to be particularly likely to adopt this position.

One thing that’s kind of disturbing about the anti-inoculation campaign is that it seems a lot of middle class parents seem to be gullible. And I do resent it in some way as kind of a Yuppydom-like entitlement thing. Like the 0.001 possibility that my little Johnny’s going to get mercury poisoning because it’s something that I read in Parent magazine somehow outweighs the combined social interest in people in eradicating this deadly virus.

Chapter Seven Summary

The healthcare providers in this study were largely unaware of the practice-side economics of vaccination; however, the few clinicians who did speak to the profitability of vaccines indicated that vaccines, if generating income for the practice, were not significant sources of profit. A few providers did report that cost was a barrier to vaccination, but primarily for young women in their late teens and early twenties, who were no longer covered by their parents’ insurance plans and no longer qualified through
federal and state initiatives and programs. Several providers lacked awareness of available resources through which their under-insured and uninsured patients could receive Gardasil. This is concerning, given that (according to three providers) some parents would vaccinate their children if they were aware of low or no cost means by which to do so. Several providers also observed a trend in vaccine resistance, associating it with higher income, well-educated parents. These observations do not appear to characterize the vaccine choices made by parents in this study.

Parents perceived that high vaccine costs and low insurance coverage accounted for low rates of Gardasil uptake in the general population. Parents’ assumption that cost is a major barrier to uptake is interesting, given that only one parent could think of individuals within her community for whom cost might be an issue. The perception of cost-as-barrier is especially interesting because no parent, regardless of socioeconomic status or insurance coverage, identified vaccine cost as a significant barrier in their own decision-making process. Indeed, in most cases, parents did not even verify that their insurance companies would cover the cost of the vaccine before having their daughters vaccinated. Even among parents who would, or had checked on coverage, the prospect of paying full cost never viewed, in and of itself, as sufficient reason to reject the vaccine. The findings suggest that, at least for this group of parents, economic issues are of minor, peripheral, or no important in vaccine decision-making. In order to understand which factors are of key importance to parents, it is first necessary to describe how parents generally perceive the benefits and risks of vaccination, for many of these broader perceptions directly and indirectly shape the ways in which parents understand the Gardasil vaccine. In order to understand how knowledge is conceptualized or how it
factors into parent-provider conversations, it is necessary to discuss some of the patterns providers observed in parental vaccine hesitation or resistance to vaccines.
Chapter Eight – Benefits and Risks in the Context of Risk Communication

Although I am specifically concerned with how parents make Gardasil vaccine decisions, particular vaccine decisions are not isolated events. It is important to have a composite picture of parents’ general and specific views on vaccination because these views – developed over many years and in the context of vast cultural, social, and individual experiences – inform the ways in which parents perceive the Gardasil vaccine. Parents’ wider, more general perceptions about vaccines shape, to some extent, the ways in which they regard specific vaccines.

Therefore, I begin this chapter by describing parents’ general vaccine practices and perceptions, discussing first the benefits they typically associate with vaccination, following by a discussion of common vaccine risks. In the latter half of the chapter, I focus specifically on the benefits and risks that parents associate with HPV-infection and vaccination. I conclude with a discussion of the ways in which particular risks and benefits are negotiated through parent-provider interactions.

General Vaccine Benefits -- Individual and Collective Benefits and Responsibilities

All of the parents that I interviewed expressed general support for immunization. With the exception of one mother who refused to vaccinate her children against chicken pox, every parent reported that his or her children had received all school-mandated vaccines. Every parent recognized at least some benefits to vaccination, most often in

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preventing disease states in their own children and in the general population. Several parents saw the absence of specific diseases in their own or other children as proof that vaccines were successfully protecting the population from illness. Barb, a mother of three, is a staunch supporter of vaccines, pointing to her own daughters’ excellent health as proof of vaccines’ benefits:

I mean, I do firmly believe in the vaccinations simply because my kids have never ever been sick. They’ve obviously worked. And they’ve done what they were supposed to do, because like I said they’ve never got the chicken pox. They’ve never got the measles or the mumps. I mean they’ve never had any type of childhood disease . . . Ever. Which I would imagine is solely because they’ve had the immunizations for those childhood diseases.

Parents, especially those who remembered contracting diseases that are now vaccine-preventable, saw the eradication or decreased incidence of a disease as a significant benefit of vaccination. In particular, parents were grateful that their own children would not have to suffer the pain, discomfort, or lasting scars associated with diseases that they themselves had experienced. For example, Natalie, also a mother of three, was relieved that her children would avoid many of the vaccine-preventable diseases that she contracted as a child: “I had every childhood disease under the sun. I had German measles, measles, mumps, chicken pox. We all had it. I’m glad that my kids didn’t have to go through the whole mumps and German measles thing. So I think there’s a purpose for them, especially when it comes to population outbreaks.”

As Natalie’s comment suggests, many parents recognized the benefits of vaccines not only to protect the health of their own children, but to minimize or prevent disease
outbreaks. Parents (n=11) who discussed the societal benefits of vaccination viewed immunization as both a parental and social responsibility – necessary to protect the health of their own child but also to protect the health and well-being of the larger community.

Victoria, a mother of two, pointed to the eradication of diseases that had, in the past, killed children, as benefit enough to support immunization. “Statistically [vaccines] have virtually eliminated some of the diseases that commonly killed children. If we think of all the diseases that have virtually been wiped off the earth because of vaccines, I think that the benefits far outweigh the risk.” Courtney, who has three daughters, expressed similar support for vaccines, especially when she considered past epidemics and their effects on society: “I understand the need for vaccines. As a society to think that all humans are not going to be vaccinated is a very scary thought. We have gone through that and it doesn’t end well.”

Included in these narratives was recognition that enough individuals had to do their part in getting their children vaccinated in order to ensure that large-scale epidemics would not occur. Mark criticized well publicized anti-vaccine movements because members of these movements not only put their own four children, but the larger population at risk: “A really trendy thing to do in Hollywood is not to [vaccinate], but what they don’t understand is if all of them buy into this then all those kids are going to be at risk. The reason that [there aren’t] epidemics is because people are all vaccinated and so we are all protected.” Mike, a father of one daughter, was also critical of parents who abstained from vaccinating their children because he saw it as a form of selfishness. “I feel like it’s too much libertarianism. It’s like those gun nuts who insist on their rights to bring their rifles into a McDonalds.” In this case, Mike felt that people’s insistence on
expressing their right to abstain from vaccinating (or bear arms at McDonalds) reflected a wholly individualistic worldview; he saw people as either unable or unwilling to consider the risks that self-interested actions posed to others.

That some parents viewed immunization as a collective responsibility for the societal good is not to say that they saw vaccination as risk free; all parents associated at least some risks with vaccination, especially to the wellbeing of their own children. Rather, these parents generally saw the risks associated with vaccines as acceptably low, given the social benefits. From their perspective, all parents had to be willing to accept the minute chance that their own children would experience complications from a vaccine in order to mitigate the much larger possibility that many children would develop a disease if individual parents did not act.

Parents valuing this perspective were likely to support vaccine mandates and view as selfish parents who sought philosophical and religious exemptions—willing to benefit individually from the sacrifices of others. Mike was skeptical of parents’ motives for refusing vaccines, dismissing claims that there is any scientific evidence to support non-medical exemptions. He explained, “Like this sort of distrust of public health campaigns. I don’t see that it’s really scientifically-based and it just seems a case of self-interest trumping civic responsibility.” One mother’s perspective towards the collective benefits of vaccination exemplified the thoughts of many parents. Faith, who has one son and one daughter, recognized that there are diverse and complex reasons that parents do not have their children vaccinated, but ultimately concluded that, “If it’s for the good of the majority . . . then it’s kind of like, you need to toe the line. I mean you don’t want kids
coming down with childhood diseases. . . Certain things we just have to do for the good of everyone”

Most often resistant parents were perceived as shirking both societal and parental responsibilities. Christina, a mother of two, for example, had difficulty understanding how parents could refuse vaccines for their own children, asking, “How many kids have to die from a disease that we could have wiped out, or that could be nearly wiped out, before you understand? It could be yours. We’re not gonna do that to our kids.” Patty, a mother of three, was bothered that her own sister had not had her children vaccinated.

“I think it’s really dumb. It really bugs me. Drives me absolutely crazy. It’s their choice, but you know . . . I just think they’re kind of relying on all the rest of us to get vaccinated so their kids don’t have to. And I think it’s dangerous for the kids. If anything should happen they would be in real trouble.”

While parents generally supported vaccination as both an individual and community responsibility, some of their own practices and comments suggest that their commitment to collective social responsibility in vaccination was stronger in principle than in practice. One father, for example, strongly valued the collectivist sentiments underlying public health and was a staunch supporter of mass vaccination campaigns. Criticizing parents who reap the benefits of herd immunity without themselves having their children vaccinated, he admonished, “Come on! Be a team player”. I asked him how he would feel if the Gardasil vaccine were available to young men. He responded, “As the father of a daughter and no boys, I’m definitely in support that all the boys should get it (laughs).” I asked him whether he would feel differently if he had a boy. He replied, “It’s not like the inoculation comes with risky side effects or something like
that. It should just be a matter of course. It’s available, you get it.” Although the father was supportive of male vaccination against a disease that he primarily associated with causing harm in females, he opposed efforts to vaccinate healthy children and adults against the flu in order to protect “babies and old people”. In the case of HPV, the father was willing to support secondary vaccination of males to protect females, but in the case of flu, he was unwilling to support immunizing his daughter against the flu to protect the health of infants, elderly, and other at-risk populations.

Victoria also expressed values regarding collective responsibility that seemed to conflict with individual practices. She could not receive the flu vaccine because of an egg allergy, but actively encouraged others to get the vaccine so that she was protected. She explained, “I tell everyone else, ‘now ya’all get your vaccine so that the germs aren’t around for me to get.’” I then asked her if her own daughter got the flu vaccine and she responded, “No. She’s not one of the people at risk.” In this example, the mother used individualistic criteria in assessing whether to vaccinate her daughter, but expected those around her to get the flu vaccine so that she would enjoy protection from the herd.

These two examples serve as reminders that individuals stated values and beliefs do not necessarily translate into specific or predictable action. To assume a one-to-one connection between values or morals and action would be misleading.

**General Vaccine Risks**

While parents acknowledged both individual and collective benefits to vaccinating their children, they also recognized that vaccines are not without risks. Every parent with whom I spoke perceived at least some risk associated with receipt of a vaccine. The most commonly expressed concerns related to disease severity, short and
long-term adverse effects, vaccine components, duration of protection, and vaccine overload. Some of the risks discussed here pertain to all vaccines, while others are associated with specific vaccines. Although parents described Gardasil-specific vaccine risks, these concerns are described separately to highlight both overlapping and unique risk perceptions.

While some parents wanted their children to receive all available, recommended vaccines, other parents preferred to consider each vaccine individually. At least to some extent, perceptions of disease severity, and thus, vaccine need, shaped parental decisions. Natalie did not question the need for vaccines in general, but rather, “the need for all of them – I think that unfortunately we don’t need all of them, of what they give.”

Skepticism and concern regarding the need for vaccines was often discussed in relation to the flu and chicken pox vaccines. Just as parents recalled some of their own illness experiences when touting the benefits of vaccines, they pointed to other experiences to question the need for all vaccines. Many parents contracted chicken pox as children and had few complications from the disease. Given their own mild experiences with the disease, some parents felt that the vaccine was unnecessary. Theresa, a mother of two, argued that in fighting chicken pox, “You’re trying to basically obliterate a benign issue. Chicken pox is not a horrible dreaded disease.” Mike agreed, “[If my daughter] hadn’t gotten the chicken pox I probably wouldn’t have had her vaccinated because I don’t see it as severe. It’s more like the flu. I had it. I see it as unavoidable.” Several providers also reported that it was not uncommon for parents of pre-adolescent and adolescent girls to question the need for the chicken pox vaccine. A few providers (n=2) themselves questioned whether the chicken pox vaccine was necessary. Laura, a
nurse practitioner, acknowledged “[Vaccines] have great benefits but I don’t think all the time that the risks or possibilities of some of the problems *always* outweigh. For instance, the chicken pox vaccination. I mean, come on. We can’t get the chicken pox anymore? I think we’ve gone too far.”

Similarly, some parents (n=6) simply felt that a flu vaccine was needless and that the possible risks of the vaccine outweighed the risks of contracting the flu. Marie, who has a son and daughter, did not vaccinate her children against the flu, reasoning that even if they caught the flu, it was unlikely that they would have severe consequences from it. In explaining her rationale, she associated severity with need: “It’s one less vaccine I feel they *have* to have right now.” Though Mike believed that the flu vaccine was an important technology for some segments of the population who could suffer severe consequences of infection, he did not believe that “a healthy 13 year old is seriously vulnerable to the flu”. He explained, “It seems frivolous and a waste of time and resources for me. I mean, fine, for infants and old people, yeah. But I’m not going to run around getting vaccines for myself or my school kids. It just doesn’t seem appropriate.” Mike’s rationale is contingent upon a connection he draws between disease severity and perceived susceptibility.

Parental decisions regarding the chicken pox vaccine perhaps most clearly illustrate the relationship between vaccine risk, perceived disease severity and susceptibility. In the case of chicken pox, age became a key variable tied to assessments of susceptibility. A few parents (n=3), who originally avoided the chicken pox vaccine when their children were young, reconsidered the vaccine years later, when they felt that chicken pox infection could pose much more serious health risks to their (now older)
children. For example, Marie resisted vaccinating her children up to a certain age, but then decided that given her daughter’s age, the risks of the disease outweighed the risks of the vaccine. “As [my children] got older I felt that they were too old to be dealing with chicken pox. I think they were 12 and 14. I felt that the chicken pox were [sic] more damaging to them than the actual vaccine.”

Individual health profiles were important in some parents’ assessments of whether vaccines were safe for their children. Most often (n=6), children’s specific health conditions were cited as reasons to vaccinate – especially against flu. Alice had all four of her children vaccinated because they suffer from asthma and Jill, a mother of three, always has her sons vaccinated, but normally does not vaccinate her daughter.

In contrast to the flu and chicken pox vaccines, which were generally viewed by parents as benign illnesses (with individual and age-related exceptions), the meningitis vaccine was seen as invaluable because meningitis, though rare, was perceived as life-threatening. As one mother succinctly put it, “meningitis is just plain scary.” Parents whose children had not yet been vaccinated indicated that future vaccination was imminent.

Elizabeth, a pediatrician, agreed that when it comes to vaccine coverage, “Tetanus is the easiest. Meningitis is probably second. Those are the easiest, top two. Hands down.” Other providers agreed that parents generally and readily accepted the meningitis vaccine. Several providers (n=4) attributed parental interest in the vaccine to media coverage documenting local deaths caused by meningitis. Sophia recalled a recent case in which a local university student died of meningitis. The case received wide media coverage. “That completely changed [how parents felt about the meningitis vaccine] and
people were coming in droves to get it, after the news.” Elizabeth referred to the same incident in explaining why so few of the parents in her practice refuse the vaccine.

“[Parents] know meningitis is bad. They know people die from it. And it’s news stories like that – they die from an illness that is preventable with a vaccine. Those parents are on board. It’s a very well accepted vaccine in my practice.”

Along with vaccine need, some parents questioned the safety of specific vaccines; again, the flu and chicken pox vaccines were commonly mentioned. In the case of the seasonal flu vaccine, the fact that a different vaccine is manufactured each year led some parents to feel that the vaccine can never be tested for long-term safety. In the case of the H1N1 vaccine, its rapid emergence onto the market led others to doubt its safety. Natalie was unwilling to have herself or her children vaccinated against H1N1 because in her opinion “there’s not enough research done on it, it was put out too fast”.

The newness of a vaccine was associated with concerns about its long-term safety. Especially when it originally came out, parents expressed fears about the newness and necessity of a chicken pox vaccine. Several parents (n=3) delayed having their children vaccinated as long and possible in order to assess the safety of the vaccine; in order to avoid making a decision altogether, three parents actively sought to expose their children naturally. Marie explained, “I did hold off on the chicken pox, just because I thought it was too new at the time. So I waited until the very last minute that they could still get it and then I decided that I probably should. I usually like to wait on them until I get some of the feedback from the vaccines.”

Along with disease severity, parents also expressed concerns about the effectiveness of vaccines, especially new ones. Many parents (n=12) worried that
vaccines would either cause or fail to protect their children from the diseases they were intended to prevent. A few parents (n=4) were concerned about a vaccine’s ability to provide long-term immunity from a disease. Especially in the case of the chicken pox vaccine, parents worried that immunity would wear off when their children were older and were more likely to suffer severe consequences from the illness. For example, Theresa, whose children had received all of their recommended childhood vaccines, did not want to vaccinate them against chicken pox. She was relieved when both of her children naturally acquired the infection. Explaining her hesitation, she recalled, “[When it came out] all I kept thinking is: you’re taking a disease that’s an inconvenience for working parents to stay home for a week with their child, and you are making it an adult disease where it \textit{does} become dangerous as an adult.” Sarah, a mother of three who described herself as pro-vaccine, expressed similar fears. “What happens if it wears off and my daughter is at a child-bearing age and she gets exposed to someone with chickenpox?” After failed attempts to have her daughter naturally acquire the disease, she eventually acquiesced and had her vaccinated.

While some parents questioned the long-term immunogenicity of vaccines, parents also questioned whether some vaccines worked at all (n=4). Questions about the effectiveness of the chicken pox vaccine caused Faith to delay making a vaccine decision: “There are kids who have gotten [the vaccine] but have still gotten chicken pox, although a lot milder. So then you’re just questioning does it really work?” Coupled with concerns regarding the efficacy of specific vaccines were fears that some vaccines could cause the very diseases they were supposed to prevent (n=6). One mother pointed to the polio vaccine and another mother to the measles vaccine when referring to this risk.
Most commonly, however, parents (n=4) implicated the flu vaccine as the prime example of a vaccine that can cause the disease it is supposed to prevent. Tony, the father of one daughter, now gets the flu vaccine but thought for many years that “The flu vaccine gives you the flu. I believed that for years and never got the flu vaccine.” Although some parents did think that children could develop diseases from vaccines, several thought that the disease would be less severe; from this perspective, the failure of the vaccine to completely prevent disease was less important than the vaccine’s ability to lessen its severity. Alice expressed this viewpoint when explaining why she felt that a vaccine-induced illness would be less severe than a naturally-acquired strain of the disease: “The main thing people think of, and I think of too, is sometimes getting what they’re trying to vaccinate you against. You hear about those live vaccines. Like the one with the flu. [But] a little bit of [flu] is better than having a full blown case of it. If it’ll help me build up what I need to not get it, then I’d rather have that.”

When considering vaccine risks in general, parents expressed anxiety that certain vaccines could cause Guillain-Barre syndrome, autism, or developmental impairments, although they were unsure which specific vaccines were associated with these perceived risks. Four parents worried that vaccines could cause Guillain-Barre syndrome, and several providers (n=5) reported that this was concern among their own parent populations.

The long-term adverse consequence that parents most often associated with vaccination was autism. Healthcare providers (n=8) also reported that autism was a significant concern among parents in their practices. While many parents (n=12) considered autism to be a possible vaccine risk, only two parents altered vaccine
decisions because of this fear. Autism concerns were key to one couple’s decision to postpone giving their daughter any vaccines until immediately before she entered kindergarten (with their subsequent three children, they followed the recommended schedule) and Rachel, a mother of two, was unsure whether her 12-year old daughter would receive her MMR booster because she was particularly concerned about autism.

Autism, in particular, was a risk associated with vaccines administered during the first few years of life. Some parents (n=4) recalled anxiety when making past vaccine decisions for their older children or current vaccine decisions for their younger children. In recalling some of her earlier vaccine decisions, Evelyn, who has one daughter, shared, “I did have an autism concern, you worry about whether your baby is healthy, and you don’t want to harm your baby. So yeah, I was concerned but I still felt that positives outweighed the negatives. I know that it’s now a huge question for a lot of vaccines.”

Many of the parents (n=6) who mentioned a possible link between autism and vaccines did not themselves believe this was a concern; rather, they attributed this fear to other parents or as a common risk publicized in the media. Both parents and providers pointed to the media role in publicizing and increasing public attention and fear regarding vaccine-related autism. As one mother explained, “I used to not worry about vaccines at all, but now that you hear so much about how they cause, can cause autism – like they think that there’s a connection with the autism, I’m more cautious.”

The actress Jenny McCarthy has been vocal in insisting that vaccines cause autism and are responsible for causing her own son’s autism. McCarthy has become a leader in the anti-vaccine and vaccine safety movements, making radio, print, and
television appearances to advocate for “greener” vaccines. Her name was mentioned by both providers (n=6) and parents (n=4) when discussing autism-related vaccine fears.

The role of media in disseminating vaccine information (and at least in the following example, shaping parents’ risk perceptions), is clearly illustrated by one father’s reflections on vaccine safety. Mark and his wife had delayed vaccinating their first daughter due to safety concerns that were intensified through popular media coverage about vaccine risks at the time. He explained that news reports “saying they’re putting mercury into your kids” are hard to ignore. He noted that he and his wife “would still have been on the McCarthy campaign bandwagon” if they hadn’t “pushed to find the other side of the story”. Interestingly, Mark got the other side of the story from another actress, Amanda Peet. The father largely accepted McCarthy’s claims until he heard a radio show in which prominent vaccine expert, Dr. Paul Offett, and Peet were discussing the benefits and importance of vaccines.

Sometimes parental concerns about vaccine-related risks were more general. A few parents felt anxious about aspects of vaccination of which they knew relatively little. One mother asked of vaccines in general, “What are the long term effects? Do they cause other things? How do they attack your body? Are they stored in our liver? Do they become toxic – do they cause toxicity in your liver? Do our bodies totally absorb them? How do we deal with antibodies?”

A few of the parents (n=4) in the study expressed fears regarding the number of vaccines administered in one visit and the age at which children receive vaccinations. Along with the number of vaccines that children received, concerns were raised by three parents about the chemicals contained within them. Natalie had heard that the flu shot has
mercury in it, which led her to question why the government would encourage its citizens to be injected with a mercury-containing vaccine when “we know there’s a possible link between mercury, autism, and Alzheimer’s”. Natalie originally feared the contents of a specific vaccine, but that fear led her to develop a more generalized concern about governmental safety and regulatory procedures and to question who benefitted from public health immunization campaigns.

That there lacks factual and scientific evidence to support beliefs that, for example, the flu vaccine contains mercury or that vaccines cause autism is largely irrelevant, because such beliefs exist and flourish irrespective of published studies and reports to suggest otherwise. More relevant is to understand not only how risk perceptions affect decisions to accept, defer, or refuse vaccinations, but also how such perceptions are both shaped by, and can shape, the ways in which parents perceive public health institutions, governmental interests, and clinical practitioners. The example illustrates, once again, that specific vaccine decisions (e.g., Gardasil) are not isolated, discrete events; rather, they are part of a much wider, contextually-located and experientially informed constellation.

**HPV Vaccine Benefits**

All but one parent discussed at least some benefits associated with the HPV vaccine. “Protection” was most commonly cited as a benefit of the vaccine, though the thing from which the vaccine provided protection varied. For a few parents, protection itself was a benefit without a necessary object. That a child was protected against

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33 The flu vaccine does not contain (methyl) mercury
something, regardless of what that something was – was central to some parents’ descriptions of why they chose Gardasil. Protection, in some ways, became a form of reassurance, both that parents were “guarding” their daughters’ long-term health and that they were doing everything they could as parents for their daughters. Alice, for example, did not know what HPV stood for or what the Gardasil vaccine protected against when her provider recommended it. She had her daughter vaccinated that same visit, explaining, “[I got it for her] to prevent disease. This is what we do for our kids. My daughter had this because it seems like it will prevent future heartache or disease, so that’s kind of why I did it.” Another woman, when explaining why she would support an HPV school mandate, said, “I just feel if it’s protecting your daughter, why wouldn’t you want to do it?”

Some parents described the vaccine as protecting their daughters against more specific diseases, but these specific forms of protection were secondary to the larger goal of making decisions that were generally protective. As one mother said it, “And of course I want to protect [my daughters] in any way that I can. So that’s why I wanted them to get the shot.” Another mother identified protection from HPV, genital warts, and cervical cancer as benefits of the vaccination, but for her, the Gardasil vaccine was really about protection writ large. This mother was battling breast cancer and worried that she might not be around to protect her daughter in the future. Any protection she could provide for her daughter was reason enough for her: “I just want to protect her. And that’s the whole thing about the Gardasil, is I get protection”.

Overall, parents saw cancer prevention as the primary (and sometimes exclusive) benefit of Gardasil. When describing the benefits of Gardasil, two parents thought that
the vaccine protected against some types of cancer, though they were not sure which ones. For these parents, the specific type of cancer-protection afforded was largely irrelevant because any reduction in the risk of developing cancer was beneficial in itself. As one mother put it, “My thought is, if it can prevent cancer or a worry of cancer, I’m there.” More than half of parents (n=16) identified prevention of cervical cancer as the primary benefit of vaccination. The fact that the vaccine could protect their daughters from the possibility of cervical cancer was a major benefit to getting the vaccine (though recognizing cervical cancer protection as a major benefit did not always lead to vaccination). Eleven of these parents had at least begun the three-dose Gardasil series.

Slightly more than a third of parents (n=10) understood that the vaccine would not protect their daughters from every type of HPV that can cause cervical cancer, but most of these parents (with the exception of one) saw any reduction in risk as a potential benefit of vaccination. As Theresa explained, “It’s good to know in my eyes that, yes, she has [been vaccinated] and no, it’s not going to prevent [cervical cancer] completely. and it’s not like you still don’t have to get exams done, but to know that she’s protected is a good thing.” Despite its limited ability to protect against all forms of cervical cancer, Gardasil provided parents with the reassurance that they had taken advantage of an available technology to protect their daughters’ health.

Only five parents knew that the vaccine protected against genital warts and all five of these parents listed prevention of warts as a benefit to vaccination. After learning through the course of the interview that the vaccine protected against genital warts, parents saw it as a significant added benefit of vaccination. One mother, who had already vaccinated two of her daughters without knowing that Gardasil protected against 90% of
genital warts was sure that her provider never mentioned the benefit to her, because if he had, she would have remembered. While she was not upset that her provider had left out this detail, she would not have minded if he had mentioned it because it would have been “one more good reason to get them vaccinated.” Another mother, whose experience was similar, described as “fantastic” the fact that her daughters were also protected against some types of genital warts.

Nearly half of the parents with whom I spoke mentioned that they or someone close to them had experienced complications due to HPV infection. All of the information that parents provided about their own or other’s experiences with HPV infection were self-reported; I did not ask parents whether they or people they knew had any HPV-related illnesses. That so many parents volunteered this type of information suggests that personal, family, and peer experiences with these diseases help parents to frame issues surrounding vaccination.

Eleven parents described their own or other’s experiences with cancer in general, cervical cancer, hysterectomies, cryosurgery, abnormal pap smears, HPV-related infertility, or genital warts. Ten of these parents specifically pointed to these experiences as a reason to consider the HPV vaccine. Along with the physical effects associated with HPV infection, parents did not want their daughters to experience the uncertainty, trauma, and fear that are associated with abnormal pap smears, biopsies, and treatments for HPV-associated infections. One mother recounted the psychological trauma that she experienced when she found out that she had abnormal cervical call

34 One woman, whose mother had a hysterectomy due to cervical cancer, was not convinced that the vaccine could prevent cervical cancer, and therefore did not see the vaccine as beneficial in this way.
growth. She would never wish that any woman, especially her own girls, feel the same sense of fear she felt throughout the diagnosis and treatment process. “I had two spots on my cervix that were removed. It was very scary. Very, very scary. [Here I was] in my mid-thirties with three small children and I would not want that to happen to my girls. They did a biopsy first and then a cone . . . I was lucky, I think, to be able to have what is a simple procedure. It could have been devastating.” In vaccinating his daughter, one father hoped to spare her the anxiety of receiving abnormal pap results. He explained that he would consider the vaccine a success if it could save his daughter from “Getting the news of an abnormal pap and not knowing what it means. If I can help her not have a couple of those phone calls then it’s worth it.”

Several parents knew of women who had developed cervical cancer or other forms of cancer. Parents did not want their daughters to fall victim to similar diagnoses if it could be prevented. One mother pointed to her own family’s history of reproductive cancer as part of the reason she chose to have her daughter vaccinated. “I have a cousin who had cervical cancer and I thought about that . . . Plus my mom died of breast cancer pretty young. So anything I can do to help my daughter, prevent her from having any serious illness.”

Several providers (n=3) also reported that parents sometimes want the vaccine because they think cervical cancer is hereditary. “I’ve had some of the parents tell me, here is what they say: HPV runs in the family. So there’s a bit of a learning issue with that. But they think it’s something a little bit more genetic and that that’s their risk factor . . . I’ve heard ‘It runs in the family’ a lot.” Another provider heard similar statements at her office. “I’ll have people say, ‘Oh, we definitely want her to get
[Gardasil] because cancer runs in our family.’ I hear that a lot. And then I explain to them that this isn’t something that would run in the family, but I hear that fairly frequently. Yes, we want her to get that because cancer runs in our family.”

**Times of Risk: Vaccine Innovation, Safety, and Immunogenicity**

The newness of the Gardasil vaccine was central to many parents’ concerns; the fear of “unknown risks” was unquestionably the most commonly associated fear with the vaccine. Twenty-four parents worried that there could be negative long-term health effects associated with the vaccine that had not yet been discovered or documented. Parents did not always specify particular types of long-term health risks that they feared, but rather spoke of the unknown consequences as anxiety-inducing. Complicating or contributing to the risk of unknown adverse effects and vaccine safety were concerns about pharmaceutical company motives and the relationships between government agencies, vaccine manufacturers, and providers; these particular concerns are discussed thoroughly in Chapter Ten.

When explaining why some parents in her practice are hesitant to have their daughters receive the HPV vaccine, Robyn, a Florida nurse practitioner, concluded, “They don’t usually have anything specific in mind. Just that it might be dangerous, and it’s all very amorphous. They don’t come in with specific dangers in mind, they just say that their kid’s a guinea pig.”

Helen, the mother of a nine year old daughter, was concerned about the newness of the vaccine, but could not pinpoint exactly what she needed to know about the vaccine to make her feel comfortable enough to give it to her daughter. “I mean, I’m leaning towards getting it for her, but I have to – I want to reassure myself to look into those,
because I just have vague questions about whether or not this vaccine is safe and how long it’s been tested and what are the side effects”. Wendy, who has a son and two daughters, also wanted to know more about the long-term effects and attributed some of her own anxiety about the vaccine to her own lack of initiative in seeking out more information about the vaccine. In describing her hesitations, she asked, “How much research is out there that shows long term statistics? I’m nervous because I didn’t do my homework on this, that’s probably why. That’s how I’d do it first. I just don’t know much about it yet. I don’t.”

Parents who did discuss specific long-term risks most often worried about detrimental effects to their daughters’ future fertility or general reproductive health. It is unclear from where these concerns arise. It might be that reproductive and fertility fears relate to the fact that the vaccine is associated with diseases affecting the reproductive tract. It also could be that parents assume that the initial cohorts of pre-adolescent and adolescent recipients of the vaccine have not yet reproduced, thereby limiting our knowledge of whether issues with fertility and pregnancy exist. Several parents also mentioned thalidomide in particular; it could be that parents recall this particular drug effect, which happened to result in high rates of miscarriages and birth defects.

Courtney took her two eldest daughters to receive the vaccine and plans to take her younger daughter to be vaccinated in the future. Reflecting upon her own concerns regarding the vaccine, she explained, “It’s something new and with anything new it’s a natural fear of what’s going to happen to my daughter thirty years from now. That was a lot of my questioning. She is still growing at 16, what’s going to happen if she wants to
become a mother some day? Are we going to see any side effects that would hinder that possibility? And not even related to that, what about the liver, kidneys?”

Natalie questioned whether the vaccine had been studied long enough for researchers to state that there were no long-term safety effects. “Tell me what, you know, ten years down the line here. Is that long enough to study a drug? I don’t know. I went to school with kids that had a short limb because their mothers took thalidomide. I went to school with kids whose mothers took tetracycline when they were in the womb and their teeth were all completely gray. And they didn’t find that out until how many years later? Twenty years later. So how long do you have to go?”

Marie, who was leaning towards vaccinating her 16-year old daughter, explained similar misgivings. “There isn’t this long history of HPV. And I wonder, what are the risks if someone takes this vaccine now, twenty years [later], is it going to mean something not so good for [my daughter]?”

Four providers noted that at least some mothers express specific concerns about Gardasil’s long-term reproductive effects. When I asked two providers to describe some of the common questions and concerns their parents expressed when discussing Gardasil, both mentioned long-term reproductive effects as a common issue. One Florida provider explained,

[Parents say,] “It might be good now but in two years they’re going to tell me that it causes sterility.” Oh! That’s a big one. That my child won’t be able to have babies because of the Gardasil. I think those are the major ones that they come with . . . I’ve had quite a number of them think that that’s going to be a problem. Or just because the research isn’t out that, you know, that . . . either they’ve heard
that it does [cause long-term reproductive problems] or what if it does? What if in 20 years she can’t have a baby because of Gardasil?

A Pennsylvania provider also self-identified long-term reproductive consequences as a common concern among parents in her practice as well.

Here’s the big one: They say that they’re afraid that it’s going to make them infertile. I hear that a lot. A whole lot. And I always tell them, “Well cervical cancer can do that to you, but there have been no reports at all about infertility with the Gardasil”. But that’s a big one. I don’t know where that comes from. I don’t know if it’s just like an urban myth that’s been spread out there or if there’s something on the internet, but there’s no, you know, logical basis for it. Then I’ll say to them, “Well where did you hear that from?” and they’ll say, “Well somebody else told me that” or they’ll say something like “My friend is a nurse and she said that you have to watch out for stuff like that. They might become infertile.” It’s just bizarre to me, I don’t know where it comes from. But I’ve heard it. I’ve definitely heard it a lot.

As this provider notes, cervical cancer (as well as pre-cancerous HPV-infection) can lead to infertility, yet only one parent viewed prevention of infertility as a benefit of vaccination. It was much more common for parents to see the vaccine, rather than HPV, as a threat to their daughters’ future fertility.

Questions regarding the duration of vaccine protection – if and when a booster would be required – also factored into some parents’ (n=7) vaccine decisions. Parents were unclear regarding the length of immunity provided by Gardasil and felt that having such information would help them decide when to vaccinate their daughters. Theresa
wanted to know “how long down the line do they know when they’ll need a booster shot? Or will they need a booster on it?” Mark asked similar questions, “Is it a one vaccination for a life type of thing? Or is it something that she’ll have to get – like suppose ten years down the road they find that those first batch of girls are no longer protected?”

Duration of immunity was especially important to four parents who did not think their daughters would become sexually active in the near future. Parents wanted to maximize “productive” use of the vaccine. One mother thought carefully about when to vaccinate her daughter given the lack of information she had about a booster. When she discussed Gardasil with her daughter’s provider she focused on vaccine coverage:

One of the biggest questions I had – and I don’t know that she gave me a straightforward answer or not – was how long they expect that vaccine to last. And I think she said five years. And I was thinking in my head, well, she’s 15 now. If it’s only five years, she’s going to be 20. Is she going to have to need another vaccine? Should I wait? Should I do it now?”

The same mother had postponed the decision several years due to concerns about vaccine timing. She felt one had to consider “how old she is and how long the vaccine was going to last. And I just think nine, ten, eleven, that’s way too young. And even thirteen. I was like, wow! She’s only going to be 18 by the time that it’s not going to be as effective.” She felt that the gap between the time when the vaccine was administered and the time a girl would likely become sexually active was too great – by the time the vaccine could protect her daughter from exposure it would already be losing effectiveness.
Booster concerns were part of the reason another mother had deferred making the decision to vaccinate her ten year old daughter. Jill wanted to ensure that her daughter benefited as much as possible from the vaccine, but she also did not want to wait so long to vaccinate her that her daughter made the decision without her input.

I think in my mind, if I gave it to her when she was ten and she’d have to get boosted again when she was 17. Hopefully – I say hopefully because I know the statistics prove otherwise – but I would hope by 17 that she wouldn’t have (whispers) had sex. Hopefully. But then at – when she’s 17 I think it’d be more her choice to have another one or not. So I don’t know, maybe if we did it when she was 14 or 15 then – that seven year window would be when she’d be more in college? (laughs) Where I wouldn’t know what she’s doing unfortunately (laughs).”

She continued, “I don’t know, maybe I have the wrong idea of it, but if you get it when you’re ten does it provide – like, what’s the immunity that it provides? You know what I mean? Like, would you have to get a booster later on or is it better to get it later on when you think you might be entering that realm of exposing yourself to that.”

These parents considered two dimensions of time when considering Gardasil. Like other parents, who were concerned with safety, parents wanted to delay vaccine initiation as long as possible, but while their daughters were still virgins. The difference is that concern regarding vaccine duration rather than vaccine safety led them to delay initiating the series. Vaccinating too early might then leave the child unprotected when she would much more likely be in need of protection. One mother reasoned that if she vaccinated her daughter at age 9, she might become vulnerable to HPV again at age 19.
Since the mother hoped her daughter would not become sexually active until at least fifteen or sixteen years of age, she thought it made more sense to vaccinate at 14 and ensure her daughter was covered through her mid-twenties.

Parents thus had to evaluate how long to defer a vaccine decision in order to maximize coverage before their daughters became sexually active. For a few parents, insurance coverage and personal control also factored into the timing/booster element. If daughters were in need to booster shots at ages 19 or 20, they probably would not be covered by the parents; insurance plan and the parents’ could not ensure that their daughter’s would actually get the booster shots.

Finally, some parents (n=8) described what they perceived to be minor risks associated with Gardasil, but emphasized that these same risks. Commonly cited risks included pain and swelling at the injection site and fever. Only a few parents (n=3) described fainting as a Gardasil specific risk.

**Provider Assessments of Vaccine Safety**

Parents looking for provider guidance in determining a timeframe for establishing vaccine safety would likely not receive uniform responses. In this study, the physicians and some nurse practitioners were confident that Gardasil was safe and had been studied for a sufficient length of time. The chiropractor and five nurse practitioners, however, were less sure of the long-term safety of the vaccine. While most of these nurse practitioners felt confident enough in the vaccine’s safety to recommend it, they were also much more willing to respect and appreciate parental concerns regarding long-term safety.
Several nurse practitioners raised concerns about long-term immunity provided by Gardasil. One nurse practitioner worried, “We don’t know how long it confers immunity. There’s just too much unknown about it.” Another NP echoed her concerns, “Exactly how effective is [the Gardasil vaccine] doing what it says it’s going to do? And how long is it good for?” A third nurse practitioner said, “We don’t know how it’s going to affect people in 15 years. The one thing we do know, pretty much about all vaccines now, is that they don’t last forever. And so when are you going to need to have that vaccine repeated? We have no idea yet.” Lydia, a school nurse, did not have any concerns about the vaccine other than the newness of it. When I asked Lydia what constituted newness – at what point the vaccine would no longer be new – she responded, “You know, that’s really hard to answer. I would like to say – and this I’m pulling out of my brain, but to me it seems like after five years [post-licensure] maybe you’re starting to get a pretty good comfort level. But again, that’s probably a real poor number because who knows?”

Lydia’s question of “who knows” is at the heart of safety disagreements between some providers and parents. Distrust and doubt can arise when parents are unsure that anyone can know when a vaccine is safe and providers believe that they, or epidemiologists and biostatisticians, or vaccine experts, or the FDA and CDC can know – and do know – that the vaccine is safe.

Different views about what constituted safety and how much time was required before something could be deemed reasonably safe led to very different assessments of vaccine safety. Physicians, and most nurse practitioners, believed that the criteria established by the FDA for establishing vaccine safety were sufficient and therefore felt confident in the safety of the vaccine. Parents, and a few nurse practitioners, were
doubtful that enough time had lapsed or enough girls had been vaccinated to confidently know whether the vaccine was safe.

Most providers felt that the pre-licensure studies provided sufficient evidence of the vaccines long-term safety and efficacy. However, parents sometimes made comments to suggest that vaccine safety had to be assessed post-licensure. The test subjects who would ultimately determine whether there were serious adverse effects were the cohorts of girls across the country who received the vaccine after it was marketed to the general public. One mother, who had not yet vaccinated her daughter, explained, “I haven’t done enough research on long-term effects or anything like that. I don’t know if that’s out yet.” Another mother had her daughter vaccinated, but originally described herself as feeling “leery of something that I feel is fairly new and untested” These comments reflect a belief that even after vaccine approval, long-term safety information is not available and that girls who are vaccinated post-approval are part of the research.

Providers evaluate safety based on population-level probabilities of risk, while parents are concerned about their child’s individual risk. Providers often trust in the vaccine review and approval process. Often times, their own assessments of safety are based on the fact that a vaccine has been vetted and approved by the government. When a vaccine has been studied for a specific period of time and on an adequate number of people deemed sufficient to detect in sufficient quantity the common and rare short and long-term effects, assessments of safety are made by biostatisticians, medical doctors, vaccine experts, and epidemiologists. A vaccine is deemed safe and appropriate for public use not when vaccine risks are eliminated, but when the vaccine’s risks are
deemed sufficiently low, and its benefits sufficiently high (Hoskins 2010; Rodricks and Tardiff 1984).

However, what might be deemed as an acceptably low risk for the population might be too high a risk for an individual child. Parents are not worried about population-level risks of vaccines, but rather, about the direct risks to their children. When it came to one’s own child, parents wanted to know how much time was really need to evaluate the safety of a vaccine. Natalie questioned, “Is ten years long enough to know?” Parents’ inability to confidently answer this question often led them to delay making a decision about the vaccine.

Lack of consensus among providers about the amount of time required to evaluate the safety of Gardasil increased some parents’ conviction that the vaccine was too new and that too many questions remained unanswered. The different standards applied by healthcare providers to evaluate the safety of a vaccine could solidify parent doubts that current safety standards are sufficient. One mother emphasized the need to use her own intuition when making healthcare decisions because “so many doctors, they’re just not on the same page. One believes this way and one believes that way, so you just have to go with your gut feeling. And that’s what I try to do. With the information that I have I try to make the best decision.”

Among the providers (primarily physicians) who had strong faith in the rigorous governmental process for evaluating the safety and efficacy of vaccines, the amount of time needed to evaluate the safety of a vaccine was the number of years the vaccine was studied prior to its FDA approval. Some providers, who felt that the current long-term safety data were satisfactory, took time to explain the process through which HPV safety
data were obtained, in hopes of allaying parent’s fears regarding the long-term safety of the vaccine. While providers reported that such explanations sometimes addressed parents’ concerns, in other cases, the most complete and accurate description of the vaccine research served not to allay fears, but rather solidified them.

Parents who expected that decades of vaccine safety and efficacy testing be completed before considering the vaccine safe and effective for use (in the general population or for their child’s use), tended to dismiss the existing HPV safety studies as incomplete. In these cases, providers’ attempts to provide the specific details of the safety studies backfired. While providers might deem the information to be proof of a lengthy and rigorous process, parents might consider the exact same information to be inadequate and premature. The ability to differentially interpret the same scientific facts should once again remind us to question the tenuous assertion that individuals are more likely to “comply” or “adhere” to public health and provider recommendations if they have more biomedical knowledge regarding a technology, disease, or process. In this case, the opposite seems to be true.

The following three quotations reveal some of the conflicting views that providers and parents have about vaccine safety and how much time must pass before a vaccine can generally be considered safe. In responding to parent concerns regarding the newness of the Gardasil vaccine, two pediatricians, the first from Pennsylvania and the second from Florida, explain:

“A common misperception that people have is they don’t think [Gardasil has] been studied well enough, that it’s too new. That we don’t know the side effects of it. They definitely think that.”
“They just don’t believe the – I’m sure they just don’t understand how stringent the process is to get something approved like this.”

“I first tell [parents] that even though it’s only been used in the US for about two years they were using it in other countries – particularly in Europe . . . for years – seven years even, before we even brought it over.”

The latter pediatrician clearly felt that nine years of research and use was sufficient evidence of the vaccine’s safety, but she further explained that many parents think nine years is insufficient. When parents say this, she asks them “Well how much research is enough for you? And I had one dad tell me (laughs) twenty years! I was like, okay sir, there’s just no helping you.”

The pediatricians’ responses not only highlight variations in the ways that they and parents evaluative the length of time necessary to conclude that a vaccine is safe, but also that the pediatrician’s view – that the government’s vaccine vetting process is stringent, thus assuring ample time was spent collecting and reviewing safety data – was the ‘correct’ view. The first provider used the word “misperceptions” to refer to the time criterion used by some parents to assess vaccine safety. In the latter case, the provider dismisses the parent’s concerns as beyond help (or, perhaps, persuasion). While differences in the ways in which providers and parents collect and evaluate knowledge are specifically discussed in the next chapter, competing knowledge claims, as expressed through provider narratives, are evident throughout the dissertation.
Risky Relations: Promiscuity and Sexual Behaviors

Another commonly cited risk associated with Gardasil had to do with the effects of vaccination on girls’ sexual behaviors and beliefs. Early research on anticipated acceptance of an HPV vaccine suggested that parental concerns regarding the effects of vaccination on sexual behavior might lead to low acceptance rates (Brabin, et al. 2006; Davis, et al. 2004a; Liddon, et al. 2005; Olshen, et al. 2005). Central to concerns regarding sexual behavior were fears that vaccinated girls might believe that they were protected from all sexually transmitted diseases and would therefore engage in unprotected sex or have sex with a greater number of partners. Another fear is that receipt of the vaccine would be viewed by girls a license to become sexually active or be interpreted as, if nothing else, parental indifference to their sexual behavior. Concerns about promiscuity, while commonly mentioned by parents, seldom played a significant role in their vaccine decisions.

Concerns regarding promiscuity were mentioned by many parents (n=17), though often when discussing fears that other parents had regarding the vaccine. When asked why other parents might not want to give their daughters the Gardasil vaccine, more than half of parents (n=18) suggested that sex-related fears would play a role. For example, Tony had no concerns that vaccinating his daughter would give her a false sense of security or be interpreted as a license to have sex; however, he observed that among his friends, he held the minority view. “[For] my evangelical Christian friends it’s more about the topics surrounding premarital sex. And they tend to equate disease with premarital sex. Disease with promiscuity.” Melissa, who has one sixteen year old daughter, felt that much of the resistance to the vaccine related to promiscuity, though she
had not spoken to anyone who actually held this view: “It seems to me that there are a lot of people that have sort of negative thoughts about the HPV vaccine, but a lot of it seems to be, ‘Well if you get the vaccine then your kid’s going to be sexually active,’ and I just think that’s a ridiculous argument.”

Several parents likened HPV vaccine decisions to decisions regarding birth control, where parents feared that accepting either technology sends a message to the daughter that sexual activity is permitted or even encouraged. “I almost questioned why they offered [the HPV vaccine] so young. Why would you do that? Like, I almost think that it maybe puts in the kid’s mind – I mean, at nine years old, I don’t know. But I think almost that’s one of those things that might put, like, that false sense of safety in their head. Like, well, if I get the shot then I’m prevented against all these things. Not just HPV.” Several other parents (n=4) also similarly questioned the age at which girls received the vaccine and whether it was too young.

Most parents (n=10), however, generally dismissed concerns that helping their daughters obtain either the Gardasil vaccine or birth control pills would actually encourage them to become sexually active. As Helen put it, “There are lots of parents that think if their children are offered birth control that it will make them more promiscuous. You know, I can understand that in a way. But if kids are gonna have sex, they’re gonna have sex.” Victoria had heard similar concerns: “That the girls will think because they have this vaccine that they can be more promiscuous because they’re protected [. . .] I know that’s why parents don’t want their girls to be on birth control. Because they’re morons (laughs). They think that that’s gonna make a difference.” These
parents reasoned that adolescents, who wanted to have sex, would have sex, regardless of whether they benefited from the protection of birth control pills or a vaccine.

A few parents (n=6) did worry about the effects the Gardasil vaccine might have on their daughters’ sexual behavior, though none of these parents reported that their fears were sufficient to keep, or have kept them from vaccinating their daughters. Jill, who had not yet vaccinated her daughter but was fairly sure that she would eventually, shared some of the concerns that she and her friends had recently discussed.

[The vaccine] might put that false sense of safety in their head. Like, “Well, if I get the shot then I’m prevented against all these things.” Not just HPV. If they think that they’re now protected against something then maybe they won’t think twice. You don’t want to encourage – I guess that’s the sense of false protection, if they’re thinking, “Oh I had the shot and I’m good”.

Even though the majority of parents did not strongly believe that promiscuity or a false sense of security would result from giving their daughters the Gardasil vaccine, such concerns influenced several parents’ (n=6) decisions to alter when they had their daughters vaccinated and/or the content of vaccine conversations. Bill, the father of two girls, explained that he and his elder daughter,

[. . .] had discussions about sex and really basically why she’s not ready for it. And she didn’t disagree at all. And with respect to this, there’s the knowledge on her part that this [vaccine] does not give you license to have unprotected sex. Not at all. And I mean, she already knows [that] HPV is one of the STIs that you may get, and maybe not the worst one, you know what I mean? Yes, HPV could cause cervical cancer, or uterine cancer, or whatever, but it doesn’t have to, and it might
not. But HIV, you know. And obviously pregnancy too, unwanted pregnancy too.

So that’s been specifically addressed, that this is not a license to have unprotected sex.

For two parents who were not planning to vaccinate their daughters, concerns regarding sexual morality and responsibility did enter into their rational for rejecting the vaccine. For Rachel, abstinence until marriage was the morally correct choice and she saw it as her responsibility to teach her daughter about the consequences of making immoral or unhealthy decisions. Rachel was against the vaccine because she saw it as a sign of permissiveness or societal leniency towards behaviors that she considered irresponsible. “When you give her the [HPV] vaccination you are basically saying, well this is just in case you choose to have sex. Let’s take away one of the consequences”

To condone the vaccine would contradict her philosophy that people accept the consequences of their actions. One of the own core lessons that she constantly imparts to her children is that all behaviors have consequences. She believed that people should think about the consequences of specific actions before taking them and then be prepared to accept those consequences responsibly. The vaccine, in her mind, took away one of the consequences of having sex.

Natalie’s views were similar: “I think it’s more my job to teach [her] about not having multiple partners. Not being promiscuous – not going to parties and getting drunk and losing your inhibitions and going home with somebody you don’t know. I think that’s more my job to let her know what the consequences can be if she does that.” Both women framed their opposition to the vaccine in terms of individual responsibility, but what they defined as encompassing individual responsibility varied. Rachel’s resistance
to the vaccine was rooted in religious beliefs regarding sexuality. For Natalie, individual responsibility had to do with more than one’s sexual behaviors, but how one chooses to live life. Aside from concerns about the safety and efficacy of the Gardasil vaccine, she felt that the vaccine was largely unnecessary if individuals made healthy lifestyle choices (such as eating a balanced diet, taking supplements, and exercising) to boost their immune system and practiced safe sex with monogamous partners.

While all parents hoped their children would practice safe sex, and many parents hoped that they would remain abstinent until marriage, only Rachel and Natalie saw the Gardasil vaccine as contradictory to these goals. In other words, no other parent saw the vaccine and education as mutually exclusive interventions.

Promiscuity also was mentioned when parents questioned the need for the vaccine, revealing their own assumptions about risk, and what types of girls constituted the true “high risk”, target population. A few parents (n=4) questioned whether girls who did not have sex with multiple partners needed the vaccine, suggesting that moral calculations factored into some parents’ assessments of their own daughters’ need. Theresa, whose daughter was vaccinated, still questioned whether the vaccine was really necessary for her daughter. “I think there’s a need for [Gardasil] but maybe it’s more necessary if you have a promiscuous child . . . [Is it] necessary for someone who’s going to have a monogamous relationship? Is it something that’s really a benefit down the line for – I don’t want to say a normal kid because you wonder if that is the norm anymore.”

Theresa’s question about normalcy speaks to a broader concern that several parents had about the societal context in which their children were growing up. Parents were particularly concerned about the perceived changes in societal sexual norms. Faith
was disturbed by sheer volume of information that children had largely unfettered access to, “I see some of these on YouTube and I kind of go online sometimes to see what’s out there. What kids have access to. And I’m sickened by it, quite frankly. And it’s normal behavior for these kids to hop from place to place, it seems like.” Another mother was convinced that children were having sex at younger and younger ages. “There are some fifth grade girls that should get in now. I mean that’s scary to say, it’s scary.”

Parents contrast these images with accounts of their own adolescent years, hoping that their children will follow a path similar to their own and not what they might be exposed to through the media, their peers, or larger society. One mother stressed the importance of “self-respect” to her daughter and hoped the message resonated, but also worried whether her own expectations and experiences were too out-dated to be realistic. “Granted, yes, I am 53 and things are different, but in high school I would have never even thought of having sex with anybody, no matter where I was. In fact, I broke up with a guy I was dating because of that, because he was pressuring me. And I was like, okay, forget it, we’re done.”

**Providers’ Experiences Discussing Sexuality with Parents**

Nearly all providers (n=14) reported hearing concerns about promiscuity from parents, but the frequency with which they heard these fears varied considerably. Jessica reported hearing this concern often, noting that “there is definitely a perception among a lot of parents that my child will become promiscuous if she has this vaccine.” Another Florida provider agreed that many of the concerns she heard had to do with parent fears that the vaccine condoned sex. Comparing Gardasil to hormonal contraceptives, she explained, “There’s a reluctance to get it because […] some people seem to equate it to
putting their 12 year old on birth control pills. And it’s like, doing a vaccine is not the same thing as you know, saying go have sex. But I think there’s an awful lot of people who view it that way.”

Several providers saw similarities in the way that parents responded to Gardasil and their reactions to the use of hormonal contraceptives for the regulation of menstruation or other non-sex related reasons. Recalling typical responses she hears from parents about Gardasil, Amelia, a nurse practitioner, said, “I would say the stigma. It’s like giving your 12 year old birth control pills to regulate the period. Do I give her the HPV vaccine which gives her the freedom to go out and have sex? I have heard that. They feel like they’re maybe promoting sexuality, promiscuity in their child.” Three providers recounted cases in which the association between reproductive technologies (such as Gardasil or hormonal contraceptives) and sexual permissiveness was so strong that some parents would not consent to therapies even if they knew their children were already sexually active because of the message consent would convey. One provider shared an example to illustrate this point. She had asked a young woman if she was sexually active and the girl said that she was. Upon hearing this

The grandma flipped out. I asked the girl what she was using for birth control and the girl said nothing because her grandma wouldn’t let her go to Planned Parenthood. The grandma responded that she didn’t want to take her to get birth control because she felt that by taking her then she was giving her granddaughter permission to be sexually active.

While many providers did hear concerns that the vaccine would lead to promiscuity or send a message that sex was permissible, most providers were surprised at
how infrequently parents raised this concern. One provider said that among her clients, there were only a few “that actually say ‘Well, if I give her that then she’s going to think it’s okay to have sex. So I can’t give her the vaccine.’” Nor do providers typically hear parents say that their daughters do not need Gardasil because they will remain abstinent until marriage. Jane said, “I’ve been surprised, I’ve [only] heard about a mother who thought that if you have a firm belief in abstinence only until marriage, then you really don’t need the HPV shot. . . Like I said, I get very little of what I expected, which has to do with sexual behaviors generally.” Other providers (n=4) heard this argument more often, but still far less frequently than they originally expected.

More commonly, providers heard parents say that the Gardasil vaccine is unnecessary because their daughters are not sexually active. In fact, all providers reported that this was a common response among parents, especially those with younger daughters. Janet explained, “I don’t get a lot of, ‘Well, then she’s just going to think it’s okay to have sex,’ which I thought I might get a lot of, but I hardly ever hear that. It’s more, ‘I just don’t think she’s going to be exposed, so she doesn’t need it.’”

Providers commonly responded to parents’ doubts about their children’s risk of acquiring HPV at a certain age. Many parents in Sophia’s practice wanted to know whether Gardasil was really necessary at a young age and “how much of a risk their child is truly at. A lot of it is a perception that it’s not something the child needs until she’s older and maybe, you know, dating or thinking about, later on, becoming sexually active. I think a lot of parents are just, just don’t think it’s a necessary thing until that point.”

Most providers were more understanding of parental decisions to delay an HPV vaccine decision for a younger girl than they were for older girls. Few providers felt that
sexual debut at age 10 or 11 was likely for the majority of their female patients, but providers also worried that parents would delay the decision too long. Providers questioned whether some parents would actually know whether their daughters were sexually active, and doubted whether most parents could accurately gauge the lead-up to onset precisely enough to ensure a sufficient window for the vaccine to be administered prior to sexual onset. Moreover, providers worried that some parents would assume that their children would practice abstinence simply because that is what the parents advocated.

One pediatrician often heard parents say that their children didn’t need to get Gardasil at such a young age. They say,

“Oh, she’s not going to be exposed at this age.” And you know, it’s funny because for some of them, I think they’re probably right. Like if we’re talking to a 10 or 11 year old child. But some [parents] feel like that and they’re like “Oh, we preach abstinence in our house.” And the girl’s like 16! And you’re like, yeah. Okay. So [the mode of transmission] does play a factor because . . . they just don’t think their daughters are going to be exposed yet.

As the above quote suggests, providers were generally less sympathetic to parental concerns about vaccine need when daughters were in their mid or late teen years, or when parents preached abstinence until marriage. Some providers found it difficult to respond to parents who insisted that the vaccine was unnecessary because their children were not going to be sexually active until marriage. One provider explained, “[Some] people just believe that their children are not going to be sexually active until they’re
married so they do not have to worry about this [. . .] They’ll say, I don’t even want to hear about it. So what do you say to that, you know? Alright.”

Another provider expressed similar frustration in responding to parents who were convinced that their daughters would not have sex until marriage, and therefore did not even need to discuss the vaccine.

The problem with these parents is they’ve already closed the doors. You’re not going to open them because they can’t see their child in any other way, which is just a whole problem with how they’re raising their child and the communication, doing all that. So I know that there’s nothing that I’m going to say that’s going to deter them.

Providers generally viewed the belief that their daughters would remain abstinent until marriage as “parent denial”. When parents refused to discuss the vaccine for this reason, many providers responded by presenting statistics that indicate most young women become sexually active during their teen years. One provider would respond, “I mean hopefully they won’t [be active until marriage]. And if that’s your belief system that’s fine but 50% of fifteen year olds are having sex so . . .” Despite these efforts, statistics were not often effective at persuading parents because no matter how large the percentage of girls having premarital sex, their daughters would always be in the percentage that were not. Another pediatrician related how the typical conversation played out:

[I say,] “Eighty-percent of teenagers – or whatever, high school students – will have sex by the time they graduate.” [And the parent responds] “Well, mine is in the 20 percent [that won’t].”’ And you know, 99% of college students are having
sex. [And the parent responds], ‘Well, mine is the one percent.’ They know that their child is the one that is not going to have sex before they’re married, and that’s just the way it is.

Rather than challenging parents regarding the accuracy of their knowledge regarding their children’s sexual activity, providers most often emphasized the prophylactic nature of the vaccine and the importance of immunization prior to sexual debut. In stressing that the vaccine is intended to be given prior to the onset of sexual activity, providers often try to appeal to common ground with parents by implicitly affirming the virginal status of the daughter and framing the vaccine as a benefit of choosing abstinence.

One provider, who receives many refusals because of a child’s age, always responds by explaining the rationale behind targeting young girls. “I explain the reason that we give it so young is so we catch everyone. That we don’t necessarily think that your ten year old daughter is going to be exposed to it this year, but we want her to be protected before she ever has a chance to be exposed. Still a lot of people want to wait.” Another common response among providers was to emphasize the limited effects of the vaccine after sexual debut. In these discourses, risk is associated not with refusing the vaccine outright, but failing to vaccinate in time to take full advantage of its benefits. A nurse practitioner generally told parents who preferred to defer the decision that Gardasil covers four strains of HPV. “If you want to wait until she’s 18 and maybe she’s just had that one special guy and she was already exposed to one, that means your shot is now only good for three. I just try to tell [parents], you want to get it done before she even thinks about having sex.”
A pediatrician coupled this perspective with research indicating that younger girls mount a better immune response,

I just say, some studies have actually found that the earlier they get it the better efficacy, the amount of better immune response to it. I talk about that. And I do tell them, I know you don’t want to think about that, that your child is just a little girl right now. But you know, 50% of fifteen year olds are having sex. So we have to think about it. And the most important thing is that they get this vaccine before they’re sexually active because it’s not going to treat HPV if they get it.

As will be further discussed in Chapter Twelve, both parents and providers sometimes tried to minimize the focus on individual responsibility in managing HPV risk by displacing the immorality linked with the vaccine from the daughter onto others, including future partners and rapists. When parents said their daughters would be abstinence until marriage, Elizabeth responds, “‘Well, what if [your daughter’s future husband] has been with a lot of partners, don’t you think she could get that from her husband?’ And then they go ‘Oh. Well I guess that’s possible, but she’ll have to deal with that later.’” Sue, a Florida pediatrician, found that mothers were much more likely to feel comfortable accepting the Gardasil vaccine for their daughters if she put “some of the burden on the boys” by reminding mothers that daughters could have sex with one man in their lives and still develop cervical cancer if he was not as responsible.

Another provider shared her own sister’s experience with HPV when parents were uncomfortable addressing their own daughters’ sexuality: “[My sister is] as straight as they come. You know, a straight-laced person who’s now in her mid-40s, was married for over 20 years and only ever had sex with 2 guys and one of them gave her HPV. And
that kind of really is an eye-opener for a lot of moms.” The provider found that sharing her sister’s experience helped many parents reframe the vaccine. “Out of the ones that I need to pull that story out on, I will say three-fourths of them get the vaccine. I think it really helps – and of course it’s an honest story too.”

When parents brought up concerns that Gardasil would encourage their girls to be promiscuous or engage in unsafe sex, providers often responded by stressing to girls that the vaccine would not protect them against pregnancy or most diseases that are sexually transmitted. One provider would say, after presenting the risks and benefits of the vaccine, that getting Gardasil, “doesn’t mean it’s okay for her to go out and you know, sleep with the football team.”

**Communicating Risk**

Providers noted that parents tended to focus on vaccine-related risks, no matter how small, while sometimes disregarding what providers perceived to be more substantial risks associated with HPV-infection. Providers tried to educate parents about HPV and Gardasil risks using population-level risk statistics. As one provider explained, the provider’s role was to help parents and young women understand, “what is your actual risk, what is your risk of disease or side effects of the vaccine, and things like that.” From the provider perspective, risks can be weighed in calculated ways to arrive at decisions. But as discussed in Chapter Two, and as will be further discussed in the following chapters, parents tend to conceptualize risk in more complex ways that are based on information provided from diverse sources of knowledge, considerations of trust, and temporal and contextual factors.
Providers never tried to completely discount the risks associated with vaccines. They always acknowledged that Gardasil came with risks. Some providers (n=9) tried to juxtapose vaccine risks against the risks associated with HPV infection. Robyn encourages anxious parents to go to the CDC website and read the studies describing in detail the safety and efficacy of the vaccine. She also tells parents, “I understand that you have concerns. Nothing in life is without some risk. But when you look at the rates of cervical cancer and HPV against the risk the vaccine poses, for the most part the benefits way outweigh the risks. And we certainly have big numbers. Lots and lots of women have been vaccinated.” Robyn, like other providers, did not dismiss parents’ safety concerns. She validated their legitimacy, but then framed them against other risks that she felt, based on population-level indicators, were more substantial.

Other providers tried to allay parents’ fears by reminding them that of course Gardasil was not risk free, but that Gardasil was not unique either. There were risks associated with Gardasil, just as there were risks associated with any vaccine, any medical technology, and any aspect of life. Over-analyzing some risks could cause parents not only to lose perspective about counter risks (e.g., associated with HPV infection), but also become crippling.

Some providers tried to allay parents’ fears by explaining that risk analyses would completely paralyze us if we considered every risk we could possibly encountering when making any decision in life. Lydia would explain to parents that there was certainly the possibility of unknown, long-term risks associated with Gardasil that might not become known for decades. She would explain that while she did not think it was likely that we
would discover adverse effects from Gardasil forty years down the road, it was a risk that could not be discounted. She then added,

But obviously that could happen from other exposures, from other things in life. It takes a lot of years to really truly know what consequences anything has. I mean, you can just sit and worry about drinking out of your water bottle, especially if it’s been in a warm car. And maybe you should worry about it, but I don’t worry about that stuff too much because it can just really get you down if you worry about everything. I’ve been talking on my cell phone for 45 minutes and I’ve probably increased my risk of brain cancer, but that study was inconclusive. And again, the Gardasil is doing some very positive things that should impact society in a very positive way, so I would not have a lot of concerns about it.”

As this provider suggests when mentioning aspirin, the most basic, taken-for-granted medical decisions also come with risks. Risk, they emphasize, is an inherent part of everyday life and all decisions require that we accept a certain degree of risk. Several providers felt that technological innovations and improvements in screening, diagnosis, and treatment had led parents to expect risk-free health care. One NP found it particularly disturbing that parents were unwilling to accept even the smallest risks associated with healthcare treatments, especially when they tended to ignore the risks of failing to treat: She explained,

Medicine is not without risk. When you subject yourself to a treatment, I don’t care if it’s an aspirin tablet – heck, you can get a GI bleed from an aspirin. People have to understand that everything is not risk free and that’s a huge problem in
our society now. We’re becoming so much more entitlement oriented. The expectation that every delivery result in a perfect baby, you know? These are very dangerous and inappropriate and expensive assumptions to make. And we have to educate people regardless of the immunization about [the risks], that these are your choices.”

Laura stressed the uncertainty of risk calculations, and the need to make decisions based on the incomplete, available information. Providers made recommendations based on uncertain risk calculations and patients had to do the same. It was always possible emerging data could lead experts to reconsider the safety or benefits of a technology that had previously been deemed safe and effective. She described how she responded to one young woman’s concerns about the vaccine, “Just the other day I said to a girl, ‘Look, margarine or butter? Margarine used to be bad and butter was good. Now it’s the opposite. At this time, with the type of information that we’re given, this is what we have. I’ll review [the information] to the best that I can.’”

While well intentioned, it is unlikely that many of the risk communication strategies employed by providers will be meaningful and significant to parents if they do not account for, and seriously consider, competing knowledge frames, which are discussed in the next chapter.

**Chapter Eight Summary**

This chapter began with a description of the general benefits and risks that parents in this study associate with vaccines and the diseases they prevent. Parents saw both individual and collective benefits to vaccination. Parents agreed that for the majority of vaccines, the individual and societal risks of failing to vaccinate outweighed any risks
associated with vaccines. They framed vaccination as a parental and social duty necessary to protect the health of their own children and the wider community.

While all but one parent had given their children all vaccines required for school entry, perspectives regarding the chicken pox vaccine (a mandated vaccine) and non-mandated vaccines were more variable. Perspectives towards and uptake of the chicken pox and flu (both seasonal and H1N1) vaccines were most varied. Doubt regarding the severity of the diseases, coupled with concerns about the safety of the vaccines to prevent them, led several parents to postpone or refuse these vaccines. It was not uncommon for parents to vaccinate one or more of their vaccine-eligible children against the flu, while leaving one or more of their other children unvaccinated. These findings illustrate that “gradations of acceptance” (Streefland, et al. 1999:1710) exist not only in terms of variation in parents’ vaccination strategies for their own children, but are vaccine-specific.

As passive acceptors (as defined in the LVC approach) of the chicken pox vaccine, several parents were compelled to accept the vaccination not because they were supportive of the chicken pox vaccine, but because their children could not enter school without it. As Mike explained, “They require [the chicken pox vaccine] for the school system so it’s sort of out of my hands. If it were up to me, I probably wouldn’t bother. So I mean I did it because it was required. I definitely choose my battles as far as bucking the system goes.”

The list of risks associated with vaccines was lengthier, including both generalized risks, and risks associated with specific vaccines, such as the flu and chicken pox vaccines. Parents drew upon their perceptions of disease severity, vaccine need
(susceptibility), and vaccine safety (e.g., newness, efficacy, contents of a vaccine) when describing vaccine-related risks.

Parents overwhelmingly listed cervical cancer prevention as a key benefit to Gardasil vaccination, though the idea of any type of protection was important to some parents. Parents who had themselves experienced complications of HPV-infection or knew someone who had, were generally more likely to see Gardasil as protective against a host of complications associated with HPV-infection.

Like with vaccines in general, the risks associated with Gardasil were more diverse. Similar to fears regarding the chicken pox and flu vaccines, parents expressed concerns about the newness of the Gardasil vaccine and the possibility of long-term consequences. The unknown risks associated with a new technology were unquestionably the most often cited (n=24), and in many cases, most significant fear that parents had about Gardasil. They also questioned whether their daughters needed a vaccine that they associated with, if nothing else, the onset of sexual activity, which no parent thought had commenced. Less commonly expressed fears were that daughters might misconstrue the vaccine as a license to engage in promiscuous or unsafe sex, or that daughters would think their parents condoned sexual behavior by giving them the vaccine.

Providers often tried to address parental safety concerns by explaining the processes through which vaccines are tested and evaluated and by encouraging parents to view vaccine risks in light of other medical risks. In response to parents’ doubts about the need for the vaccine, providers often stressed the prophylactic nature of the vaccine or
presented statistics suggesting many girls become sexually active before one might expect.

In the following chapter, I describe some of the predominant sources through which parents and providers obtain vaccine relevant information and how differences in the ways that they view this information can lead to challenges in communication. Unlike providers, parents make risk calculations based on information that comes not only from scientific sources, but from personal experience, religious beliefs, notions regarding sexuality, trust (discussed in Chapter Ten) and assessments of their daughters’ personal risk profiles.
Chapter Nine – Sources and Types of HPV-Related Knowledge and HPV-Related Risks and Benefits

The risks and benefits that parents associate with vaccines, including Gardasil, are shaped by past experiences, broader attitudes towards vaccines, and the types of information that parents obtain (and differentially validate) from various sources. This chapter begins with a description of the sources through which parents learn about vaccines; particular attention is paid to sources of information regarding HPV-related infections and the Gardasil vaccine and the types of information acquired from different sources. Specifically, I begin with a description of the roles that the media, vaccine manufacturer, and family, friends, and other parents play as sources of particular types of information. I then discuss the central role that parental knowledge and action plays in understanding the need for Gardasil. Subsequently, I provide a detailed consideration of the healthcare provider’s role as a potential source of vaccine information. Positioned at the service-delivery interface, the clinician is a potentially important source of vaccine information. Given the providers’ important role in vaccine decision-making, I present their own perspectives regarding the Gardasil vaccine. I describe the strategies used by providers to present particular types of information to parents. I then describe parents’ accounts of HPV discussions with providers, highlighting the types of information that parents recall providers sharing with them. Finally, I conclude by comparing the sources through which parents and providers obtain and evaluate vaccine relevant information,
highlighting tensions that can arise when different sources present conflicting information.

**Media Sources of Information**

The media play an important role in disseminating information, especially about vaccine risks, to parents. Several parents and providers noted that their concerns about the severity of meningitis – and subsequently, their support for the meningitis vaccine – largely resulted from media reports publicizing deaths of young people from the disease. Most often, however, parents were particularly likely to associate their own (or general parental) fears of vaccine overload and vaccine-caused autism and deafness to reports or stories they heard through the media. Parents (n=6) and providers (n=6) were especially likely to mention Oprah and Jenny McCarthy as vaccine-related media figures.

The media were sources of Gardasil-related information as well. Three parents had read or heard media reports describing Governor Rick Perry’s attempt to mandate the vaccine and concerns that the vaccine would lead to promiscuity. Three women had read informational pieces in a local newspapers or magazines describing the vaccine, what it prevented, who was eligible to receive it, and how much it might cost. One woman had heard about the vaccine on the radio, and another woman saw an episode of a popular medical-drama that dealt with HPV. Tony had seen an MSNBC health report that described the prevalence of HPV in the general population, which was one reason he ultimately opted to vaccinate his own daughter. The report summarized findings from a study in which “They found [HPV] on little kids’ hands. There are strains of HPV cause warts on your hands. It’s so common.” Only a few parents (n=3) in this study had read
news reports linking the Gardasil vaccine to increased risk of fainting or death. However, providers reported that parents in their own practice sometimes brought up these risks.

Parents actively sought information about the vaccine using online resources. Ten parents had visited, or planned to visit online sites in order to learn more about the Gardasil vaccine. When parents said that they had or would obtain information about the vaccine online, I asked them which types of sites they would visit, how they would find them, and how they would evaluate the quality of the information presented on each site. Some parents had narrow conceptions of what constituted a legitimate and reliable online information source, while other parents had less defined processes for evaluating online material. A few parents (n=3) were unsure of their online research techniques, beyond the use of specific search engines. Wendy was unsure how she would proceed with an online search, other than to say, “I would Google it first”.

Some parents were not exactly sure which sites they would visit, but stressed that the types of information that would be available online would be partial. Natalie commented, “We always go online for anything. But we’re not getting the whole big picture online. We’re getting bits and pieces of information.” Mark tried to provide a more detailed strategy for evaluating websites, but found it difficult. “I’d go to Google, type in HPV and see the most popular [results]. I mean something, obviously if it’s Wikipedia you take that with a grain of salt. But, I know there’s WebMD and then . . . it’s just the quickest.”

When selecting reliable sources of health information, some parents have go-to sites that they trust. A few parents (n=3) went, or would go, to university or government-affiliated websites to gather what they considered reliable information about the vaccine.
Bill explained, “I’ve gone to certain websites, like the Mayo Clinic website and other kinds of – you know, not the Gardasil website. More independent medical specialization websites.” In excluding the Gardasil website from his search, Bill suggests that the information contained on manufacturers’ websites is partial and biased. Helen thought she would eventually read the FDA website to learn more about the vaccine and Tony described the CDC website as his go-to source for reliable and trustworthy information, but also conducted Google key-word searches to learn more about Gardasil. In describing the problems he perceives of assessing the reliability of online sources, he also articulated his own process for evaluating knowledge claims.

The hardest thing is separating . . . . what is the phrase? The chafe from the wheat? Separating the junk – the pseudo-science, the anecdotal information – from the truth. A lot of websites that end in “org” might as well be ‘junk.org’ because they’re funded by people who have ulterior motives. When Gardasil [came out], I Googled it. And then all the sudden you get all this stuff and you start looking through everything and it’s like, whoa! How come what this says over here doesn’t match with what this says over here? And it isn’t until you look at the cdc.gov [website], for example and you go okay, this and this make sense. This is the CDC, I know who they are. It’s the government, I know who they are. Let me find out who these [other] people are. And then you find out it’s the Committee for the Advancement of Family Values. And then you find out what their mission statement is and you go, I get it. And then it all clicks and you’re like okay, this I can discard. I’ll read it. I’ll read it. But when the BS meter goes off I’m like okay, I got it.
Only two parents had or would visit the Merck website for vaccine-related information. Evelyn visited the site after seeing the “One Less” commercials. “I went online to the Merck website to read up on it . . . the website has a reminder email system for the second and third shots.” Gretchen, a mother of two, received a Merck-sponsored Gardasil pamphlet at a health fair and subsequently went to the Merck website to gather additional information. On the other hand, some parents (n=4), like Bill specifically noted that they would not visit the Merck website, because they did not believe they could obtain unbiased vaccine information from the manufacturer, again speaking to issues of trust, which are discussed in Chapter Ten.

Despite the fact that Merck was not always deemed a reliable or credible source of HPV-related information, Merck was unquestionably the most pervasive source of information about Gardasil. As described in Chapter Six Merck’s campaign to advertise the link between HPV and cervical cancer, and the vaccine itself, was unprecedented. The advertising campaign clearly reached parents in this study, who overwhelmingly (n=24) referred to Merck or Merck-related advertisements as a source of information about HPV and the vaccine.

The advertisements resonated strongly with many parents, who could in some cases describe the Gardasil commercials months or even years later. More than half of the parents with whom I spoke mentioned the “One Less” slogan during the interview and the “One Less” commercials were often the first time that parents had heard about HPV itself, or a vaccine to prevent it. A few parents could only recall the “One Less” slogan from the commercials, but most parents associated the slogan with other facts or sentiments.
Many parents found the commercials catchy and appealing. Perhaps most vocal in her praise of the commercials was Lucy, who has one daughter. The specific images and values presented in the commercial particularly resonated with her. When asked where she had first heard about HPV, she responded, “The commercial. The ‘One Less’. Oh my God, have you seen it? The commercial was snappy as hell. I wish I could get a t-shirt.” Describing the commercial for me she began snapping her fingers and singing, “‘One less, one less, I’m gonna be one less!’ The girl is skipping rope and I’m like ‘Okay!’” Lucy was so moved by the commercials that she began referring to her daughter as ‘one less’. “I’ll call her up, ‘Hey darling – oh hey one-less, how you doing?’ And that’s her new nickname. One-less.” The images of mothers and daughters making the decision together was especially appealing to Lucy: “Whether they were real mothers and daughters [depicted in the commercials] or not, they kind of looked alike. You could almost think that they were. But that commercial, it hit home for me. It made the home run.”

The themes of empowerment and protection were appealing to other parents too, who specifically liked the commercials because they touched on these themes. In reference to the “One Less’ campaign, Melissa commented,

I thought it was an interesting campaign and you could really see the imagery playing with mother and daughter. I’m protecting my daughter. But sort of also the daughter being empowered – I want to be one less daughter, or sister, or whatever. I want to be one less. So that’s probably the first time I heard it.

Jean, who has one daughter, appreciated that the advertisements included daughters and sent the message that young women can and should be a part of making
this vaccine decision. “I see all of the commercials on TV – one less. Which I think are very clever. I just think that they appeal to the younger generation and I think it’s important that the girls know the importance of the vaccine, what it’s supposed to do.” Jean was able to recall specific dynamics portrayed in the commercial, and she appreciated that both the mothers and the daughters played (unequal) roles in the decision to get the vaccine.

Yeah, I think if I remember the mother talks about what HPV viruses are, and usually the mother and daughter are sitting in a situation together. And the mother talks about how it’s important to protect against the virus because it can potentially cause cervical cancer at a later time. And then the daughters come into the conversation and they talk about how it’s important to be one-less.

Apart from empowerment, the “One Less” slogan also appealed to parents’ desires to protect their daughters, but from what? For many parents, the “one less” slogan was understood exclusively in relation to cancer – not genital warts or HPV infection. Merck’s marketing strategy to frame Gardasil as a cervical cancer prevention technology paid off. In recalling what types of information were presented during the commercial, most parents exclusively conceptualized “one less” in terms of cervical cancer. Like many parents, Lucy recollected, more than anything else, that the commercial was about “Cancer. They kept saying cervical cancer over and over. I don’t even remember them saying warts on the commercial. But it just kept saying cervical cancer and over it – subliminally or whatever, but it was cervical cancer.”

The commercials evoked parental fear about cancer and for them, “one less” was not about one less daughter with genital warts or HPV, but one less daughter (presumably
their own) at risk of developing cervical cancer. According to Victoria, “the commercial works. One less. I want [my daughter] to be one less. If this will help [her] not have cervical – or have a better chance not to have cervical cancer then I’m all for it.”

Other parents acknowledged the powerful message captured by the simple slogan. Theresa recalled the message, “I’m gonna be one less. That’s the one that sticks out more in my mind. And it grabs your attention. It makes you think about it.”

Most parents responded positively to the cervical cancer association suggested through the advertisements, but Natalie thought the ads were deceiving because the vaccine did not protect against all strains that cause cervical cancer: “One less. My daughter’s gonna be one less. I’m like, one less what?” When I asked her what she thought “one less” referred to, she replied, “One less woman whose gonna die of cervical cancer. How do you know that? That’s what I want to say to these moms. How do you know she’s gonna be one less? How do you know that the vaccine is going to protect her against that one strain that she might get anyway?” Natalie acknowledged that at some point a narrator mentions that the vaccine cannot protect against some strains of HPV that can lead to cervical cancer, but she believed this fact was deliberately under-emphasized and was inserted at the end of the commercial, after audience attention had waned.

If it doesn’t catch our attention we’re already on the phone, doing other stuff. So that’s why they keep repeating – this girl and this girl. One less, one less, one less. At some point in time you’re gonna walk back in the room and you’re going to hear one less. And that’s the whole point, is that people are sucked in to that and then they’re already out of the room by the end of that commercial. Do they hear that this isn’t going to protect against [some strains of HPV that cause
cervical cancer] - the little man that is at the end of the commercial that’s talking really fast, that we don’t hear anyway, that we tend to block out? No.

Aside from the connection between the vaccine and cervical cancer, few parents remembered gathering additional information from the commercials. Evelyn recalled that the ads, “asked if I wanted to protect my daughter from a disease she couldn’t detect on her own.” Barb understood that the vaccine protected against HPV, not cervical cancer itself. “It’s just the virus that can cause cervical cancer, it’s not actually the cervical cancer itself.” The incomplete ability of the vaccine to protect girls from all cancer causing HPV strains was mentioned by Patty, who understood from the commercials that the vaccine was best administered as a prophylactic, and that it only protected against certain HPV strains that can lead to cervical cancer, though she (inaccurately) understood that all four strains included in the Gardasil vaccine were cervical cancer causing.

Finally, Rachel honed in on the sexually transmitted nature of the virus, and could recall nothing else from the commercials: “I remember the ones . . . where it’s just one – or one less? One less who will get it – I believe it’s a sexually transmitted disease.”

Merck-sponsored advertisements were, unquestionably, the most common source of Gardasil information obtained through the media, but parents also learned about the vaccine through other media sources.

**Friends, Family, Colleagues, and Daughters**

Some parents (n=7) had not discussed the vaccine with their friends, family members, or peers prior to having their daughters vaccinated (or in one case, deciding against it), but three of these parents did have subsequent conversations about the vaccine. More typical, however, was for parents (n=16) to indicate that they had or
would talk to friends, family members, and colleagues about the Gardasil vaccine. In most cases, at least some of the conversations parents had about the vaccine with others occurred before parents made decisions for their own daughters, though three parents only discussed the vaccine with others after having their own daughters vaccinated. Some parents actively sought the opinions and perspectives of others, but most conversations about the vaccine came up during a child’s band rehearsal, a sports practice, a school event, or at the park, when parents were already gathered together.

While many parents who had already vaccinated their daughters did discuss the vaccine with other parents before getting it, none described these conversations as significantly factoring into their decision. However, it is worth noting that few of these parents had spoken with parents who reported serious consequences from the vaccine or serious resistance to it, so it is difficult to gauge whether parental perspectives would have factored more heavily into the decision had they been negative.

For most parents, the main purpose of discussing the vaccine with other parents was to learn of any potentially serious side-effects that might be associated with vaccination. The lack of adverse events experienced by individuals within their close social network reassured parents of the vaccine’s safety and might have helped to boost their overall confidence in the vaccine. Five of the seven parents who had not yet made a definitive vaccine decision had, and/or planned to talk to other parents about the vaccine. Two of these mothers knew that many of their peers had already vaccinated their daughters and wanted to know whether their friends’ daughters had experienced any complications from the vaccine before making a final decision.
For other parents, it is unclear from their own accounts whether discussions with peers, parents, and family members influenced their decision in any significant way. For example, Jill, who thought she would have her daughter vaccinated in a few years, had spoken with other mothers about the vaccine. Like her, they had some concerns about how to explain the vaccine to their young daughters, who were between 9 and 11 years of age. They also expressed some minor concerns about promiscuity. Through these conversations, Jill’s own anxieties were validated, yet these discussions did not significantly influence her perspective on the vaccine, which was that eventually, it would be something beneficial for her daughter to have. As these examples illustrate, while parents are interested in knowing how other parents perceive the vaccine and whether they have vaccinated their own daughters, they do not always feel compelled to adopt similar practices.

It is possible that in conversing with others about the vaccine, parents selectively “hear” or focus upon information aligned with their pre-existing perspective, while filtering out contradictory information. The two parents who were generally against the vaccine recounted discussions with family and friends that highlighted negative experiences with the vaccine, but it is unclear whether these accounts led to concerns, or more likely, were seen as evidence to support already existing concerns about the vaccine.

Parents who were supportive of the vaccine tended to highlight the lack of reported problems when discussing Gardasil or their friends’ support of it. Two parents who were leaning towards vaccinating their daughter(s), or had already done so, did mention that some of their friends were against the vaccine, but either dismissed outright
these concerns or attributed them to specific characteristics that made these concerns individualistic and non-generalizable.

For example, Helen became more certain of her desire to eventually vaccinate her daughter after talking to a friend who was not planning to give her daughter the vaccine. In this case, hearing her friend’s reasons for opposing the vaccine, and reflecting on her own reactions to these reasons, helped to solidify her own confidence in choosing to vaccinate in a few years.

Several parents reported that their daughters provided them with information about the Gardasil vaccine, mostly by relaying conversations that they and their own friends have about it. Five parents said that their daughters talk about the vaccine with their friends and generally know who has and has not been vaccinated (four of the five girls were 13 years of age or older). Courtney explained that her daughter,

\textit{knows} out of her group of friends who’s gotten [Gardasil] and who hasn’t. They share that with each other. I’ve heard them in their youth club saying, “Well next week I have to go for my last injection,” and then they’ll say, “Oh yeah, I’ve done that. I got mine last year.” So they talk about it as a group: “Well I know such-and-such hasn’t done it yet because she’s afraid of needles”. So they’re very aware, much more so than I realized.

Melissa, whose daughter talks to her friends about the vaccine had not yet made a final decision to vaccinate her daughter, but felt reassured that so many girls seem to have safely received it (yet another example of the role social norms can play in allaying fears regarding vaccine safety). Two parents said that their daughters learned about the
vaccine in health class (ages 15 and 16), and two daughters conducted some of their own research on the vaccine prior to receiving it (both 15 years of age).

**Parental Knowledge: Sex Education, Sexual Readiness, and Knowing**

Parents themselves become important sources of knowledge in assessing their daughter’s need for Gardasil. Important to decisions about if and when their daughters needed the HPV vaccine were evaluations of their daughters’ sexual maturity. In evaluating their daughters’ sexual development and readiness, parents relied on sex-related discussions they had had with their children, their children’s responses to these conversations, and information on their activities derived through parental monitoring. To a large extent, however, parents’ assessments of their daughters’ sexual maturity were based on faith – both in their abilities as parents to ‘know’ when their daughters were thinking of becoming sexually active, and faith that their daughters were being honest with them about their level of readiness. In this section I discuss the different strategies, or sources of knowledge, that parents deployed to evaluate their daughters’ risks of coming in contact with HPV in the near or distant future.

None of the parents with whom I spoke thought that their daughters were currently sexually active or had been sexually active in the past. Most parents did not foresee sexual debut occurring for a significant period of time, though a few parents with older daughters (ages 15 and 16) suspected that sexual debut would occur in the nearer future. Even these parents, however, then provided counter information that made them think their daughters might not become sexually active “any flipping day now,” suggesting that assessing and weighing indicators of sexual debut is challenging. Because timing was a key issue in many parents’ vaccine decision, having a sense of

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when their child would become sexually active was critical. I asked parents whether they thought they would know when their child became sexually active and if so, how they would know.

Many parents relied on discussions they had with their daughters about sexuality as tools to gauge their daughters’ sexual maturity levels. Often times, parents referred to their own experiences of learning about sexuality to explain their own rationale for approaching sexual education in a particular way. Some parents made a point of discussing sex with their daughters because they did not receive sex education from their own parents. Rachel made a concerted effort to be open and honest with her own daughter about sex because her own mother had not had those conversations with her. As a result, Rachel felt “clueless” about a lot of things, reflecting “I’m still learning a lot of things because there’s a lot of things my mom never told me.” Faith explained that her mother was a very private person who never discussed sex with her. She thought that “maybe it’s because she was so not sharing that I want to be, because I’ve had questions that are unanswered”.

Other parents strived to be open and honest with their daughters about sex because they valued the open and honest relationship that their own mothers fostered with them. One mother explained that when she was growing up, she knew that she could safely approach her mom with any sexual health question and she wanted her girls to feel the same level of comfort with her.

Of course, hoping that children feel comfortable talking to their parents about sexuality does not imply that parents feel comfortable talking to their children about these topics. Parents found talks uncomfortable for several reasons. At the societal level, sex
has a dual role. While sexual themes are commonplace in the media and sex is often openly discussed among peers, intergenerational discussions about sexuality and sexual health issues are often perceived as awkward and uncommon. The fact that sex education is a politically contentious and emotive issue, suggests that sex is seen as a private, and sometimes shameful act that is not to be discussed. A sexually conservative cultural environment hardly fosters a sense of comfort or ease in discussing sex-related issues.

While parents might feel comfortable discussing sex with their partners or friends, it was clear that some parents felt less comfortable broaching the subject with me. Parents who shared with ease their family medical histories and religious views, found it difficult to speak directly to sexual health issues, sometimes alluding to sexual topics and themes without directly speaking to them, or speaking in a whisper when talking about sexual intercourse, genital warts, or sexually transmitted diseases. When it came to initiating sexual health conversations with their own children, additional factors led them to feel discomfort. Many parents felt that they lacked the experiential knowledge or training to fluidly engage in these types of conversations.

Moreover, because parents associated sexuality with adulthood, talking about the subject with children seemed contradictory, inappropriate, and awkward. Parent-child conversations about sex threatened both intergenerational and role boundaries, challenging the distinct roles separating parents from children and adults from non-adults. Discussing sexuality with children tested parents’ conceptions of their children as innocent, asexual beings. Educating children about sex required acknowledgement from parents that while their children will always be their children, they will not always remain innocent or childlike.
Nearly all parents expressed discomfort, anxiety, or dread when describing past or future conversations about sexuality with their daughters, but they also felt it was part of a parent’s responsibility to have these discussions, no matter how difficult. Tony’s evaluation of sex education encapsulated the sentiments of many parents:

People are so uncomfortable talking about sex. Especially sex and their daughters. I am too. I haven’t had that talk yet but I will. Yugh. I’m just as uncomfortable as the next parent. But you got to do it. You suck it up. I [think] it’s a poet that says at a certain point in life it’s time to put away the toys. And certain things in your life you gotta do. It’s time to put the toys away and be a grown-up. . . Talking to your daughter – she’s the only one I got. I’m trying to do it right this time ’cause I don’t have another child, you know? That’s it.

Some parents found sex education talks with daughters to be especially difficult because they perceived the physical, social, and emotional risks associated with sex to be graver for girls. Pregnancy was at the forefront of parents’ physical concerns, but they also thought that their daughters were more likely to experience long-term reproductive health problems from engaging in risky sexual activity. Parents were not only worried about sex-specific diseases, such as cervical cancer, but also perceived that females were more likely than males to experience infertility as a result of engaging in sexual activity.

Regardless of the challenges involved, parents wanted their daughters to feel comfortable approaching them about sex. Fostering this trust required parents to convey to their children openness and ease discussing sex, regardless of whether such openness or comfort came naturally. To maintain open communication channels with their daughters, parents often had to respond carefully and calmly when their children talked
about sexual norms among their peers. Lucy routinely struggled to preserve the open relationship that she had with her daughter, whose accounts of peer activities horrified her. She provided one such example where her daughter might tell her, “‘Oh, Suzy gave such-and-such a blow job in the girl’s bathroom today.’ And you have to be careful because you can’t go ‘What the fuck!?!’ You have to go, ‘Oh, okay’ (laughs nervously).”

The importance that parents ascribed to sex education surmounted any awkwardness of discomfort they personally felt. Most parents described their relationships with their daughters as abnormal, in that they perceived they were more likely than other parents to talk openly to their children about sex. Often times, parents also expressed confidence that their children would be more protected or prepared to respond to sexual issues due to these discussions or a sense of openness that parents felt they had with their children. Gretchen felt confident that her 17-year old daughter would make healthy sexual decision for herself, not only because she was mature, but because she had access to parents who were supportive and open to discuss these issues with her. Of her daughter, who was a freshman at the time, she remarked, “I think she’s pretty much . . . ahead of the game . . . I’d say most of her friends are pretty knowledgeable but they probably aren’t as free to talk to their parents about things like we are.”

Rachel, who was not going to vaccinate her 12-year old daughter, felt confident that her strategy for preparing her daughter for the world would protect her more effectively than a vaccine: “I know that there are a lot of kids that are sexually active at this age, but I also know that in teaching my daughter I am doing something that everyone seems to leave out, and that’s preparation. I’m preparing my daughter and my son for, as they get older, the things that are set before them and what can happen.
Children’s reactions to sexual health discussions often provided parents with an indication of their maturity level and readiness to become sexually active. Parents sometimes provided examples of their daughters’ responses to sexual topics as indications that they were not yet interested in romance or sexual relationships. Several parents (n=6) pointed to the “eww” or “ick” factor as an indicator that (at least one of) their children were not yet sexually active and unlikely to contemplate it in the near future. As Barb put it, two of her girls (ages 9 and 11) were “still like ‘Eww! Boys! Yuck!’” Parents provided recent, specific examples of interactions they had with their daughters that led them to believe their children were not approaching sexual maturity. Sarah pointed to her 14-year old daughter’s recent reaction to materials covered in health class: “She came home a couple of weeks ago and was like (gasp) ‘Oh, this is so disgusting, why do I need to know this?’ And I said, ‘What are you studying about?’ [And she responds] (whispering) “the male reproductive system.” (laughs).” Mark was also confident that it would be many years before any of his daughters, the oldest of whom is 11 years of age, considered engaging in sexual activities, remarking that his eldest daughter still, “gets grossed out when [my wife] and I are kissing in the kitchen”

Some parents (n=5) of older daughters (ages 15 and older) trusted that their daughters told them the truth when they assured their parents that they were not yet having sex. These parents talked to their daughters about health and sexuality frequently and generally described their relationships as close, honest, and open. For these reasons, parents felt fairly confident that their daughters’ reassurances that they were not yet sexually active were accurate and honest.
Aside from conversations about sexuality, parents relied on observations, monitoring, and control of their daughters to gauge their sexual maturity. For example, two parents drew upon their daughters’ inability to recognize (and failure to respond to) flirtatious behavior as an indication that they weren’t interested in sex quite yet. One mother explained that while she knew her daughter would likely become sexually active in the near future, she was confident that her daughter was not yet active, partially because of her daughter’s obliviousness to boys’ flirtations. She recalled a recent exchange when they were ordering food.

The little boy was flirting with her so desperately I had to walk away because I was about ready to laugh. And it just went over her head. He goes, “Oh, I’ll give you these three really big nuggets.” She’s like, “Yeah.” She’s looking around, you know? He goes, “Okay, well you want some soda with that?” And she goes, “No!” He was doing everything he could to get her attention and nothing worked.

Four parents with older daughters described their involvement in their daughters’ lives as a key reason they did not yet think they were sexually active. One mother simply said she knew her girls were not sexual active “because they’re not out of my sight long enough.” Another mother recognized that her daughter might not be completely honest when she plans to become sexually active, but felt confident her daughter had not reached that point yet because her schedule did not allow for it. “I can look at it and say, okay, activity wise, I pretty much know where she is at every given point in time, just because of her activities and what she’s doing.”

Many parents had to evaluate competing evidence to assess sexual debut, which made it difficult for them to express confidence in their sense of “knowing”. In
evaluating her own daughter’s sexual maturity, Melissa considered her daughter’s age, her daughter’s reassurance and general discomfort with the topic, and her own history. She began by stressing, “She’s 16, she could be sexually active any flipping day now!” At the same time, her conversations with her daughter led her to think her daughter might not be at a stage to consider sex yet. Recounting their last conversation, she said, “She seems to still have this ick factor about sex, just in our general conversations, and we’re pretty open talking to each other. And she’s like, just the whole idea of male-female sex is disgusting to me.” However, Melissa also noted that a disinterest in heterosexual sex did not necessarily mean her daughter was not interested in sex. She noted that on her social networking page, her daughter identifies herself as bisexual, “and she’s dated a girl for two weeks and she said they never kissed or anything. And she’s like, in my mind I want to date girls, but with my body I can’t quite do it yet.”

Parents use different criteria and a variety of strategies to assess their children’s sexual maturity and sexual activity. Despite these strategies, and the hope that their daughters would come to them before becoming sexual active, some parents recognized that these expectations might be unrealistic. Deborah, a mother of three, worried that despite the very open dialogue she maintained with her two daughters about sex, they might still have difficulty approaching her to talk about it, “When I was a teenager my mom was very open and I could talk to her about anything, but I know I wouldn’t have gone to her [before I had sex]. I think it’s harder for them than for me.” Theresa expressed similar concerns, also based on her relationship with her own mother, and her own sexual health choices: “For myself, I would look at it and hope that [my daughter] would tell me [when she is thinking of having sex]. Which is being in La-La Land.
Because I’m thinking, did I tell my own mother? No.” Victoria echoed the same concerns, arguing that “if kids are going to have sex, they’re going to have sex. And they’re not going to talk to their parents about it ahead of time. I mean I didn’t talk to my parents at first.”

Like these mothers, some providers worried that parents would misjudge their daughters’ sexual debut, thereby missing an opportunity to provide maximum benefits from the vaccine. Sophia felt that most parents did not know when their children became sexually active, and often spoke to adolescents privately about sexual matters of which their parents were unaware. Ann felt that there was a “huge gap” between what adolescents are actually doing and what parents think they are doing. “It’s just very difficult for most families to have a dialogue about those things. Money and sex in our society are kind of taboo, even within families. So sure, I think that adolescents are having sex at a younger age a lot of times than their parents suspect.”

Parents partially relied on their own sex education efforts and beliefs that sex education would translate into certain behaviors to evaluate their daughters’ sexual risk levels. They also hoped that by establishing open and honest communication channels with their daughters that daughters would speak honestly with them about their sexual intentions. Despite varied strategies to evaluate daughters’ sexual readiness, both parents and providers acknowledged that in many cases, parents simply would not know when their daughters first became sexually active.

Providers’ Sources of Information

In this study, twenty-four parents had or planned to discuss the Gardasil vaccine with their daughters’ healthcare providers. While parents solicited vaccine-related
information from their healthcare providers, they also obtained information from family members, other parents, and media sources. Parents collect information from diverse sources, but do not grant equal relevance or importance to it. As will be discussed in the following chapter, the credibility of a source can largely affect the weight parents assign to information from it.

Providers, while hearing about Gardasil through multiple sources, overwhelmingly used a scientific, epidemiological model to assess the credibility of information that they received. Providers tended to value knowledge generated from their own training and expertise, as well as from bench scientists, vaccine experts, public health officials, and to a less extent, their peer providers and vaccine manufacturers. Data published in or supported by peer-reviewed academic journals, the CDC, and professional medical associations.

**Providers as Sources of Vaccine Information**

Despite differences in the ways that they evaluate the relevance and weight of vaccine information, providers are a fundamental source of disease and vaccine-related information for most parents. In this study, twenty-four parents had or planned to discuss the Gardasil vaccine with their daughters’ healthcare providers. Given the central role that providers hold as sources of information, it is important to understand what types of HPV-related information healthcare providers actually share with parents and under what conditions. In the following sections I describe provider reports of typically Gardasil interactions – including if, when, and how providers approach the conversation. I then present parents’ reports of their own HPV-related interactions with healthcare providers, highlighting important areas for future research.
Provider Reports of Interactions

When and how providers choose to discuss the vaccine depends on several factors, including the needs and characteristics of the practice population, the age of the child, the assessment of the individual child, and sometimes, the response of the parent to other information covered during the visit. Seven providers reported that they always tried to bring Gardasil up at visits after girls reached a certain age. Jessica always tried to have sexual health conversations while both the parent and daughter were present, but if she saw strong resistance on the parent’s part, she would sometimes make a note in the chart to resume the conversation at the next visit during one-on-one time with the daughter. In knowing whether to have an in-depth talk about sexuality with adolescents, she explained, “You just kind of feel it out. You get a sense. It’s a vibe. They either look you in the eye or they don’t. I mean, I don’t know, maybe I do it wrong every time for that matter, but you just get a sense about whether or not this is something that’s appropriate.”

Five other providers usually brought the vaccine up with parents, but reported that they usually did not use acute care visits as Gardasil opportunities, primarily because they perceived a lack of interest among parents in having their children vaccinated while they were ill and felt Gardasil could usually wait. One provider did not herself bring up the Gardasil vaccine because of her own misgivings (discussed in the subsequent section) about it. If parents asked her about the vaccine she would provide them with objective information, but preferred not to encourage vaccination by introducing the topic herself. Another provider knew that some of her colleagues never initiated conversations about Gardasil, but would discuss it if parents brought it up. “I think the practitioner has a
significant influence – usually the provider has to bring it up. It depends on whether they choose to talk about it or not. I’ve seen physician after physician just walk in and out. . . If the practitioner clearly is against the vaccination or associates it with promiscuity then they will never bring it up.”

The school nurses and chiropractor did not initiate conversations with parents, but would discuss Gardasil if parents asked them about it. One of the school nurses who worked with the high school population did frequently talk to girls about the vaccine, especially if they were thinking about becoming or already were sexually active. In these cases, she included Gardasil among safer sex strategies and encouraged girls to talk to their parents about their sexual health.

Many providers reported that they were less likely to bring the Gardasil vaccine up with the youngest eligible age groups, and if they did bring it up, were less likely to explain mode of transmission or other specific information about the vaccine. Unless a parent brings it up, one doctor does not begin to have discussions about Gardasil until daughters are eleven years old, because she felt that nine year olds were too young to understand why Gardasil would be important. She also felt, in most cases, that there was little danger in delaying vaccination from ages nine to eleven, saying, “Maybe this is all our naiveté, but God help us if our 11 year olds are having sex. I mean that’s just really bad.” She also explained that discussions with parents of eleven year olds were difficult enough, “it’s hard enough to push Gardasil that I don’t need to stress myself out and spend the time trying to push it to a 9 year old. I just try pushing it at 11.” At the eleven and twelve year old visits, Elizabeth does not generally mention anything about the link between Gardasil and sex when introducing it to parents. With her teenage population,
however, she does explain how HPV is transmitted and what the vaccine will and will not protect against.

Another provider said that she was the only doctor in her practice that routinely discussed Gardasil with eleven year olds. The other providers in her practice – who were all male – told her that they infrequently or never introduced Gardasil to parents of girls that young.

Some providers felt it was important to initiate Gardasil conversations from a young age, even if few parents would immediately get the vaccine, so that parents had time to think about the vaccine for the future. For example, two parents who planned to have their daughters vaccinated, said that their providers initiated conversations about Gardasil as a recommendation for the future, not for the present.

Several providers approached Gardasil like they would any other vaccines. They would refer to the medical chart and list the vaccines (sometimes only Gardasil) for which a girl was eligible to receive. Nina described how she would approach the vaccine with a 13 year old and her mother:

I’d say, ‘These are the vaccines that she needs today. I would highly recommend the Gardasil that protects us girls from HPV. It protects us from 70% of cervical cancer, 90% of genital warts.’ And then I say, ‘the most important thing – I know it’s not something you really want to think about, your little girl having sex. But it’s something that will protect her from possibly getting cervical cancer in the future so you have to think about it *before* she becomes sexually active, so *now* is the time to think about it, to bring it up
Nina, in recommending the vaccine, frames it collectively, as something “us girls” need. In doing so, she emphasizes the shared connection between herself, the mother, and the daughter, speaking to them not only as a physician, but as a woman.

In describing routine conversations they have with parents and patients about Gardasil, all providers reported that they typically explain that the vaccine can prevent cervical cancer. In describing typical Gardasil conversations, some providers (n=4) explained that the vaccine did not protect against all types of HPV that can cause cervical cancer. The other providers simply described Gardasil as a vaccine that was developed to protect girls from developing cervical cancer. It is unclear whether providers, in actual conversations with clients, do stress the limited protection.

Two providers always included in their conversations that the vaccine prevented the two strains of HPV that caused 90% of genital warts. Four providers mentioned genital warts protection only with older girls (usually 15 years of age or older). Nina explained that parents of younger girls “don’t seem to like the genital warts so much. I don’t usually mention that unless they’re a little older. Usually if they’re 15 and up I’ll mention it. If they’re younger than that I usually just say cervical cancer.” Robyn brought it up with older adolescents and their mothers at the teen clinic. She explained that while protection against genital warts was not the most important information to share about Gardasil, girls found the information particularly important in assessing the benefits of the vaccine. “I’ll tell you who it really resonates with more than the parents, it’s the kids. Because the idea of having warts is just so creepy to kids. For parents it’s usually the severe health consequences, for kids it’s the gross warts stuff. It just creeps them out.”
Four providers seldom, if ever, mentioned genital warts because they conceived the major benefit of the vaccine to be in the prevention of cancer and therefore did not think it was as important to mention warts. They also noted that parents received a pamphlet that contained information about warts. Jane did not view protection against genital warts as a significant benefit of the vaccine. “Why I don’t bring it up as much? [Parents] don’t seem to know as much about it. It doesn’t seem to have as much importance to them, and I guess it’s true that it isn’t really as important to me. You know, I think, (sighs) it’s more important that people don’t get cervical cancer than that they don’t get genital warts.” It is interesting that part of the reason Jane does not discuss genital warts is that parents do not seem to have a previous awareness that the vaccine protects against them. Of course, parents cannot evaluate whether genital warts protection is an important benefit of the vaccine if they are unaware that the protection exists. Parents in this study rarely knew that Gardasil offered protection against genital warts but upon learning this information found it to be a significant benefit to vaccination.

Jane, who worked both in a family practice and in a non-profit teen clinic, saw many girls who she diagnosed with genital warts. In further reflecting on why she typically does not mention genital warts protection when discussing Gardasil she asked, “I don’t know, do you think we should? I see so many warts and I see so much hysteria about the warts that I get tired of . . . I don’t like it brought up a lot because it just – people have it blown way out of proportion and then when they get it you would think I told them that were dying of something. You know?” Jane’s experiences diagnosing and treating warts led her to exclude wart protection from her Gardasil conversations, which
is interesting given that the stigma associated with the benign forms of HPV would likely lead some parents and young women to view Gardasil protection against genital warts as an additional reason to vaccinate their daughters.

It is possible that a few providers did not mention genital warts when presenting Gardasil information to parents because they were misinformed about Gardasil’s protective benefits against warts. One provider, when asked why she did not mentioned genital warts, replied, “I don’t because it’s my understanding that it does not protect against the physical genital warts. Am I wrong about that?” After I explained the relationship between strains 6 and 11 with genital warts, the provider felt that she still would not mention this protection to clients unless they specifically mentioned it. She replied, “I think in some ways, knowing the population of young girls, they don’t even want to think about the sexual activity aspect of it. [The genital warts] might be bringing it a little more in their face than they want to acknowledge.”

Another provider admitted that she rarely mentioned that the vaccine protected against genital warts. She explained, “I guess I think that the main thing that we’re trying to prevent is the cancer and the other thing is, it doesn’t prevent –this vaccine doesn’t prevent all genital warts. It prevents the ones that cause cervical cancer.” Like the other provider, this practitioner did not view genital wart protection as a key benefit of Gardasil, but also, she seemed to believe that the vaccine only prevented HPV strains that led to cervical cancer, not the more benign, external warts.

A few providers did not discuss sexual transmission every time that they presented Gardasil information; rather they chose to exclude, mention, or stress the sexual aspect after assessing the knowledge and needs of the parent and daughter. Ten
providers reported that they always included in their conversation that HPV was sexually transmitted, but three of these providers only included the transmission route in all conversations with older girls (depending on the provider, beginning at age 12 or 13). Some providers, such as Nina (quoted above) and Maggie (a nurse practitioner) brought sexuality to the forefront of the conversation in hopes of providing parents with an alternative way to conceptualize the vaccine to defuse anticipated parental concerns.

Maggie, for example, tried to turn abstinence into a selling point for the vaccine. She immediately tells mothers and daughters that HPV is sexually transmitted, but uses that information to discuss the importance of abstinence and why abstinent girls can benefit the most from the vaccine. She explained,

I try to bring it to the forefront as quickly as possible. You have a window of opportunity, which is sexual exposure. If you can put your hand on the Bible and say that you have never had sexual activity then this is a critical window. It’s just like never putting a cigarette in your mouth – a great thing that we want to commend you for, and want you to continue not doing. But with the HPV vaccine you have an opportunity because you haven’t had sex.

In this pitch, the provider approaches the daughter’s proclaimed abstinence not with a challenge, or reminder that she will eventually become sexually active, but as a commendable decision that makes her eligible to receive a vaccine that other girls (who presumably made less commendable decisions) cannot. Along with Maggie and Nina, two other providers also routinely emphasized that Gardasil was a prophylactic vaccine.
Provider Vaccine Recommendations

The providers with whom I spoke were well aware of the influence their Gardasil recommendation could have on parental vaccine decisions. One provider believed that within her own practice, the provider made a huge difference in determining whether adolescent girls walked out of the office having received Gardasil or not. “I think if you walk in and the same family either gets to talk to me or talks to somebody who says, ‘Well it’s really your choice. If your daughter’s not sexually active then there’s not really a real need to get it,’ then they’re not going to get it. Apparently any kind of skepticism of the medical community is going to make them not get it.”

Janet recognized the important role she played in parents’ Gardasil vaccine decisions. “I think a huge deal is the provider and patient conversation. Many times they’ll ask me what I think about it, and many times they end up getting it because [...] I stress how important I think it is.” Other providers also reported that parents typically wanted to know how they felt about the Gardasil vaccine and whether they would recommend it. Jane explained that many of her parents ask her whether she “believes” in the vaccine or not and Laura stressed that the most common questions parents ask her is, “What do you think?”

Most of the providers (n=12) highly recommended Gardasil to parents and young women and strongly endorsed it regardless of whether their endorsements were specifically requested. One pediatrician noted that parents frequently asked her for her opinion on Gardasil. She replied, “I mean, I’m not sure what they think I’m going to say. I mean of course I’m going to say that I think they should have it, that I think it’s a wonderful vaccine, [that] I think it’s wonderful that we have something that can help
prevent cancer, and I think it would be silly to not protect yourself against that given the opportunity.”

The pediatrician’s surprise that parents felt they had to ask if she endorsed the vaccine revealed her own expectation that parents should know that she, a very vocal advocate of vaccines, would obviously recommend Gardasil. At a more latent level, her comment suggests an assumption that all providers would endorse the vaccine. This provider worked in a large practice; it was not uncommon for her to see new adolescent patients. That the provider was equally surprised when their parents asked for her Gardasil opinion suggests that she assumes all providers are supportive of Gardasil and recommend it. While it is true that all of the providers I interviewed were generally supportive of vaccines, and that all of the pediatricians endorsed Gardasil, it is not the case that all providers recommended Gardasil.

Four providers – three nurse practitioners and the chiropractor – were less comfortable recommending the vaccine. These providers attributed their discomfort to their aspects of their nursing or chiropractic model of care, and to their perspectives regarding vaccines in general and Gardasil in particular.

The chiropractor and nurse practitioners emphasized the importance of patient participation in healthcare decision-making, especially when they perceived treatments to be optional or less necessary to ensure the health and safety of individuals or communities. These four individuals strongly emphasized the importance of including girls and parents in the healthcare experience by empowering them to learn about their bodies, educating them about healthcare options, and encouraging them to participate in healthcare decision-making. These providers tried to provide accurate medical
information about the vaccine, but preferred not to be put in a position where they felt the parent would accept or reject a vaccine based on their recommendation.

All four providers noted that they felt more comfortable recommending other vaccines to their clients. A key difference between Gardasil and other vaccines was that providers did not consider Gardasil to be a necessary vaccine. They did not perceive all girls to be at equal risk of being exposed to HPV, nor did they perceive that girls who developed HPV were at equal risk for developing cervical cancer.

Like the nurse practitioners, the chiropractor was not opposed to vaccination in general; rather, he felt that Gardasil was a less necessary vaccine due to most individuals’ ability to clear infections naturally and because of public health screening programs. One NP agreed, arguing that Gardasil should be presented as a choice that parents need to make themselves. She stressed that the practitioners’ role should be to equip parents with information so that they can make informed decisions for themselves.

We have to educate people about their choices. There’s over 100 types of HPV. This protects you against 4. And, furthermore, the vast, vast majority of people who are caught with HPV will clear it with their own immune system. And so what are the percentage of people that we’re really protecting from death with these vaccines? You know you do have to take these things with a grain of salt and so it should be a choice that’s presented to people. It shouldn’t be a high pressure situation, I don’t think. That’s where I’m coming from anyway.

One of the nurse practitioners additionally worried that adverse reactions to the vaccine could make it more difficult to convince parents to accept vaccines that she felt were far more important. She would not initiate Gardasil conversations and preferred
neither to recommend parents to accept or refuse the vaccine. She did not view Gardasil as a necessity and worried that adverse events associated with Gardasil could make parents leery of accepting other vaccines that she felt were critical to ensuring public and individual health. She explained that Gardasil is not *necessarily* a life-saver, if you will, the way that whooping cough vaccine has been or things that have really been these hallmarks of public health and infectious disease. HPV is a vaccine that could sort of tip public perception of the value of vaccines. Because when adverse events occur, it just becomes something that is not necessarily needed.

Jessica’s concerns about the necessity, safety, and cost of the vaccine, coupled with the fact that Gardasil was stocked on-site, led her to avoid initiating conversations about the vaccine. She explained,

> In my current setting I don’t bring [Gardasil] up unless asked, even though I should bring it up more because I have it sitting right there in my refrigerator. But I mean, it’s funny, I was almost more likely to talk about it in my previous setting where I didn’t have it sitting in the refrigerator because it was more of – I’ve done the counseling piece, they can absorb the information, and if they want it we can work on getting it. But I have my bias against it.

She further clarified, “I sort of feel like people should be informed before they make the decision and I think informing them and then ten minutes later giving them the injection isn’t being truly informed. I’d like them to sort of digest the information and then come back.” When I asked Jessica if her philosophy towards time and informed consent was true of all vaccine decision-making, she replied,
No, it’s specific. And that’s my bias. It’s interesting, the thought just popped in my head . . . I don’t agree with pharmacists that won’t dispense contraceptives or whatever based on moral/religious grounds. I feel like maybe that’s how I am about the HPV vaccine. But it’s not on moral or religious grounds, it’s just on a show me the evidence ground.

The provider’s ambivalence highlights some of the ethical issues that practitioners grapple with in the provision of healthcare. The provider found herself struggling to disentangle her personal and professional vaccine concerns and questioned how these concerns related to her responsibilities as a practitioner to protect patient health and inform patients of available preventive technologies. She was not comfortable enough with the safety of the Gardasil vaccine to initiate conversations about it, because she feared that parents would interpret initiation of conversations as a vaccine recommendation. At the same time, she was uncomfortable with the implications of being inactive in initiating conversations and the reasons underlying her inaction.

In describing the strategies they use to initiate, discuss, and recommend the Gardasil vaccine, it becomes clear that there is a high degree of variability in the types of information parents likely receive from providers. For example, few providers mention to parents, especially to those with younger girls, the protective benefits of Gardasil at preventing genital warts. Of more concern is that during recounts of typical discussions with parents, only four providers mentioned that Gardasil only protects against certain types of HPV that can cause cervical cancer. If in practice, providers are touting Gardasil as a cervical-cancer prevention vaccine without also stressing its limited protective abilities, both parents and girls could mistakenly believe that pap smears are no longer
necessary. On a more subtle level, failing to stress the limited benefits of the vaccine could lead individuals who later develop HPV-related infections to lose faith in the efficacy of vaccines.

The Parent-Provider Interface: Parent Reports of Interactions

I asked parents to recall, to the best of their ability, the first time that they had discussed Gardasil with a healthcare provider, who initiated the conversation, what types of information were discussed and by whom, and how materials were presented. All but four parents had discussed the Gardasil vaccine with at least one of their children’s healthcare providers. Some parents, who had originally spoken to providers about the vaccine years ago, had difficulty recalling specific details of visits. Other parents, who had recently made Gardasil decisions, recounted greater details. Some parents had seen healthcare providers several times before making a decision to vaccinate their daughter. Other parents who continued to defer making a Gardasil decision had spoken once or more to their providers. Parents with more than one daughter in the eligible age range sometimes had not talked to their provider about Gardasil for all of their daughters.

Four parents reported that neither they nor their providers had initiated a conversation about the vaccine. The mother of a sixteen year old daughter attributed this to the fact that her daughter did not currently have a regular healthcare provider and thus only saw providers, usually at walk-in clinics, when she was sick. Wendy, whose daughters were 12 and 15 years of age, had a regular provider, but only took her children to the doctor for acute care visits and sports exams. The last time the girls went for sports physicals their grandmother took them, and while Wendy knew from talking to her mother that the provider had mentioned Gardasil, she knew nothing of the actual
interaction. The other three parents had daughters between 10 and 11 years of age. The mother of an eleven year old was not interested in having her daughter vaccinated, and therefore did not bring the vaccine up at her daughter’s most recent visits; her provider did not mention Gardasil either. One father had not heard of the vaccine until recently and thus had not thought to ask his ten year old daughter’s pediatrician about it. Jill had thought about mentioning the vaccine during her daughter’s ten year physical, but was uncomfortable initiating the conversation, hoping instead that her pediatrician would.

I thought about asking about the vaccine at her last visit but then something came into my mind that it’s kind of linked with, I don’t know, what we think of as (whispering) sexual activity. So I was like “Oh my God! She’s ten! I’m not talking about that!’ (laughs). . . I think most people probably have the same [reaction as me]

She continued, “I almost think that if something was initiated with a professional, not just me talking to her, it would probably be better. For me anyway.” If Jill’s hesitation to initiate the conversation itself is shared, it is possible that some parents who are interested in the vaccine will not discuss it if the provider does not take the initiative. In the previous cases described, it is possible that the provider will discuss the vaccine with these parents during future visits, when daughters are slightly older and perhaps, when providers perceive that the conversation will be received more openly. As providers in this study and national studies (Daley et al. 2010) confirmed, many practitioners do not begin recommending the vaccine until girls turn 11 or 12 years of age or enter their teen years.
Twenty-two parents had spoken at least once to a provider about the Gardasil vaccine. Fifteen parents reported that the provider initially brought up Gardasil. While parents did not always recall exactly how providers initiated the Gardasil conversation, several parents explained that the provider mentioned Gardasil as one of several vaccines for which their daughters were due. In other cases, providers discussed the Gardasil vaccine as a separate vaccine that, unlike other vaccines, was not required for school entry.

In recalling HPV conversations initiated by providers, parents reported that providers always presented some information about the vaccine to parents verbally. Eight parents also remembered receiving some type of flyer or pamphlet that contained information about the vaccine. Three parents could not remember any specific details of their conversations with providers. One mother heard the provider say the word “Gardasil” and interjected that she had no interest in the vaccine. The provider replied by handing her a pamphlet and telling her that she recommended the vaccine.

Slightly more than half (n=8) of the fifteen parents who reported a provider-initiated Gardasil conversation believed that the provider explained that the HPV vaccine prevented, or could prevent, cervical cancer. According to parents, three providers stated that the vaccine would also protect against genital warts. Four providers discussed that HPV is sexually transmitted and three emphasized that the vaccine was only effective as a prophylactic. Two providers explained that the vaccine only provided protection against some strains of HPV and one provider mentioned that abstinence was the only sure way to protect oneself against sexually transmitted infections. One provider urged that the parent verify that Gardasil was covered by her insurance company and another
provider emphasized that the vaccine was not school mandated and did not need to be administered immediately. Five parents reported that the provider included the daughter in the conversation.

After discussing the vaccine with providers, nine parents (out of the 15 who reported provider-initiated conversations) agreed to begin the vaccine series during the same office visit. The other six parents did not have their children vaccinated after the initial conversation and one of these mothers had no plans to vaccinate her daughter in the future. Among the other five mothers, two mothers eventually initiated the series, while the other three planned to begin the series at some point in the future. The two mothers that eventually initiated the series had planned to begin the series immediately, but one provider recommended she first make sure that her insurance would cover the series and the other mother wanted her daughter to actively consent to the vaccine, which she was unwilling to do at the time. Eventually, both mothers had their daughters vaccinated. Among the three women who continued to delay beginning the series, two mothers, with nine and eleven year old daughters, said that their providers initiated conversations about future vaccination. Both providers recommended that the girls receive the vaccine, but in a few years. Finally, one mother was still concerned about the newness of the vaccine, but was leaning towards initiating the series when her daughter turned seventeen.

Two of the six mothers who did not initially have their daughters vaccinated reported that providers initiated follow-up conversations regarding the vaccine at future appointments. Marie, who had deferred the decision for more than three years, recalled that her pediatrician, since retired, had brought up the vaccine at every visit. The other
woman, Lucy, recollected that the pediatrician initially introduced the vaccine during her daughter’s thirteenth year wellness exam. While the mother was ready to vaccinate her daughter after the original discussion, she wanted her daughter to take an active role in the decision-making process and consent to receive the vaccination. Over the course of the next two years, her daughter needed to see the doctor on six occasions, and at each visit, the doctor reminded them of the vaccine. The mother finally had her daughter vaccinated for her fifteenth year check-up.

In seven cases, the parent initiated the conversation about the Gardasil vaccine with his or her child’s provider. All of the parents who asked their providers about the vaccine ultimately had at least one of their daughters vaccinated; however, three of the parents did not begin the series during the same visit. One mother, over the course of a year, asked two pediatricians and her own gynecologist about the vaccine; all three providers strongly recommended it, but she waited several more months before beginning the series. Two fathers who conducted their own research on the vaccine asked their daughters’ healthcare providers about the vaccine, and based on responses, delayed vaccination.

Parents who initiated conversations with providers described the exchange in less detail than parents who said providers began the conversation. In recalling their own conversations with providers, three of seven parents said that upon asking their providers about the HPV vaccine, the providers replied that they thought it was a good idea. Other than a provider recommendation, they did not think the provider discussed more about the vaccine. Only two parents recalled providers discussing specific information about the vaccine or the virus it prevents. One parent asked her provider about the vaccine,
explaining that her mother-in-law had had cervical cancer. He responded that the vaccine was not a cancer-preventing vaccine, but could prevent some of the causes of cervical cancer. He also stressed that the vaccine was not required for school entry. Another mother asked her provider if she thought the vaccine was a good idea. “She said that it can help to prevent a certain type of cancer, I believe. And she said ‘I think it’s a good idea. I don’t think it can hurt your daughter in any way and I think it can only help.’ Those are the things I remember for the most part.”

It is unclear why parents’ recollections of HPV vaccine discussions seem to differ depending on who initiated the conversation. It appears from parent recollections, that providers might share more information about HPV and Gardasil when they initiate conversations. One pediatrician’s own account of her approach to Gardasil lends some weight to this difference. In a routine clinical visit with patients 11 years of age and older, Elizabeth only discusses the benefits of Gardasil, what it can and cannot protect against, how HPV is transmitted, and the risks associated with HPV and the vaccine if parents do not immediately consent to the vaccine. If the parent consents to have her daughter vaccinated, Elizabeth simply moves on to the next issue. She explained, “If I say to the mom of an 11 year old ‘okay, these are the vaccines that we’d like to give. They’re due for the tetanus, the meningitis, and the Gardasil’ and the mom already says ‘okay, yeah,’ then I don’t actually explain Gardasil.”

Despite this one provider’s account, there is no way to know whether the providers seeing the two groups of girls have different strategies for discussing the vaccine. We cannot know whether parent’s recollections accurately portray the conversations that took place in the provider setting. It could be that parents who initiate
the conversation do so by asking pointed questions that narrowly define the discussion, while when providers begin the discussion they have a broader scope of talking points. It might also be that parents who initiated conversations were most interested in hearing whether the provider recommended the vaccine, and therefore were more likely only to recall this feature of the conversation. It is also possible that providers assumed that parents who asked about the vaccine were either interested in receiving it or had already done research on the vaccine, and therefore did not require additional information about what it protects against, how it is transmitted, and so on.

Another interesting difference between parents’ descriptions of interactions had to do with the daughter’s role during the discussion. In all but one case, daughters were present for parent-provider conversations regarding the Gardasil vaccine. Fourteen of fifteen parents said their daughter was present when the provider brought up the vaccine. Five of these parents (daughters ages 13, 14, 15, and 16) specifically noted that the provider addressed the daughter when initiating the conversation; the mother was included in the conversation, but as a peripheral participant. Among the seven parents who brought up the vaccine themselves, each had at least one daughter (ages 11-16) present at the time, and two parents had two daughters present. None of the parents who initiated the vaccine conversation mentioned that the provider said anything specifically to the daughter during the conversation. It is unlikely that the child’s age can explain the difference in approaches, since in both groups at least a sub-set of daughters were of the same ages. It might be that providers addressed parents in parent-initiated conversations precisely because the parents started the conversation.
As previously mentioned, there are plenty of reasons why parents’ descriptions of HPV conversations differ. It is impossible to determine, based on the way that I collected my own data, whether conversations actually differed, or whether parents recollect different aspects of the interaction. It would be worthwhile in future studies to examine the actual differences in provide-parent conversations based on who initiates the conversation, because such differences could have effects on the breadth and scope of information that parents receive.

If providers are indeed presenting less information to parents who initiate conversations about the vaccine, there is a chance that parents and daughters will make semi-informed vaccine decisions or have a less complete understanding of the complete, but limited benefits of the vaccine. Providers might be missing important opportunities to discuss abstinence and safe sex with girls, or opportunities to involve them directly in a decision that affects their personal health.

**Provider Sources of Information**

Data from provider interviews reveals that differences in the ways that they and parents assess the credibility and relevance of vaccine-related information can sometimes lead to conflicts, frustration, and misunderstandings in the clinical encounter.

As discussed in Chapter Eight, providers tried to respond to anticipated and stated concerns that parents might have about the Gardasil vaccine. Whether responding to concerns about the newness of the vaccine, the age at which it was administered, or its effects on sexuality, providers sometimes responded to parent HPV-related concerns by elevating their own expertise or knowledge system over the source in question. While well intentioned, such approaches could diminish trust or discourage parents from sharing
concerns with providers, especially if parents feel the providers are condescending or reproachful. Consider one provider’s account of her response to parents who ask her about adverse vaccine effects they have heard about through the media or friends.

You know, you can’t just go by a news report or something else you hear on TV because anything can happen within 24 hours of giving a vaccine that has nothing to do with the vaccine. And because it was given within 24 hours it’s still reportable. So just because someone got into a motor vehicle accident and died [it gets reported in VAERS], because death was within 24 hours of Gardasil. Do you really think that was the cause? The Gardasil? No! So you can’t go by just hearsay and what’s talked about.

Moreover, risk statistics are of little help to parents if parents do not perceive that population-level statistics are relevant to their individual case. In Chapter Eight, I presented an example in which a provider tried to counter parent claims that the Gardasil vaccine was unnecessary because their daughters would not be sexually active until marriage. The practitioner commonly presented national statistics to parents that suggested the majority of youth became sexually active before marriage. In response, parents countered that their daughter was in the minority percentage that were not. The strategy, based on population statistics, was of little relevance to mothers who made assessments for individual daughters. Moreover, such responses might be interpreted by parents as indications that providers doubt their own awareness of their daughters’ sexual readiness or moral characters.

Conflict and misunderstanding can arise when providers try to use scientific or medical information to “correct” a belief. This most often became an issue when parents
held views about reproductive technologies that conflicted with their own. Providers had particular difficulty responding to parents who felt that technologies such as birth control (for acne or menstrual cramps) and Gardasil either directly promoted promiscuity or conveyed a message that parents and providers passively approved of premarital sexually activity. Maggie found it particularly difficult to respond to parental concerns about promiscuity but saw the conflict as educational. She had knowledge, the parents did not:

The religious stuff does become an issue when the kids become adolescents. It definitely becomes an issue of what parents think and this huge wall comes up between me and them because of a lack of knowledge [on parent’s part]. I give [adolescents] a vaccine, education, medications to prevent disease. This does not equate with promiscuity.

Recall from Chapter Seven that one pediatrician drew upon her own clinical experience to argue that education and vaccine resistance were intertwined. She observed, “We gave the Gardasil at 9 and hardly anybody refused it, because of the population. You probably know this – the lower educated population refuses vaccines a lot less. They kind of just do whatever the doctor tells them to do.” Janet encountered little Gardasil resistance in the less educated, low-income population that she treated, despite the fact that the vaccine was brand new at the time. When it came to vaccines, Janet preferred working with this parent population because they usually readily accepted vaccines, which she thought were fundamental to the health and well-being of individual children and the larger population. While Janet wanted her parents to be well-informed and educated, her conception of what constituted information or education was narrowly defined. Reflecting on her observation that parents with lower education levels tend to
do whatever the doctor recommends, she replied, “It has pros and cons. I think it’s good to be educated, I think it’s good to ask questions. But I don’t agree with refusing vaccines, which some of the higher educated families try to do. Which seems counter intuitive (laughs).”

Janet’s assertion that it is good to ask questions is qualified and contingent: education was acceptable as long as it did not cause parents to make decisions that providers felt were the wrong decisions. In this case, outside sources of information were encouraged as long as they led parents to vaccinate. Janet recounted a recent exchange she had with a mother who was refusing the DTaP vaccine based on a chiropractor’s recommendation. The provider explained,

I was very angry. I was just so irritated that the chiropractor told them to refuse [the vaccine] because it is not safe. I was like, you have got to be kidding me. We ended up talking them into getting the tetanus by itself without the pertussis, since that’s the problem according to the chiropractor. And I’m not against chiropractors, but I don’t want them telling people that they shouldn’t be vaccinated. (laughs).

Whether more frequent among highly educated parents or not, several providers observed a trend between consumer education and vaccine resistance, where parents who are “more likely to say “no” are the ones that have done research.” While Janet’s examples are more illustrative than some other provider examples, most providers expressed similar types of sentiments. Yes, providers want parents to be involved, informed advocates for their children’s health, but at the same time, they only want parents to seek and value certain types of knowledge.
It was clear that many providers did not believe that some of the sources from which parents gathered information would lead to well-informed decisions. Providers recalled many instances in which parents chose to refuse or delay vaccine decisions because of information they obtained through sources that providers found questionable or downright rejected. According to many practitioners, it was not uncommon for parents to have vaccine concerns because of something they read, saw, or heard in the popular media. Several providers expressed frustration that parents seemed to blindly accept unsubstantiated claims reported in non-scientific venues regarding the possible effects of a vaccine on one individual, while challenging provider and expert knowledge claims and ignoring the hundreds of thousands of cases in which the vaccine was administered without incident.

Providers noted that the internet has provided parents with an overwhelming amount of information about vaccines that parents selectively read and address during the office visit. Sue recounted a case in which a mother sent her a newspaper article reporting that a girl developed chronic fatigue syndrome from Gardasil. No matter what Sue said, the mother could not be convinced that Gardasil was safe after reading the article. Sue expressed frustration that parents seemed to put more faith in a journalistic news report than in the public health system or a licensed physician, and that the internet has led parents to falsely believe that they are capable of making expert decisions. “Of course, the parent reads about one article stating an association and now that parent is a medical expert.”

Other providers shared similar experiences. Parents hear from friends, family, or the media that girls suffer adverse effects after being vaccinated with Gardasil and then
question the vaccine’s safety, but without validating the claims or understand how adverse effects are reported through the Vaccine Adverse Event Reporting System (VAERS). Providers (n=9) frequently mentioned having to talk to parents about how VAERS worked in response to stories they heard about adverse reactions. One provider responded to these concerns by explaining how the VAERS worked, though sometimes parents do not believe her: “They believe a lot of those things that they see online where 27 girls died after [getting the Gardasil vaccine]. I get that a lot. And you explain to them that there were other conditions and it was just, oh by the way, they also had the HPV vaccine. It wasn’t due to the HPV vaccine but [not all parents] believe that.”

Some providers understood why parents were concerned by news reports, but also did not consider these stories to be forms of “evidence” upon which vaccine decisions should be made. In response to parent concerns that Gardasil causes Guillain-Barre syndrome, one provider said, “We’ve given 23 million doses [of Gardasil] and all of the adverse reports are entered into the VAER system. Guillain-Barre occurs in a certain percentage of the population anyway, I don’t feel like there is an association based on the evidence.”

Providers often had to respond to parent concerns regarding vaccine side effects, many of which were publicized in the popular media and for which there was little or no scientific evidence to support. Providers found it particularly frustrating when parents put more weight on celebrity recommendations than their own. For example, Kelly, a school nurse, was not uniformly opposed to non-medical exemptions, but was opposed to exemptions based on certain types of knowledge. She was particularly frustrated that several parents were resisting specific recommended childhood vaccines because Jenny
McCarthy (a vocal Hollywood celebrity) insists that they caused her son’s – and many other children’s - autism. Kelly recalled several recent cases in which parents sought vaccine exemptions specifically “because Jenny McCarthy said that her son got autism from it and that’s reason enough.” She continued,

Parents aren’t abstaining for the right reasons. They’re [abstaining] because they see some kind of celebrity spokesperson saying “Don’t get vaccinated,” which I think is crap. If you don’t want your kid vaccinated, you better find out why. I understand some of that. I can see why some parents would think that and if they do I can respect their opinion, but don’t just say you’re not getting your kid vaccinated because Jenny McCarthy says you shouldn’t. I find that very hard to believe that somebody would make a decision based off that, and people tell me that, so I know they do.

For Kelly, there were clearly “right” and “wrong” motives to abstain, or legitimate and illegitimate reasons to be wary of vaccines. Sophia described parental resistance to the MMR vaccine as a “huge issue” in her practice. Aside from her concern that children were being left unprotected from vaccine-preventable diseases, she was also frustrated that parents found celebrity spokespeople more credible than their own primary care provider. When I asked her why parents were declining the vaccine, she explained that it was due to concerns about autism that parents heard from “news stories and Jenny McCarthy. It’s on Oprah. And I guess Oprah’s got a lot more credibility than I do.” Indeed, four parents that I spoke with specifically mentioned Oprah, Jenny McCarthy, or both women, when describing sources of general and specific vaccine information.
There was a sense of frustration among healthcare providers that parents validated information from sources that, when pressed, they could not identify. Nearly all providers felt that a lot of the information that was available to parents was inaccurate, and yet, providers felt that they had to spend a lot of time in a limited visit to respond to inaccurate information. Healthcare providers also found it ironic that parents would discount their professional medical opinion regarding one aspect of healthcare and in the next breath ask for their medical advice. The following example illustrates this point well: Elizabeth was perplexed that parents would refuse to follow her recommendation to follow the AAP vaccine schedule, which is what she recommends, and then ask her to recommend an alternative. Thus, parents are rejecting a biomedical recommendation because they discredit or distrust it, while simultaneously asking for biomedical expertise on how to proceed. Describing her policy, she emphasized that parents who want to split vaccines,

are well aware that it’s against guidelines and it’s not what I would recommend. So I don’t allow them to tell me, “I want them split up but you need to tell me how to do it.” I say, “No. I’m telling you get six. So if you want them split up, you’re going to tell me how you think it’s appropriate.” And when I say that, about fifty percent will say, give me all the vaccines.

Chapter Nine Summary

Generally, parents legitimized knowledge from a wider variety of sources than did providers. Consistent with findings reported by Litton and colleagues (2011), the vaccine manufacturer and healthcare professionals were leading sources from which parents learned about Gardasil. However, parents often obtained information about vaccines
from their own experiences, their family members, peers and colleagues, other parents, vaccine manufacturers, biomedical and alternative healthcare providers (such as chiropractors), news, radio and television programs, and myriad websites. Providers, on the other hand, obtained and legitimized knowledge published in peer-reviewed academic journals, promoted by specific member groups (e.g., ACOG, APA), or recommended by national and international health organizations.

The Theory of Reasoned Action posits that social norms regarding vaccination can affect parental vaccine decisions. However, it is unclear what role these conversations and social norms actually played or could play in parents’ vaccine decisions. Parental narratives suggest that conversations with friends, family members, and other parents about the vaccine enabled parents to get a general sense of the safety of the vaccine and the social norms surrounding receipt of it. In particular, parents valued these discussions in assessing the safety of the vaccine; reassurance in the safety of the vaccine was affirmed as a greater number of girls within their social circle received the vaccine without incident.

The fact that vaccine-skeptical parents tended to report negative conversations about the vaccine and vaccine-supportive parents disregarded negative reports suggests that some parents might selectively filter out contradictory information shared by their peers and other parents, while amplifying experiences and perspectives in line with their own (Leask, et al. 2006; Meszaros, et al. 1996). If this is indeed the case, then it lends support to the argument that other factors, unrelated to knowledge play a role in these decisions.
The two most common sources of parental HPV-related information were Merck (through Gardasil commercials) and healthcare providers. The predominance of certain sources in conveying vaccine information might help to explain why some types of information, such as the relationship between cervical cancer and Gardasil, are commonly reported, while other information, such as the association between genital warts and Gardasil, is less known. However, it is important to remember that information is filtered and evaluated within larger social fields and in relation to other, sometimes competing and conflicting information.

Parents and daughters became important sources of information in assessing the need for the vaccine. Parents seldom felt comfortable talking to their daughters about sex, but did so anyway because they wanted their daughters to feel comfortable approaching them with questions and concerns about sex. Sexual communication also offered a means by which parents could assess their daughters’ sexual maturity and anticipate sexual debut. The strategies employed by parents to gauge their daughters’ sexual readiness and maturity were largely founded on notions of trust – trust that their educational efforts are effective, trust in the accuracy of their strategies and assessments for evaluating sexual maturity, and trust that their daughters will come to them before they think about having sex. In the following chapter, I will argue how parents’ notions of trust in their daughters and in others intersect with parental conceptions regarding Gardasil, risk, and time.

The types of information that parents obtain from providers not only has to do with the quality of the professional relationship, but provider perceptions regarding HPV infection, vaccine safety, efficacy, and need. Provider accounts of typical Gardasil
conversations reveal that there are significant differences in the scope of HPV-related
information that providers share with patients and when and if providers initiate
conversations. Even within their own practices, providers shared different types of
information – and present that information in different form – depending on
characteristics of the patient. Along with other considerations, such as the type of office
visit and insurance coverage, these factors can shape the ways in which Gardasil
conversations are (or are not) initiated, by whom, and what types of information is
shared.

What constitutes knowledge, and how to negotiate different knowledge claims, is
key to the parent-provider interaction. Differences arose when parents and providers
were discussing the need for, and risks associated with the vaccine, but when neither
party was willing to accept the validity (or perhaps superiority) of the other’s knowledge
system.

What Janet (and other providers) saw as a paradoxical relationship between
advanced education and vaccine resistance was founded upon two taken-for-granted
assumptions. First, Janet and other healthcare providers assumed that individuals with
advanced education are more likely to deem as superior scientific forms of information in
making vaccine decisions and, that upon reviewing these data, parents would similarly
conclude, as she did, that Gardasil was safe, effective, and beneficial. However, not even
the providers in this study, who did rely on a shared set of scientific knowledge to
evaluate the vaccine, could agree among themselves the safety, necessity, and efficacy of
Gardasil. Four providers were unlikely to universally recommend the Gardasil vaccine.
What Janet’s observations and other narratives reveal are taken-for-granted notions about the constitution of knowledge, how knowledge should be used, and who should possess it. Parents and providers often enter into interactions with differing ideas about what constitutes legitimate information, and subsequently, what types of information should be used to inform vaccine decisions. Conflicts can arise when providers and patients feel that their own criteria for evaluating and valuing knowledge are dismissed. As will be discussed in the following chapter, such conflicts can damage the trust that parents have in providers, and subsequently, the confidence and value that parents place on their providers’ vaccine recommendations.
Chapter Ten – Trust and Risk Evaluation

The risks and benefits that parents perceive regarding a disease and the vaccine it is developed to prevent are largely shaped, as has already been discussed, by antecedent events, decisions, and policies that frame the structural field in which parents seek healthcare and conceive of vaccines. Moreover, parents obtain information used to assess vaccine risks and benefits by diverse sources; however, the validity and weight granted specific information varies. To some degree, the weight assigned to particular information relates to the trustworthiness of the source. As will be discussed shortly, the political efforts to mandate HPV vaccination for school entry, and subsequent revelations that key actors spearheading these efforts were receiving funds from or were personally connected to Merck, led both parents and providers to question specific sources of information and the vaccine itself.

Though no interview questions contained specific references to trust, parents and providers continually invoked notions of trust to frame vaccine decisions and engage in risk assessments. Parental trust in the public health system, pharmaceutical companies, healthcare providers, daughters and their future partners, other parents, and society were central to the ways in which parents conceptualize the HPV vaccine and decisions regarding it. The trustworthiness of a source was an important consideration for parents who attempted to evaluate the credibility of information; the safety of the vaccine; the motives of manufacturers, regulators, and providers; daughters’ sexual preparedness; and the social world in which daughters interact.
In the first section of this chapter, I present information on pharmaceutical companies and government agencies, and historical and more contemporary events that shape the ways in which parents’ assess not only the trustworthiness of these stakeholders, but of the Gardasil vaccine itself. Within this section, I also present providers’ views on the vaccine and their own trust or distrust of Merck, regulatory oversight, and the vaccine, because, as shall be discussed, provider recommendations and insight regarding a vaccine are highly valuable to parents. Thus, providers’ evaluations of the trustworthiness of the vaccine can potentially affect if, how, and when providers discuss and recommend Gardasil.

Subsequently, I discuss the ways in which trust is gained and lost through the service-delivery interface. I rely primarily on parental narratives to describe the criteria upon which parents assess the trustworthiness of healthcare providers, and how such sentiments can alter the ways in which parents approach vaccination. Finally, I discuss the role that trust plays in parents’ evaluations of their daughters’ disease risks.

It is important, when reading this chapter, to remember that trust operates on multiple and intersecting levels that are not easily disentangled. To speak of trust solely as it relates to singular stakeholders, such as pharmaceutical companies or providers, is difficult and somewhat artificial, for parents sometimes evaluate the trustworthiness of one stakeholder or entity based on the actions or trustworthiness of another (i.e., trust or distrust by proxy) or measure trustworthiness in relative degrees (e.g., the lesser of two evils). In the following discussion of trust, I present parental perceptions of trust as they apply to both specific entities and relationally, acknowledging that such an attempt can neither adequately capture the complexity of parents’ actual perceptions regarding the
trustworthiness of any or all groups, nor explicate the subtle and nuanced ways in which trust (or distrust) in one group can affect perceptions of the trustworthiness of other actors.

Pharmaceutical Companies, Government, and Providers

As discussed in Chapter Six, general population distrust about the composition of vaccines, their effects on the body, and laws regarding vaccine mandates is not new, nor is distrust of the role or motivations of pharmaceutical companies and the government vis-à-vis vaccination (Blume, 2006; Colgrove; Durbach, 2002; Fenner et al., 1986; Offit; Spier, 2002; Sturm, Mays, & Zimet, 2005; Wolfe & Sharp, 2002). Indeed, one might expect that distrust in either or both entities would increase with time, as history and technology provide a cumulative, well documented, and easily accessible record of alleged errors, mishaps, and tragedies attributed to vaccines or vaccination campaigns.

Both parents (n=6) and providers (n=5) expressed HPV vaccine safety concerns that directly or indirectly stemmed from (or resulted in) a lack of trust in governmental or pharmaceutical interests, relationships, or processes. Individuals pointed to the capitalist model of healthcare practiced in the U.S., pervasive use of drug marketing and advertising, historical cases of drug recalls, the high cost of many drugs, and the politics of drug regulation as some reasons to feel distrustful. While some individuals’ general distrust of providers, public health, or pharmaceutical companies led them to view the HPV vaccine with caution, other individuals identified the sources of their distrust as originating in processes or characteristics unique to the HPV vaccine.

Distrust in government and pharmaceutical companies often related to a general distrust in capitalism and a perception that values and goals of the capitalist-driven
biomedical system conflict with the values of human health. Several individuals’
distrust was directed squarely at the pharmaceutical companies, who they perceived as
powerful, profit-driven corporations that valued profit margins far more than consumer
health and safety. As Bill, a father of two daughters put it, “One should be wary of big
pharma and their interest in all of this.”

In viewing biomedicine as a capitalist form of healthcare, some individuals cast
the net of distrust even wider to include any stakeholder, including public health
practitioners, insurance companies, politicians, lobbyists, and healthcare providers, who
could potentially profit from the use of new biomedical technologies. Laura, a nurse
practitioner, lamented that treatments seem to benefit everyone but the consumer
stakeholder. She questioned who benefited from the current recommendation that the
Hepatitis B vaccine be administered to infants, despite not knowing length of coverage:
“What about re-vaccinations? We aren’t even sure how long Hep B is going to last and
we’re doing this to newborns?” Although supportive of vaccines in principle, Laura
found that in practice she had more difficulty confidently recommending vaccines to her
patients due to her misgivings about stakeholders’ interest. Expressing concern about the
increasing number of vaccines available to the public and their questionable safety she
said

Once again, I cannot believe we’re going to add more [vaccines to the
recommended schedule]. Meningitis is questionable . . . Listen to our history in
America. We’ve given medicines and ‘Oh! – they seem to cause birth defects and
all sorts of problems for women and babies’, and ‘Oh! Now we’ll take it off the
market’. The problem I have is the way we run, and how we can get rich or make
a profit off of healthcare in America. So people who are doing things, usually, are – and the drugs that get put out by the FDA – is messed up. It’s all about money. Just like the lobbyists and other things. We don’t do what’s best for Americans, really. We do what is the loudest, noisiest, making you the most money. That’s what gets through. Not the actual common sense portion of it. Or it’s 100% time and face. So that always bothers me because later you’ll see there are problems.

Natalie clearly explained how far such a web of distrust can extend if one views biomedicine as a purely capitalistic endeavor: “Pharmaceutical companies are a business. Insurance companies are a business. So you know, they pay big bucks to those lobbyists up there. It’s about business. It’s what’s going to be passed and what’s not going to be passed.”

Like Natalie, several other parents were concerned about the relationship between pharmaceutical companies and healthcare providers, either because they worried providers would push specific brands or products to receive kickbacks, or because they feared providers simply regurgitated vaccine safety information given to them by the manufacturer. Mark, a father of four, felt ambivalent about going to his healthcare provider to learn about the HPV vaccine.

I don’t know that we would necessarily go to a doctor and say ‘hey, I want to get some information [on the HPV vaccine]. Just because I feel like a lot of the information I’m going to get typically would come from the drug rep who’s selling the vaccination who’s more of a marketing package. And so it has to be more balanced. You can get that little brochure that you get at the doctor’s office online from the pharmaceutical company.
Several parents generally questioned whether direct-to-consumer drug marketing was ethical. That such advertising creates a link between the pharmaceutical companies and healthcare providers further caused some parents to mistrust the information they receive from healthcare professionals. A general distrust in pharmaceutical drug information, coupled with an overall increase in direct-to-consumer marketing and advertising caused some parents and providers to view the HPV vaccine with caution. The multi-million dollar Gardasil advertising campaign was successful in reaching most providers and parents, but the response to the Gardasil campaign, and pharmaceutical advertising in general, was not always positively received. Jessica, a nurse practitioner, said, “I have a few issues with Merck and some of their advertising campaigns, not just with Gardasil but with Zostavax, with Vioxx”

Some parents also felt that the Gardasil vaccine was marketed far more heavily than other drugs, and therefore a particularly suspect drug. That Gardasil seemed to be unusually well advertised, led some parents to question how much the company stood to gain from the vaccine. Melissa, a mother, reasoned that the company would not invest what she perceived to be an unusually large amount of money in advertising if there were not an exceptional amount of money to be made off of the vaccine. She explained,

It seems like the Merck pamphlet is the only hard information I have, and it’s from Merck. And it’s been such an advertising campaign, as opposed to information through a health provider, which I would see as more legitimate. I see their ad campaign . . . and I think, is this really something that’s good for you? Or is this just advertising, like we just want to sell this drug? Because it was so heavily advertised I’ve kind of stuck it in this same sort of – well, okay, here’s
just another drug trying to sell itself. And because it’s so expensive, for me, I go, well, that just goes to show you that they just want to make money off of it.

The cost of the vaccine raised alarm bells for other individuals as well, who saw the high price tag associated with the vaccine as an indication that profit, rather than public health, was the company’s bottom line. One provider generally supported the idea of an HPV vaccine, but had misgivings about the current vaccine. “[Gardasil is] an insanely expensive vaccine. And Merck has a history of coming up with these pretty expensive things, like Vioxx. Getting them out there and making a whole heap of money off them. Where’s the cost-benefit ratio analysis?” A parent asked, “If it’s so beneficial to have that [the HPV vaccine], why is it so expensive and why can’t the price go down?”

The two quotes above illustrate two different values regarding the relationship between the benefits and costs of technology. The provider suggests that expensive treatments and interventions are acceptable if the benefits are vast, but does believe that the benefits of the Gardasil vaccine are sufficient to justify the cost. The parent suggests quite the opposite – that high-benefit interventions should be low cost. In both cases, the cost of the vaccine led individuals to distrust the pharmaceutical company’s motives, but based on differing sets of ideas regarding price points associated with beneficial health technologies.

Trust is often gained and lost through experience. As I will discuss shortly, many parents gain trust in their healthcare providers after providers have demonstrated – in some form or another – competency and demonstrable concern for a child’s health and safety. In the case of pharmaceutical companies and governmental regulating agencies, trust can be lost when drugs have to be recalled due to deleterious effects. There are
plenty of historical cases in which treatments administered to the population were only later discovered to cause severe, and often long-term, ill-effects.

New technologies can produce anxiety-related unknown effects precisely because they are nascent and possible long-term effects may not appear until decades later. However, risks associated with innovative treatments are not always wrapped up with notions of distrust. One can have the utmost trust in the researchers or agencies that develop, test, and oversee the creation and use of a new technology and still perceive risks associated with the technology itself. Concerns regarding the long-term consequences of technologies can be linked to distrust if individuals perceive that such risks can be prevented or at least minimized with greater research, monitoring, oversight, etc. While nearly all parents (n=24) expressed at least some concern about the newness of the HPV vaccine, only a few parents connected their concerns regarding the newness of the vaccine with distrust in its manufacturers or regulators.

Several parents coupled concerns regarding the newness of the HPV vaccine with references to past medication recalls to explain why they felt distrustful towards pharmaceutical companies and regulatory oversight. Bill, a father of two, explained, “I think [other parents] probably delayed the decision for the same reasons that I did. We don’t know the long-term effects and there aren’t studies because it’s so new. And let’s face it, there are all these other things that have happened with particular drugs that parents have taken. So it’s good reason that you want to be cautious.”

One mother pointed to more recent cases of drug recalls when expressing her own doubts about the safety of the Gardasil vaccine. She recalled,
I know that Merck makes Gardasil. . . And it seems like – if Merck did Vioxx, and I know that there is a recall– the drug that they developed and was approved by the FDA caused a lot of problems. I don’t know the specific details but it’s like, Merck, you have a habit of pushing things through and maybe not following up. So if I have any sort of misgivings about the HPV vaccine my misgivings would be: Okay, well it’s connected with Merck and Merck has done something in very recent history that has been bad for people.

Distrust also arises from fears and suspicions that early recipients of approved vaccines are essentially test subjects, or “guinea pigs”, used to determine the long-term safety of new drugs. Explaining why some parents refuse to have their daughters vaccinated, Isabelle, a Florida nurse practitioner said, “Some people are just nervous about anything new that’s on the market and they’re afraid they’re being used as guinea pigs.” Jessica, a nurse practitioner, described her own hesitation in recommending the Gardasil vaccine to her patients,

Well I would say professionally my main criticism of [the Gardasil vaccine] is that the safety data isn’t fully released yet and I don’t understand how something can have FDA approval before that safety data is back. I also tend to be a relatively conservative provider and prescriber. I generally do not prescribe a medication that has not been on the market less than five years. I am not one to jump and try the latest or greatest because I want to see – I mean I know that studies only look at a couple hundred people or whatever – not a whole heap. And I want to see what plays out among all these other guinea pigs before I prescribe it.
While any new vaccine can cause both providers and parents to feel some level of anxiety regarding the unknown risks associated with the drug’s use, the manner in which the product was introduced and marketed amplified some individuals’ distrust of the vaccine. Marie was not about to give her daughter a vaccine simply because it was heavily marketed – in fact, the heavy marketing gave her great pause: “Before I just jump on the bandwagon and do Gardasil for my daughter I want to look at safety issues, or how long it’s been in testing, or how long has this vaccine been developed. Because it just seemed like boom! It was just there and it’s being pushed on TV.”

Tony had followed the development of the vaccine and had planned to have his daughter vaccinated as soon as it was approved. He changed his mind after learning about the effort to mandate the vaccine in Texas, which caused him to question the motives of the manufacturer and the safety of the vaccine. He recalled, “And then Texas tried to make it mandatory and [there was the] whole mess with them. I waited a year and a half just to hear if there were adverse events. And when the CDC published that it was nothing that they didn’t see with other vaccines, mostly site related, [then I had my daughter vaccinated].

Ann, a nurse practitioner, felt that the immense direct-to-consumer advertising campaign, coupled with intense and immediate efforts to mandate the vaccine, did little to allay public or personal concerns regarding the safety and benefits of the vaccine. I’d like to see some more studies on the shot. My big thing about Gardasil is that it’s still very, very new. . . We just need to get more information out there, more studies on what the outcomes are. And I think that that will reassure people and allow people to make better decisions about the vaccine. And it will calm down
some of the controversy because a lot of the controversy has really been – here’s this brand new thing on the market and you’re trying to push it down our throats.

The effort to mandate the HPV vaccine so shortly after its development concerned some providers, who felt the move was irresponsible given the newness of the vaccine, its mode of transmission, and general controversy surrounding it. The chiropractor who participated in the study was particularly suspicious of the push to mandate the vaccine, given its cost:

Again, I know that it hasn’t been mandated, but I know when it came out they were trying to mandate that everybody gets it, and again, I don’t like those mandates that you have to do something because this vaccine, I believe, is the most expensive one on the market. Any time I see something that tells me that everybody has to do it, I always think money. Because it goes back to that. If it’s the most expensive and everybody has to do it, who stands to gain the most? The company that’s making it. If everybody has to do it. It just makes me skeptical about it.

Several providers felt that such politicized efforts to mandate the vaccine only served to further erode parental trust in pharmaceutical companies, the public health system, and vaccines. Reflecting upon the mandate’s effect on her professional opinion of the Gardasil vaccine, Ann explained,

I think the company made a bit of a mistake in letting some of that happen in Texas, because it caused a lot of bad press. And unfortunately one of my first exposures to Gardasil was extremely negative because of Rick Perry in Texas, trying to politicize the vaccine when he had not made flu vaccine mandatory,
which kills a hell of a lot more people. So things like that really will leave a bad
taste in your mouth as someone who wants to make a scientific decision about
things.

Another provider worried that there were still too many unanswered questions
regarding the vaccine, and that the effort to rush the vaccine onto the market might end
up diminishing public trust in vaccines. She argued,

There’s just too much unknown about [Gardasil]. It’s like, it’s just an experiment.
We don’t know what we’re doing. We [healthcare providers] don’t even know.
And then the risk of that is that people are going to get turned off by vaccines. So
not the risk of the actual vaccine but the roll out, if you will.

Sophia recalled that some parents become defensive when the HPV vaccine
initially came out due to fears that it would be mandated. “There was the big brouhaha in
Texas when they were trying to make [the Gardasil vaccine] a mandatory thing and
parents were saying, no, not my good girl!” The push to mandate the vaccine, she felt,
likely polarized opposition and resistance to it, making it more difficult for her to discuss
vaccine options with parents.

It is important to note that distrust in a pharmaceutical company or government
agencies safety record, motivations, or relationships does not necessarily translate into
support for or resistance against a vaccine. Several of the parents who distrusted
pharmaceutical or governmental agencies had already vaccinated or planned to vaccinate
their daughters. Similarly, providers who expressed distrust, disappointment, or
skepticism in pharmaceutical industry motivations did not wholesale reject the value or
benefits of the vaccine.
It is also the case, however, that four of the providers (three nurse practitioners and the chiropractor) who opposed the way in which the vaccine was marketed, its high price tag, and the rush to mandate it given its newness and mode of transmission were less likely to provide resounding recommendations in favor of the vaccine, or push refusing or deferring parents to reconsider their position. The specific ways in which provider distrust affected their discussions and willingness to recommend the vaccine are discussed, in detail, in the following chapter.

While none of the parents or providers claimed to trust the pharmaceutical industry, some people felt that concerns regarding industry motives or power were exaggerated. One parent felt that some people are just very wary of big companies, and big pharma especially. And if they say this is good for you then they’re going to take the opposite, just because that’s their knee-jerk political reaction. I know I identify with that but then you also have to say, wait a minute, let’s see what’s what. But let’s face it, [some people] will always say it’s a conspiracy.

For the majority of parents, trust in governmental agencies and healthcare providers was associated with a conviction that these stakeholders made decisions based on scientific evidence and a desire to protect public health, not in collusion with, or for the benefit of the pharmaceutical industry. For some parents and providers, the fact that a vaccine had been approved by the FDA was reason enough to trust in its safety. These individuals had faith in the regulatory system and stringency of governmental approval and oversight processes to have confidence in the safety of a vaccine. Monica, who has a son and three daughters, deemed a technology safe if it had been clinically tested and,
based on such tests, was approved by the FDA. To gain approval from the FDA was an indication of vaccine safety: “I think if the vaccine has been tested and approved and it’s safe, I don’t know why any parent wouldn’t want to get their daughter vaccinated”.

Other parents had faith that the government would address any issues found with vaccines and felt that the systems in place and experts employed to guarantee the safety of recommended vaccines were trustworthy and competent. Patty pointed to the government’s steps to remove thimerosal from vaccines as proof that the government would not intentionally allow harmful substances to be injected into its citizens. She also dismissed fears that vaccines could cause development disorders, such as autism, arguing that if links existed, researchers would have found them by now: “They took all the mercury out of vaccinations. If there was really something to it people would have found something by now. Because I think people are looking for, have been looking for that link [with autism]. There’s just no scientific proof”.

Parents who trusted in governmental oversight made little effort to investigate themselves the safety and efficacy of a vaccine, both because they felt they lacked the expertise and training to interpret the results of large-scale clinical trial data themselves, and because they had faith that the individuals assigned to do this job were honest. As Mike said, “I trust our public health system and see it as the aggregate, a shared responsibility for one another. I expect them to advise us which vaccines are required and which are optional. The flu and HPV vaccines are optional.” Sarah expressed her leap of faith more simply: “If the vaccine was available and recommended by their healthcare provider, then I just have to take the faith of the system.”
Trust in providers

The relationship parents perceive between themselves and their healthcare providers plays a key role in healthcare decision-making. Results from other studies indicate that provider recommendations are an important way in which parents report making healthcare decisions. What parents in this study made clear is that the value placed on a provider’s recommendation is contingent upon trust; not all healthcare provider recommendations are equal.

Giddens argues that while we can make decisions to trust someone or something, the “faith which trust implies also tends to resist such calculative decision-making” (Giddens 1993:293). Trust implies faith, and while faith in a person or institution can be lost or gained through singular experiences, the process is often subtler, built on cumulative experience and largely unconscious. In this study, parents often espoused their unwavering trust in a provider, but without explaining why the provider was worthy of such unflinching faith. When probed to explain how providers gain or lose trust, parents often had to pause and think, suggesting that decisions to trust are not calculated or consciously made, but are unconsciously garnered. Many parents eventually pointed to the fact that under a provider’s care, their children either recovered successfully from illnesses, or never became seriously ill. However, a provider’s affect, communication style, and concern for the individual child were also factors associated with trust. A sense that clinicians treated children as individuals, rather than as representatives of an aggregate was continually mentioned as proof of providers’ intentions and trustworthiness. Though most parents expressed a strong sense of trust in their provider, some parents shared experiences – mostly in the past – that led them to distrust specific
providers, or providers in general. Often times, the same criteria that led to trust, could lead to distrust.

Many parents conceptualized their provider as an intermediary who sorted and translated abstract medical knowledge into relevant information for parents. The provider was often seen as filter and stop gap, someone who could advise parents towards worthwhile technologies and treatments, while cautioning them against innovations and interventions that might not be as safe or necessary as pharmaceutical companies, the public health system, or larger medical community might believe (or have the consumer believe).

For most parents, trust was placed in their specific healthcare provider, not in healthcare providers as a whole. Indeed, many parents trusted their providers because they were seen as unique – engaging with parents and children in ways that they saw as exceptional. Thus, while parental trust in individual providers was high, the tendency to highlight the uniqueness of their own providers as unique suggests that their trust in the broader healthcare provider community is more tenuous.

Some parents trusted healthcare providers with whom relating was effortless, indicating that to some degree, trust was established through an underlying sense of understanding and familiarity. As Christina put it, “A doctor should fit like a good pair of jeans. It should be a comfortable experience when you go into a visit a doctor. And if it’s not, then you’re not with the right doctor. Period.” The provider’s disposition could itself contribute to a sense of trust. Barb concluded, in trying to explain why she trusted her daughters’ provider, “He’s just very personable. He’s a nice guy in general.”
Parental perceptions in the unique and exceptional skill of their specific providers were often the result of particular experiences in which other providers had misdiagnosed or failed to diagnose a condition that their trusted doctor found immediately, or eventually. One mother explained, “Part of what makes me trust this particular doctor is that my son was diagnosed with a heart defect and he caught it *immediately* and he told me in ten minutes what it took the pediatric cardiologist about a month to find out. . . This guy has just proven himself to me.”

When assessing the trustworthiness of a provider, parents often referred to their cumulative experiences and successes with a provider. Explaining why she trusted her doctor, Barb said, “He hasn’t steered me wrong into anything yet (laughs). I mean, every time we go in for anything, the treatment he gives usually takes care of what the problem was and we don’t have to repeatedly keep going back because what he does isn’t working.” Barb’s trust in her provider is contingent – though laughing, she notes that her provider has not failed her “yet”. At the same time, in noting that her provider’s treatments “usually” take care of the problem, Barb seems to indicate that even with trusted practitioners, some degree of “error” is acceptable or expected.

Another mother, who switched physicians, agreed that it was unfair to expect that physicians could always accurately diagnose and treat illnesses on the first try, but she did expect providers to accurately diagnose problems or refer cases that they could not diagnose or treat. She lost faith in her previous provider’s ability to safeguard her children’s health after he unsuccessfully prescribed her daughter a series of medicines to treat a condition that he would not diagnose. Ultimately, Deborah questioned whether the provider was harming her daughter’s health by prescribing medications without
knowing what was wrong with her. She recalled “He put her on a whole bunch of medicine, but would never say what was the matter. He just kept putting her on medicine and putting her on medicine.”

Particularly in regards to pre-adolescent and adolescent children, parents emphasized the relationship between the provider and child, specifically how the provider interacted and involved the child in the healthcare visit. An important component of establishing a trusting relationship was that providers speak honestly, clearly, and directly to children and young adults about issues that affect their health, but without dismissing or disrespecting the parent’s role in the making healthcare decisions.

In explaining why she trusts her daughters’ provider, Courtney recounted the way that the doctor discussed the Gardasil vaccine with her sixteen-year-old daughter. When the doctor described how HPV was transmitted, she “turned from me and was talking directly to [my daughter] about it. And she’s wonderful. She’s very matter-of-fact. And she doesn’t skirt around any issues or think ‘Oh well this conversation might make somebody feel uncomfortable.’” Other parents also described their providers’ openness and frankness with their daughters as a key reason they trusted them. Gretchen also noted that the pediatrician primarily spoke to her daughter about the Gardasil vaccine. Gretchen attributed her daughter’s active role in making healthcare decisions to the provider’s long-term efforts to develop a trusting and empowering relationship with her daughter.

The provider-daughter relationship was particularly important to parents of maturing girls, who wanted to ensure that their daughters would feel comfortable sharing personal health information with providers, even if they did not feel comfortable sharing
the information with their parents. In other words, parents wanted their children to trust in the provider. Thus, parents trusted providers who worked to create trusting relationships with daughters.

When providers were not deemed skillful at relating to children, parents lost faith in the relationship. Theresa explained what she looked for in a trustworthy provider, and why her previous provider’s failure to meet these expectations led her to seek care elsewhere:

[Someone with] an ability to relate to the kids. Somebody that watches what [the kids are] doing, not just asking me what they’re doing. To be able to talk to the kid and relate to the kid, not just the parent. Because the kid isn’t going to trust – I can’t imagine as a teenager walking in to any doctor and saying ‘I want birth control’, or ‘I need birth control’, when they’ve never really even talked to me as a person. If they want a kid to have trust in the doctor then they need to relate to and trust the kid.

Theresa continued by explaining that while her previous provider espoused the importance of establishing a trusting relationship with her daughter, in practice he did little to foster this trust. The provider did not direct questions to her daughter, nor appear comfortable discussing sexual health issues, which ultimately led Theresa to find a new healthcare provider:

Well you have to understand this [former] pediatrician. He would come in and look at me and whispering, say, “Has she gotten her period yet?” Like, whispering it to me. And I’m like, “She’s sitting right here, ask her.” And he would whisper, “Has she developed breasts yet?”, and I’m like, “Well, take a look
at her!” It doesn’t take a rocket scientist [to know whether she has breasts]. It was almost like he was uncomfortable. It was like, if you can’t even discuss her having her period, then it’s time for us to change doctors. After Theresa confirmed that her daughter had begun menstruating, the pediatrician replied, “Okay, well now it’s time for our talk. I’m no longer your doctor, I’m her doctor, yada, yada, yada, and if she feels that she needs to discuss anything I want her to feel free.” And I’m like, you can’t even ask her if she has her period. Do you think she’s going to be comfortable coming to you and saying I want birth control? You know, it was just not a good match.

Aside from including children in healthcare conversations, parents instilled trust in providers who spent time with them. Parents generally recognized the time demands of health practitioners, which might be one reason that parents often pointed to the length of time providers spent with them as a key ingredient in forming a trusting relationship. It was not only the amount of time that a provider spent with parents and children, but the efforts taken by the provider to solicit and respond to parent and child questions and concerns and educate and inform parents as to the basis of their recommendations and advice.

Parents did not want to feel rushed. They wanted to feel that their providers were fully engaged in the visit, open to their questions and concerns, and willing to answer questions thoroughly. A rushed provider, parents felt, was less likely to detect specific issues or conduct an exam or evaluation based on the child’s unique, individual medical history. Faith valued her pediatrician’s “never-in-a-hurry attitude” and Courtney boasted that her daughter’s last wellness check – when the provider also discussed the Gardasil
vaccine – lasted an hour. For Courtney, the amount of time the doctor spent with them was “what made me comfortable as a mother. Where at other times with other physicians you feel like they’re just trying to get you out the door for the next patient to come through. You never felt you were being rushed.” Christina appreciated the time and care her provider took to answer her questions. “He would talk over anything with you, if you had a question it was going to be discussed until you felt comfortable. He’s an older doctor but he’s very cool about giving you the time you needed.” Again and again, parents equated trust with the sense that providers were engaged in the visit and willing to take the time required to answer questions and thoroughly examine the child:

**Putting the Child First**

The time providers spend with parents is one of a larger constellation of trust-building activities or behaviors related to putting the needs of the child first. Parents trusted providers who demonstrated a commitment to the parent and child, especially when parents believe that these commitments were not in the provider’s own economic or personal interests. Melissa recalled her former pediatrician, who knew the family was uninsured, used to give her sample medications rather than writing her a prescription and would encourage her to go the health department for vaccines so that they did not have to pay any out-of-pocket expense.

Another mother, whose son has a rare disorder, recounted one of many experiences that led her to trust his doctor. Concerned about some of her son’s symptoms, she called the physician, who instructed her to meet him at the emergency room. She felt that most doctors would have deferred the exam until the work week, when they could examine her son in their offices. She explained, “This was that Sunday
morning of that Miracle Network Marathon, where [the doctors are] on TV all the time. He was dressed to be on TV and he came to meet my son in the ER.”

Developing trust in a provider also related to the prescription or non-prescription of therapies, especially when parents’ perceived that the provider was making a recommendation specifically based on the needs of the child, and not as standard practice or routine. In some cases, this entailed the prescription of medications that were not usually given to children. In other cases, it involved withholding routinely prescribed medicines due to unique factors. Several parents pointed to cases in which they themselves had asked providers about newer drug treatments for their children, only to be advised that these treatments were not in the best interest of the child. In these cases, parents respected that providers did not simply acquiesce to their own (parents’) desires for the newest and most highly advertised technologies.

Conservative prescribing also assured some parents, especially those who were concerned with the general over-use of medications, that their provider would not give their children any treatment that was unnecessary. In particular, some parents interpreted conservatism in the prescription of new medicines as a sign that providers were immune to pharmaceutical lobbying, thus making careful and deliberate decisions based on the safety, efficacy, and need for a treatment, rather than on heavy marketing, manufacturer incentives, or media and consumer hype.

Melissa, who had recently moved states, worried about pharmaceutical influence on provider recommendations; for this reason, she had found it difficult to find a new pediatrician who she felt she could trust. Selecting a trustworthy provider was challenging not only because it required her to know something of the factors that
motivated him or her to practice medicine, but also because she had yet to establish close ties to other parents in the community from whom she could seek provider recommendations.

I worry about the sway of advertising. And I don’t know anyone down here so I don’t know who’s a good doctor, who’s a bad doctor. Who prescribes or pushes certain things because of the drug company? I had a friend who was in pharma sales, so do [the providers] push certain things because they’re getting perks or because they really believe in that medicine? Have they done recent research, have they looked at the medical journals and then say, “Okay, yeah, this is what we should be using”? Or are they just like, “Hey, I remember that pharmaceutical sales woman came by and said I should use this, so I’m going to use it.”?

Like many parents, Melissa also differentiated between individual providers and the healthcare provider community as a whole. Before moving to Florida, Melissa had a pediatrician who she described as incredibly trustworthy. However, she also believed that her provider was unique, or at least that he was not the only type of provider who practiced medicine.

**Trusting Mother’s Instinct**

Although many parents pointed to their faith in a provider’s medical expertise as a reason to trust him or her, some parents, especially mothers, trusted providers who trusted the “mother’s instinct” and that took seriously the observations, concerns, and intuitions of mothers. Just as some parents trust providers who trust daughters, mothers trust providers who trust mothers. Several mothers pointed to specific cases in which their
faith in providers was solidified or challenged based on providers’ willingness – or unwillingness – to trust the mother’s instinct that something was wrong.

When providers were perceived to discount, ignore, or belittle a mother’s knowledge, a sense of trust was lost. One mother explained that in her younger years, she used to follow doctor’s orders without question. She reconsidered that approach when a doctor failed to diagnose her son as asthmatic.

When I had children I took the doctors at their word. When the doctor said he couldn’t hear the raspiness in my son’s voice, my life changed. Because I realized that as a mother I am more in tune with my children and sometimes you have to fight for what your child needs. Where somebody else might not recognize it because they’re not around your child 24 hours a day, 7 days a week.

Providers as Parents

Often times (n=9) trust was associated with attributes or roles of the provider beyond that of healthcare practitioner. Most often, parents ascribed trust to providers who shared a dual role as parents themselves, and who could consequently understand the anxieties, fears, and realities unique to parenthood. Parents appreciated when providers made treatment decisions and recommendations that accommodated parents’ busy schedules. They also found that providers with children were more understanding when parents had difficulty adhering to all of their treatment recommendations.

Christina stopped seeing a particular physician after he refused to prescribe her son with an antibiotic for an earache. She felt that the provider made a poor decision in withholding medication for her son due to his specific medical history. She also felt the provider (who did not have children of his own) discounted the physical suffering her son
would endure if his condition worsened, the sleep she and her husband would lose if he failed to improve, and the time and money that would be wasted if he required additional treatment. She explained,

[The doctor] looked in the ear and the ear looked questionable, which is a term – when and if you have children you’ll hear that a lot and want to punch somebody because it means that you have an ear ache developing. So he’s not going to treat it today. Nope. Your kids going to have to get sick over the next 48 hours and you’re going to have to come back, pay another doctor’s bill – which doesn’t grate you that much because you’re going to do what you got to do for your kid.

It’s the trip back with the sick kid when you could have prevented it.

In describing her reaction to his clinical decision, Christina highlights the importance of treating children as individual cases, valuing the mother’s intuition, and respecting the demands of parenthood in establishing and maintaining trusting relationships. She felt that the provider, aside from ignoring her own instincts and her son’s medical history, failed to appreciate the additional burdens on the family that a provider with children of his own might understand.

Some parents worried that providers without children of their own could not understand the fears, concerns, and anxieties that parents face when making healthcare decisions on behalf of their own children. Deborah wanted providers to empathize with her reality as a parent. When her pediatrician tried to allay fears she had about vaccinating by telling her that she was worrying for nothing, she responded, “Yes, but when you’re a mom, you worry about everything”. Parents feared that childless
providers might make recommendations to parents based on population-based health priorities, rather than on the characteristics and needs of individual children.

One mother described how her opinion of one pediatrician in her practice changed considerably after the pediatrician herself became a mother:

There’s one doctor [in the practice] that I didn’t think much of and then she had her own children and she’s a much different doctor. She’s a much better doctor. She gets it. She understands it. You know, it’s one thing to be a doctor and to say, ‘Well you know, you should be doing this, this, and this’. Okay. And in reality, yes, I should be. But, the other side of that reality is that it doesn’t always work that way. You know, and now that she has children she realizes that it’s not just textbook. It’s, you know, yes, you should get your child to take his vitamin every day. And you think they’re taking it every day and you find a pile underneath the bed one day and you say, “What the heck, what’s going on here?” You know, she’s just, you know she’s learned through first-hand experience. But really she’s my favorite doctor now.

The common assumption woven throughout many of these trust narratives is that parents’ providers are special, and the level of care, time, concern, and understanding shown by their providers is rare, or at least not representative of all providers. In differentiating their providers as unique, parents either implicitly or explicitly communicated a lack of trust in providers as a whole. The general lack of trust parents had in healthcare providers might actually foster an increased sense of trust, and confidence in their individual providers. In perceiving their children’s providers as
uniquely skilled, highly involved, well-informed, and well-intentioned, parents might be willing to put more faith in their providers’ recommendations.

**Provider Trust and Vaccine Recommendations**

Provider recommendations are key to parent healthcare decisions, both regarding vaccines, and in general. A specific recommendation for the HPV vaccine was a significant motivator for many parents to get the vaccine, but only among parents who also had faith in their provider. For example, one mother was originally unsure about Gardasil, but ultimately had her daughter vaccinated. “What really swayed me was what my pediatrician thought and he strongly recommended it. One pediatrician [who recommended the HPV vaccine for my daughter] has been with her since birth and the gynecologist [who also recommended it] delivered her. I trust them implicitly.”

The vote of confidence in provider recommendations was a recurring theme in most interviews. Explaining the underlying reason she vaccinated her daughter, one mother said, “For me it’s a trust issue. I do what my provider says.” Another mother echoed this sentiment, “I put a lot of trust and faith in my kids’ pediatrician. And if he recommends it . . . then I think [the vaccine is] a good thing.”

As the above quotes indicate, “trust” is key to validating the provider recommendation. Several parents clearly emphasized the fact that their faith in a provider recommendation was contingent upon the trust relationship that they had established with a particular provider, meaning that an unknown provider recommendation was of little value on its own. As one mother explained it, without trust, provider endorsements mean little: “We do what the doctors say because we trust our medical professionals. We won’t stay with a doctor we don’t trust. I doesn’t take but two visits to say, mmm, not gonna do
it.” Another mother expressed similar sentiments, “It’s something that, if the doctor says it’s good – and I trust our doctor. I mean, if it was a doctor I didn’t trust I’d probably second guess myself, but I don’t have any qualms about [my doctor’s] decision [to recommend Gardasil to my daughter].

In other words, the status of “healthcare practitioner” or “medical expert” carried little weight on its own; to gain credence, trust was essential. Lest the relationship between trust and provider recommendation be unclear, consider the following two examples:

Even Melissa, who did not currently have a primary care physician for her daughter, thought that she probably would have already had her own daughter vaccinated if they still were seeing their previous provider in another state. Her indecision about the vaccine largely related to the fact that she did not know any healthcare providers in Florida, and therefore could not be sure that their recommendations would be trustworthy. She explained,

I think as sort of a normal parent, I’d go to my doctor and whatever my doctor says, I trust my doctor. So if I had a regular care physician who I had built a relationship with, and he said, ‘I really think your daughter should get this. I feel like the evidence shows that she’d be safe and that this would protect her.’ Then I’d say okay, I’m on board with it. So it’d be really dependent on that relationship with him and what he felt about it. But I don’t have a relationship with a primary care provider here, so I don’t know.

Just as parents place trust in providers who are parents themselves, parents value recommendations based on providers’ willingness to vaccinate their own children. If
providers felt confident enough to give the vaccine to their own children, then surely, parents reasoned, the providers truly believed in the benefits and safety of it. When Alice took her 9 year old daughter for a wellness exam, she had heard of the HPV vaccine but had not done any research regarding it.

I asked the pediatrician about the shot because I trust her and I know her. And so I just asked her her opinion on it because she’ll tell me the truth. And she has two daughters of her own so I said, ‘Would you get it for your daughters?’ And she’s like, ‘Oh yeah, definitely. When my girls are old enough they’ll be getting it too”. So when she said that it just definitely made up my mind that I would get it for her.

For Alice, her provider’s endorsement was sufficient because she trusted her competence and believed that her provider would never give her own children a vaccine that she did not believe was safe and worthwhile. It is also significant that Alice emphasized familiarity with the provider in establishing trust. Alice’s children were Medicaid recipients and she took them to a university-affiliated teaching clinic for care. Before her regular-care physician saw the children, they were examined by an attendant. Alice took attendant recommendations with a grain of salt, not so much because they were residents in training, but because she did not have a well-developed, long-term relationship with them. They did not know her or her kids. Consequently, she felt like they would view her children as if they were any other children. She had faith that her primary physician would make decisions and recommendations for her children as individuals.
Several parents (n=4) specifically asked their providers whether they had or would have their own daughters vaccinated; in some cases (n=3), providers mentioned that they had vaccinated their own daughters before parents even had a chance to bring it up. Faith asked her provider for his opinion after she read over HPV vaccine literature. “He said, ‘I think the benefits outweigh the risk. My own daughters have had it.’ So I mean, upon faith is what I have done with [my children’s provider].”

Two parents also delayed or refused Gardasil based on provider disclosures that they had not, or would not, vaccinate their own daughters. In one case, a father who had planned to have his daughter vaccinated with Gardasil deferred the decision after discovering that his pediatrician had not yet decided whether she would vaccinate her own daughters. A year later, when she told him that she planned to have her daughters vaccinated, he consented to have his older daughter begin the series.

Chapter Ten Summary

Because trust is situated within larger socio-political, interactional, and relational contexts, its nature cannot be understood by approaching vaccine decisions as singular outcomes (Brownlie and Howson 2005). When considering vaccines, parents’ motivations to trust different actors must be seen as multi-dimensional and context-dependent, but also as processes that are situated, temporal, and child-dependent. In assessing trust in Merck, government agencies, healthcare providers, and society as a whole, parents spoke to the importance of institutional and systemic qualities of trust, which parents used to position actors, define their roles, and assess the trustworthiness of their motives. Structural relationships among pharmaceutical and insurance companies, government agencies, and public health laws are important to examine historically.
generally, and in relationship to specific vaccines, because, as I have argued throughout this dissertation, these processes shape the ways that parents come to perceive vaccines as manifestations, actions, and symbols of larger systems.
Chapter Eleven – Decision-Makers

As previously discussed, parents gather information from diverse sources, including vaccine manufacturers, media reports, government agencies, healthcare providers, family members, personal experience, and other parents, peers, and colleagues in an effort to inform themselves about the risks and benefits of Gardasil vaccine and HPV. When it comes to making vaccine decisions, all of this information, and the sources from which information is obtained, has to be weighed: Are sources credible? Whose interests are various stakeholders protecting? Can providers be trusted to put the needs of children first? Can daughters be counted on to communicate truthfully about their sexual readiness?

Who sorts through competing and conflicting information and decides what information is paramount to making an HPV vaccine decision? This chapter describes the roles that parents, spouses, and daughters play in the decision-making process and how notions of gender, maturity, and responsibility become central to defining who participates in the decision and to what degree.

I begin by describing the role that parents, as mothers and fathers, take in decision-making. As will be demonstrated, the expectation that one or both parents contribute to healthcare decision-making is intrinsically connected to assumptions about motherhood, parenthood, and parental responsibility. In the latter half of the chapter, I address the daughters’ role, or lack thereof, in general vaccine and Gardasil-specific
decisions and the types of information that parents think daughters should be privy to regarding the purpose of the Gardasil vaccine.

**Parental Responsibility**

In general, parents identified themselves as the key decision-maker in all vaccine decisions, including Gardasil. Fathers (n=3) were more likely to describe vaccine decisions as an equally shared responsibility between themselves and their wives. Only one father described himself as the sole decision-maker in his partnership. Mothers, on the other hand, rarely described their husbands (or daughters’ fathers) as playing a key role – if any role – in the process. Sixteen mothers said that their husband or daughter’s father had little or no role in vaccine decisions. Five women said their partners had a peripheral role in decision-making, and only one woman said she and her husband equally contributed to vaccine decisions.

That the majority of women claimed sole responsibility for vaccine decisions reveals the gendered nature of decision-making. The idea of their partners contributing to vaccine decisions was so inconceivable and ludicrous to some women that they responded to inquiries about their partners’ roles with laughter. I asked Natalie whether her husband played a role in decisions and she responded, “No! (laughs). Absolutely not. He pretty much goes with what I felt they should get.” Lucy was laughing so hard when I asked her if her husband contributed to vaccine discussions she could only shake her head no and point to herself to indicate that she was the only parent involved in the decision. Wendy scoffed when I asked her if her husband knew which vaccines their children had received, replying, “Oh my gosh. He’s been to one parent conference out of
all three kids. *One.* For [our son], in fourth grade. It’s easier for him not to be involved."

Many women took it upon themselves to make these key decisions and often times either did not mind, or appreciated that their husbands/daughters’ fathers trusted them to make these decisions. When describing the role her husband plays in vaccine decisions, Rachel said, “I talk, he listens (laughs)”. Faith explained that her husband had little role in most healthcare decisions, especially vaccinations, because this was part of her domain. “We certainly talk about medical issues, but that’s my domain. He trusts me in that regard. I mean that’s kind of why I’m a stay-at-home mom. That’s my job. You know, I trust him to do his job and he trusts me.”

Five women described their husbands as having at least some peripheral role in vaccine decisions. Deborah always discussed vaccines with her husband before taking her kids to the doctor, but stated that his interest was short-lived and largely economic: “He discusses these things for about 20 seconds. [He might ask], Is it really expensive? Can we afford it? What’s the long run? I mean he’s just like a couple of questions and move on.”

The father’s limited role in vaccine decision-making could relate to the fact that these women typically take their children to the doctor, and many parents make vaccine decisions during the office visit. Jean noted that her husband doesn’t have a role in vaccine decisions because “He’s usually not the one taking her. Because my schedule is always more flexible and I was the one going back and forth to the doctor. I mean we might talk about it but he’s actually never been in involved in the decision making process.”
Three of the four fathers described vaccine decision-making as a joint process where both partners contributed to decisions. “We talk about these things and it’s a joint decision . . . It’s not my domain or her domain in terms of the household decision-making.” Mark said that he and his wife “would have a big conversation” about the Gardasil vaccine, but that he would never make a decision without her input. On a general level, as well, most fathers (n=3) said that they would not make a vaccine decision without first consulting their wives.

Providers noticed a similar pattern. Providers observed a significant caregiver gender bias in their own practices. One provider estimated that at least 85 percent of the parents that accompany children to the office are mothers. In fact, providers so strongly associated mothers with healthcare decision-making, that all providers used the word “mother” to indiscriminately discuss parent healthcare decision-making at least once, if not throughout the interview. Even when fathers brought children to the office, providers noted that mothers generally remained the decision-makers. Several providers observed that most men who accompanied their children to the office would not make healthcare decisions without first speaking to their wives. In three years of recommending the Gardasil vaccine, Nina recalled only one father who consented to having his daughter vaccinated during the visit. She recounted, “I think I’ve had one dad in the last three years that said okay to the HPV. One dad. That’s all I can remember. All the other dad’s say, ‘Oh, nope. Have to talk to mom about that.’ It’s one man that stands out in my mind. He said ‘Yeah, go ahead. Do it.’”

Providers noticed this trend regardless of whether the father was the primary caretaker or person to typically accompany children to healthcare visits.
In describing the gendered nature of healthcare decision-making in her family practice, Jane observed that men tended to consult their wives not only regarding their children’s healthcare, but their own:

The times are such that we see more and more fathers as primary care-givers – as the person who watches the kid during the day and then works at night. We have a number of fathers that bring their kids in. I wouldn’t say it’s the majority, but [even in these cases] the mother makes the health decisions, even for the man. Not just for the kids. The mother’s making the health decisions for her husband too. That’s one of the problems when the man brings them in is they need to now call up the wife to ask what she wants. So they’re the caregiver but they don’t make the health decisions. I mean each case is different but I would say that’s very common, that the dad brings the kid in but the dad doesn’t know anything about what they want. You know, or what they’ve had. But cell phones have solved that problem. It used to be more trouble – just call them up.

Through countless clinical exams, providers begin to observe patterns in the ways that parents respond to particular types of information. Provider expectations about parents can shape the ways in which they choose to interact with the patient and parent during a clinical exam. For example, Nina generally accepted that when fathers brought daughters to see her, she would not be able to administer the Gardasil vaccine to them. She said, “[When] I see they’re with dad I think to myself ‘Ugh, well I know they’re not going to do any of the HPV. It’s definitely out’. I know it. Like I already know. Of course, I broach the subject but I know it’s out because he has to talk to mom.” Although the provider mentions that she broaches the topic with men, it is unclear whether her
assumption that they will definitely decline it factors into the amount of information she shares with them or how she presents material.

Parents, especially mothers, placed upon themselves the primary responsibility for protecting their daughters and making healthcare decisions for their daughters. In explaining why they made (or likely would make) specific HPV vaccine decisions, many parents talked about parental responsibility to protect and prepare daughters for the future. The two mothers who were not planning to vaccinate their daughters (Natalie and Rachel) both referred to parent responsibility when explaining why they were against the vaccine. These two women saw it as their responsibility to educate their daughters about sexuality and making healthy choices, though what constituted healthy choices varied considerably. A description of how these mothers conceptualizations were linked to promiscuity are discussed fully in Chapter Eight. Here, I touch only upon aspects of Natalie’s perspective that are specifically relevant to notions of parental responsibility.

Natalie saw high rates of teen pregnancy and sexually transmitted diseases as the result of poor parenting. She remarked, “This generation knows more about birth control than any other generation, so why is there still teenage pregnancy? I think parents need to start doing their job.” When I asked Natalie what a parent’s job was, she replied, Well their job is to teach – their job is to equip their children to go out into the world and make good decisions for themselves and for their lives and for their bodies. That’s what I think part of their job is . . . I think it’s our job, to just keep them informed and keep them, you know, thinking critically about their decision-making.
For Natalie, the best way to protect her daughter from HPV was to teach her to treat her body well, which included, among other things, eating a balanced diet, exercising, taking probiotics and supplements, getting annual pap smears, avoiding casual sex, and having protected sex with mutually monogamous partners. The mother reasoned that if her daughter followed this advice, she would likely be healthy enough to naturally clear an HPV infection, even if she acquired it. Both of these parents saw protection and responsibility in black and white terms: parents either educated their daughters or vaccinated them, but not both. These mothers framed the issues of protection and responsibility in such a way that responsible parenting precluded giving their daughters the Gardasil vaccine. It did not cross Natalie’s mind that other parents might both educate their daughters and vaccinate them – for her education and the vaccine were mutually exclusive alternatives. “To me it’s like, where are the parents? Why would you choose a vaccine for your child over educating them about what they should do?”

Natalie and Rachel’s conceptions of parental responsibility were markedly different from other parents in that responsible behavior led them away from vaccinating their daughters against HPV. For other parents, and some providers, responsible parenting meant that parents provide their children with every safeguard and protection available, including education and vaccinations. Ann felt that with time, parents were reframing Gardasil to fit more closely with a frame that commands that responsible parents vaccinate their children. With time, the Gardasil vaccine is “just like any other shot. If you’re a good parent you get your child all the recommended vaccine. There’s that big group of people that that kind of applies to. And so they’ve kind of gotten beyond the sex thing. They can just think to give it as a vaccine now.”
The parents that are expected to make healthcare decisions, and on whom responsibility is both self and externally assigned, are overwhelming mothers. In many cases “parent” is a proxy for “mother.” As previously discussed, most mothers take their children to healthcare visits and are the sole or joint vaccine decision-maker, even when they are not the ones accompanying children to the appointment. Many mothers internalize the responsibility of making the best decisions for their children and see it not only as a strategy to protect the wellbeing of their children, but as a reflection of their parenting and an evaluation of their ability as “mothers”. Courtney’s rationale for vaccinating as an effort to do “anything that I possibly could, as a mother, to help ward off any type of cancer” was prototypical.

The ability to make the “right” healthcare decisions for the “right” reasons was one way in which women assessed their own and other women’s mothering abilities. When women spoke about non-vaccinators, critical commentary was nearly always directed at mothers who were perceived as making irresponsible decisions. One mother criticized mothers who refused the vaccine as arrogant and ignorant. “I’m just saying there may be some mothers that are like (snobby voice) ‘My daughter’s not going to be getting the disease from having sex. I’m not giving her the vaccine.’”

For four mothers, good mothering meant taking a more active role in vaccine decision-making. Good mothers protected their daughters’ health, bad mothers did not. Notions of motherly responsibility emerged when discussing the possible licensure of Gardasil for boys. When I asked Monica whether she would vaccinate her son against HPV, were a vaccine available, she responded, “I think that the moms of the daughters can vaccinate their own daughters. I mean that would be kind of the selfish feeling, I
guess. It would be nice if the mother of the boy would have the boy vaccinated so that girls wouldn’t be harmed, potentially, whose moms didn’t take them for the vaccine.” In Monica’s view, mothers should vaccinate their sons to protect daughters whose mothers were irresponsible. Lucy expressed a similar sentiment when I asked her how parents might respond to an HPV vaccine for boys. Again, she placed the onus of responsibility specifically on mothers: “’What? You want me to protect someone else’s kid? Why don’t they protect her? Why should I protect them? They’ve got a mom.”

Natalie was recounting a conversation that she had with her twenty-two year old son about safe sex. She asked her son whether he was using protection, and he responded that his partner was using birth control pills. She replied, “I’m not asking how she’s protecting herself from being a mother. I’m asking how you are you protecting yourself from being a father? So okay, she can take one for the team, but we’re not talking about her. That’s her mom’s job. To talk to her about what she’s doing. With you, it’s my job to talk to you about what you are doing with her.” Once again, mothers perceive it as their role – or the role of other mothers – to ensure that children make responsible decisions and protect themselves or others.

Some women saw it as their responsibility not only to protect their own children, but the children of other, (presumably) less responsible mothers. Jill spent an entire day discussing puberty with her daughter, “not so much for her physically, but some of her friends. We got this book and I said, this is what’s going to happen to you and right now it’s happening to some of your friends. And maybe their mom’s aren’t talking to them, so I want you to be able to understand or help them if something happens.” In this case, Jill believed not only that it was a mother’s job to prepare her daughter for developmental
changes, but that it was the responsibility of other women (and girls) to educate daughters when their own mothers failed.

Because all of the parents I interviewed saw themselves as the primary or joint decision-makers regarding Gardasil, they were well positioned to speak to the role their daughters played, or might play, in vaccine discussions and decisions. The next section deals specifically with the daughters’ position in relation to vaccine information and decision-making.

**Daughters’ Roles in Gardasil Discussions: Sexuality and Childhood**

The most significant difference between general vaccine decisions and the Gardasil vaccine decision was the daughter’s role in the process and the types of information parents felt compelled to share with girls about this vaccine. Most parents, regardless of their daughters’ ages, did not typically ask their daughters how they felt about receiving recommended immunizations. Normally, parents consented to vaccines on behalf of their daughters without asking their daughters whether they wanted to be vaccinated. In some cases, parents or providers explained to girls something very general about why the vaccine was necessary, though this was not always part of the regular vaccine routine.

The extent to which daughters played a role in the decision-making process depended on a complex web of factors, including the parent’s comfort level discussing sex and his or her perception of vaccine need and benefit. Along with these considerations, parents also evaluate their daughter’s age, her level of emotional and sexual maturity, and her ability to make careful, balanced decisions regarding her long-term health and well-being.
Many parents perceived that their daughters were more involved with and played a more active role in the Gardasil decision-making process that with other vaccines. However, in a few cases, Gardasil was intentionally administered at an early age so that parents would not feel obliged to include their daughters in the decision or explain to them how HPV was transmitted. In other cases, Gardasil vaccine decisions were delayed either at the request of the daughter, or so that the daughter could eventually take part in the decision.

A central concern for many parents regarding this vaccine, and not others, pertained to the amount and types of information a child should receive about the purpose of the vaccine. With the exception of Gardasil, explanations of vaccine benefits, disease risks, and mode of transmission did not routinely factor into parent-child communication about vaccines they were going to receive. Not a single parent explained to his or her child the purpose of the other childhood vaccines that she would receive or why the vaccine was important. Yet many parents either intentionally wanted their daughters to understand what the HPV vaccine protected against, and in some cases, how it was transmitted, or explicitly wanted this information to be withheld from them. In either case, considerations regarding HPV information sometimes led parents to delay vaccination or vaccinate earlier than they might otherwise.

By administering the vaccine before their daughters understood the link between HPV and sexuality, some parents (n=4) hoped to avoid grappling with questions about the role daughters should have in choosing the vaccine or to alleviate concerns that they would interpret the vaccine as a license to have sex (or be at a stage where they were even interested in sex). Barb, who had her daughters vaccinated, treated Gardasil like
any other vaccine they receive. “I just told them it was something they had to have and they just went with it.” When I asked her why she vaccinated her daughters’ years before she expected them to be sexually active, she answered, “I guess just so we don’t have to cross the bridge later. Once they do become active it’s not something that I want to have to talk about, saying you know, just because you’re doing this, maybe you should get this shot. Have it now and they don’t have any questions and it’s in their system (laughs).”

Victoria, who planned to have her daughter vaccinated in the next few years, planned to tell her that Gardasil protected against cervical cancer. When I asked her if she would explain to her how HPV was transmitted, she replied, “Probably not. I will probably leave that little bit out.” When asked why, she explained, “Well, probably for the same reason that (laughs) there will be parents that don’t want to give it. If she is under the impression that it protects her more, that she could have unprotected sex, then I don’t want her knowing that because that’s only one reason – you still shouldn’t have unprotected sex. Period.”

Some parents questioned whether they needed to tell their daughters anything more about this vaccine than they did about other vaccines. These parents saw no reason why their daughters should know that the vaccine protected against a sexually transmitted disease, and Tony argued that this was a simple way to allay fears that girls would interpret the vaccine as a license to engage in sexual activity. He recounted several conversations he had with friends who said thing like, “I’m never going to get that for my daughter because that promotes sexual behavior.” When he would hear this type of argument, he would respond,
You don’t have to explain what it is to her. [And they say], “Oh no, I’m real honest with my daughter.” “Did you explain what the chicken pox vaccine was for? No? Why?” “Because she was little.” “Well she’s too little to know what [Gardasil] is too.” “But I – she needs, she has the right to know [what Gardasil is for].” “No she doesn’t. No she doesn’t. How old is your daughter? Thirteen? They don’t have the right to do anything. She has the right to do what you tell her to do. You want to explain it to her, tell it’s for cancer? You’re not lying.”

Many parents did not, or would not consult their children when making HPV vaccine decisions because they doubted their daughters possessed the maturity and long-term foresight necessary to make an informed decision about the HPV vaccine. In particular, parents questioned whether their daughters had the ability to differentiate the short-term risk of vaccination – primarily pain and fear of needles – from the long-term benefits of the vaccine. Evelyn had hoped her daughter would recognize the benefits of the vaccine and independently ask for it, but her daughter simply could not get past the short-term pain associated with vaccinations: “She was focused on the negative because she doesn’t like to get shots. But you know what, at 15 you just don’t get it. . . [Her] whole focus was on getting the shot. She doesn’t know anyone who had cervical cancer. At 15 you’re invincible. The idea of doing preventive stuff doesn’t hit home. For her it’s subjecting herself to pain but without the insight about the long-term benefit.” Another mother doubted that her daughter would be able to partake in any vaccine decision because of her fear of needles: “I know she’d probably freak out if she knew she had to get a shot. If there was an option to say no, she would say no.”
Often girls became so fixated on the anticipated pain of receiving an injection that parents and providers questioned whether they could even process the information that was being presented about the vaccine itself. Patty tried to explain to her girls why they were getting the Gardasil vaccine, but she wasn’t sure that the message sunk-in: “I don’t think they really understand what cancer is or how dangerous cancer really is. They weren’t happy because it’s three shots (laughs). One’s bad but oh my gosh, you have to go back two more times? They were horrified”.

Providers agreed that if left to their own devices, many girls – regardless of age – would probably refuse all vaccines for no other reason than their short-term desire to avoid pain or their fear of needles. In most cases, mothers ended up invoking their parental authority to ensure that the vaccines were administered. Jane described a routine interaction she observes in her practice, “I see lots of arguing, but it’s usually the child saying, ‘I don’t want a shot’ and the parent saying, ‘you’re taking it, I don’t care’. I see that a lot with pre-adolescent and especially adolescent girls. They don’t want them. And the mother says get them anyway.”

However, some parents provided their daughters with at least some role in the vaccine decision-making process or planned to include their daughters in the decision when they were more mature. Some parents were willing to postpone making a decision about the Gardasil vaccine until their daughters were emotionally mature enough to have a conversation about HPV disease transmission and balance their fear of needles with an assessment of the risks and benefits of the vaccine. Courtney had tried discussing the Gardasil vaccine with her twelve year old daughter, but dropped the conversation when she became upset about the possibility of receiving shots. While she would eventually
have her daughter vaccinated, she was unsure when they would have it done: “I’m going to actually gauge the conversation, when it gets closer to September, with [my younger daughter]. When we have to start talking about shots again. If she is not understanding why we’re doing this, what in the world it’s about, I probably won’t do it. I don’t see a negative from waiting from age 12 to let’s say 15.”

Though few parents required – or even invited – their daughters to participate in other vaccine decisions, it was essential to some parents that daughters accept some degree of responsibility in choosing to receive this particular vaccine, because unlike most other vaccines that children receive, Gardasil protects against a disease that is sexually transmitted. Thus, while most children are at relatively similar risks of contracting other vaccine-preventable diseases, they are not at equal risk of contracting HPV. In the case of HPV, the daughter plays a key role in determining her own level of exposure to the virus.

One mother waited over two years to have her daughter vaccinated because she wanted her daughter to not only understand why the vaccine was important, but want to get the vaccine. After five visits, her daughter still did not want the vaccine. On the sixth visit, Lucy decided that her daughter would be vaccinated, regardless of whether she was ready. When I asked her why it was so important that her daughter participate in this vaccine decision, she explained:

For those kinds of disease that the regular vaccines are for, she’s not really going to be – I don’t feel she’s going to come in contact with anybody really. You know unless she travels outside the country. But for this vaccine it was very important for me to show her how responsible, and how sex is not a laughing
matter. And for her to understand how easily things can get transmitted. And I wanted her to understand where we were coming from and then be able to tell me, ‘Okay mommy, I’ll do it [...] I wanted her, you know what I’m saying? That sex is a choice. The other vaccines are not a choice. You know, someone’s not going to come up and rub you and say, ‘Here, here’s rubella’. Or you know, she doesn’t have to think about it. But this one, you have to put more thought into it and make her more responsibility and maybe think more before she leaves.

Mark was conflicted about whether he would involve his daughter in decision-making about Gardasil given that she does not have a role in other vaccine decisions. On the other hand, because the disease was sexually transmitted, he thought it might be a good opportunity to incorporate the vaccine into future sexual health talks.

Don’t say any of the other ones, but the other ones aren’t necessarily anything that would be preventable by their choosing. I mean, by saying, “listen we’re getting you vaccinated for chicken pox because there might be some day that you decide to hang out with somebody who has chicken pox and you might get it.” So we’re – in other words we don’t do that but it’s nothing that they would – this is something that, in theory, they wouldn’t get except for that type of contact. Which makes it, you know, something that could be part of the talk.

Some parents wanted their daughters to act autonomously and responsibility in choosing the Gardasil vaccine, partially so that their daughters understood the limits of vaccine protection, but also to reassure themselves that their daughters were capable of making responsible choices (both regarding healthcare and in protecting their own sexual health). Lucy stressed values of individuality, individual responsibility, and self-
protection when explaining to her daughter why she should get the vaccine, “You know, you have to do this for yourself. Because you don’t know what other people have been through and what they’re doing with their selves. But you need to take care of yourself.”

Parents provided a limited and contingent role in the decision-making process. Granting power – not just consideration – to the thoughts and wishes of the daughter was provisional and dependent upon the child making a decision that was congruous with the desires of the parent. In other words, daughters’ vaccine desires were respected so long as they conformed to the parents. Melissa explained that while she, her husband, and their daughter discuss issues as a group, parents have the final say: “We joke that we’re a democracy but my husband and I still win – are in charge. But we seriously consider all opinions when we’re discussing anything.” Parents maintain and justify an unequal share of power in making healthcare decisions for their daughters because they still see their daughters as lacking the experience and wisdom to always make informed decisions. Parents want to give their daughters the opportunity to develop these skills without giving up the protective ability to override what they see as poor decisions. Jean put it like this: “In my house [my daughter] gets to be involved in making decisions but she doesn’t usually have the final say. She’s a young adult but she’s still not worldly and doesn’t always know to make the best decisions for her.”

While parents were generally comfortable having their daughters vaccinated even without their daughters assent, several parents would go to lengths in order to convince their daughters to get the vaccine. Bill, for example, would have researched the vaccine with his daughter and arranged discussions with his daughter and her provider in order to gain her assent, though ultimately, he would have had her vaccinated either way. Lucy,
who strongly desired that her daughter assent to receive the HPV vaccine, delayed the decision for several years because her daughter had not wanted it. “Every time I took her to the pediatrician he would say to me, “Are you ready to give her the Gardasil?” And he’s been saying this for maybe a year and a half. And I said, ‘Well I’m not sure, it’s really up to her’. And then she would say no. Only because she was afraid of a shot.”

Finally, Lucy decided that her daughter would receive the vaccination, regardless of whether her daughter wanted it. “I said, you have to do this for me, you have to do this for yourself. And she goes, “Okay mommy, I’ll do it, but you owe me twenty bucks.” But this time if she had said no – we weren’t gonna walk out of there without it. So whether I would have had to beat her or pay her off, we were gonna do it.”

Most parents of older teens were not overly concerned with giving their daughters a role in the decision, not only because they felt comfortable overriding decisions if they felt them to be harmful, but also because most daughters, when provided with a role in the decision, deferred to the recommendation of their parents. One mother predicted that her daughter, if given a choice about the vaccine, would do whatever mom said was best, “She tends to follow exactly my opinions very closely.”

In some cases, daughters specifically asked their parents what they thought was best (n=4), and in all cases, took that advice. Providers affirm a degree of dependence among older teenagers on the advice and recommendations of their parents. As Sophia explained, at ages 16, 17, and 18, adolescents are still not making the [vaccine] decision for themselves.

For some parents (n=2), Gardasil vaccine decisions can be deferred until a daughter’s eighteenth birthday, when they become legally emancipated adults. Several
providers also recounted experiences where parents, either out of principle or due to safety concerns, did not want to have their daughters vaccinated and would therefore allow them to decide at eighteen. One provider recalled a mother who was scared to vaccinate her own daughters because she thought her niece had become paralyzed after receiving the Gardasil vaccine. The mother told the provider, “In theory I believe in [Gardasil]. I think my girls should get it. But I’m going to wait until they’re older. If they want to make their own decision when they’re 18 to vaccinate.”

The significance of the eighteen birthday results from a taken for granted notion “that the process of maturing from child to adolescent to adult unfolds as a series of naturally occurring stages, that there is a ‘right age’ at which children should develop certain competencies and acquire particular freedoms and responsibilities” (Jackson and Scott 1999:92). The age of eighteen, for some parents, marked the boundary between childhood and adulthood, not only legally, but in a wider sense. The association between legal emancipation at eighteen and adulthood is so widely accepted that, on one level, it is taken as an unquestioned truth. In practice, however, many parents and providers realize that such a clear line demarcating adulthood seldom exists.

While at age 18, young women have the legal right to make autonomous vaccine decisions, few parents expressed a desire to delay the decision until the child turned eighteen. Some parents and providers questioned whether the average 18-year old was capable of making an informed, responsible, and largely independent decision. They also doubted whether parents who took such a view were acting responsibly. For most parents, childhood extended beyond the age of eighteen.
Sometimes parents and providers attributed the need to remain involved in their children’s decisions to immature brain development and an inability to think critically about risks. From this perspective, adolescence becomes a time of danger, when poor decisions can result from hormonal impulses or inadequate brain development. As Natalie saw it, part of a parent’s job was to continually help children make good decisions, regardless of their age:

They still make bad decisions when they’re 21 years old because [...] the risk-taking and critical thinking part of their brain is still not fully developed. So they drink and they get in the car and they drive drunk. You know, and they do things they’re not supposed to do but they know is wrong and do anyway. I think it’s our job to just keep them informed and keep them thinking critically about their decision-making.

Isabelle, a nurse practitioner, doubted that adolescent girls were able to make well informed decisions about Gardasil or other reproductive health technologies. She used the example of Depo-Provera – an injectable form of hormonal contraception lasting three months – to illustrate the short-sighted approach adopted by many of her young female patients:

I’m not even sure the way that adolescent minds work, I’m not sure that they’re even able to think about – it’s just like when I would talk to girls about Depo. Depo is the very last thing that I recommend. There really have to be extenuating circumstances before I give somebody Depo, and yet when I talk to the girls about these are the reasons why – that is leaches the calcium from the bones and I worry about them when they get a little older. They look at me like, what are you
talking about? The idea of them ever getting older is just beyond them. They want to know *today* what it’s going to do for them.

While parents thought they could take a less active role in their children’s healthcare, they still thought they needed to provide their children with guidance and ensure that they were making good decisions. From Jean’s perspective, “even at 17 or 18 [years of age] we have to guide our children in the right direction. Kind of like a one-sided conversation. It’s stunning to me that some parents feel that when they get a child to 17 or 18 we have done what we as parents are supposed to do”

Parents seemed to be unsure of when they could trust their children to make responsible decisions regarding their own health. On one hand, parents recognized the need to prepare children for adulthood by allowing them space to participate in their own healthcare decisions, while also (perhaps) having difficulty in letting children take responsibility for their own health. Alice recounted a recent experience with her eldest son to explain why her mothering role did not end with legal emancipation. Her son had turned eighteen, stopped seeing the pediatrician, and had a job with an insurance plan that allowed him to choose his own doctor. Despite the appearance of autonomy, Alice explained that her role of mother, “really doesn’t stop.” Alice was not sure that was a bad thing either. She recounted that her son had recently called her to ask, “Mom, my temperature is 102. What do I do?” ‘Go to the doctor, son (laughs).’ It doesn’t end. They grow up but they *never* stop being your baby. As much as people say, get out of the house, I want them out – they really don’t. Don’t believe it.”
Providers who work with young adult populations seem to agree. Jane, who works with college-aged students, suggested that young adults were more dependent than ever on the guidance and support of parents:

Oh my goodness, the school – the college group is unbelievable. These kids are on the phone with their parents in the waiting room. And okay, she’s calling me in, I’ll call you back when she’s tell me what I have. And the minute you ask them a question, they say let me call my mother and I’ll ask her. And I thought geez when I went to school I thought I was . . . and I work with mother’s who have kids in college and here they are talking to them like three or four times a day. Call them up. How did the chemistry exam go? Call them up. Did you get – call them up, I have one mother I work with, she calls her daughter every morning to get her out of bed. (laughs). And they call them – what do they call them? Helicopter pads? It’s amazing. They haven’t left home anymore. It’s not like when you and I went off to school (laugh).

**Chapter Eleven Summary**

In this section I have argued that parents see themselves as the primary vaccine decision-makers. Both from provider observations and from the ways in which parents in my study describe decision-making, it is clear that many parents take it without question that healthcare decision-making is the responsibility of mothers. Women, in particular, view healthcare decision-making as their responsibility. That fathers typically will not make healthcare decisions without their wives’ consent, yet mothers overwhelmingly make decisions without consulting their husbands, suggests that child and adolescent healthcare is a strongly gendered domain, even with evolving, more gender-equitable
care-giver roles. As gendered events, women often describe vaccine choices not just as
decisions influencing the health and well-being of their children, but as assessments of
their own worth as parents and mothers.

For many parents, the typical vaccine ritual was altered – sometimes dramatically
– when it came to the Gardasil vaccine. In the case of Gardasil, some parents discussed
the vaccine beforehand with their daughters and provided more information about the
reason the vaccine was important. Some parents noted that the provider spent more time
explaining aspects of the vaccines to their daughters than was usual. And, as noted
previously, in some cases parents delayed making vaccine decisions, or intentionally
made them, in order to allow or circumvent child participation in the decision-making
process.

From interviews, it is clear that parents hold differing opinions regarding the
types of information that girls can comprehend – or should be given – regarding the
purposes and protections of vaccines, especially the Gardasil vaccine. Also differing
were perspectives on what roles girls can and should play in making their own healthcare
decisions and when they are capable of making informed decisions about interventions,
such as vaccination. In working through some of these issues, the concept of age became
significant, as did notions of childhood, sexuality, autonomy, and vulnerability.

Often the role that a daughter played, or would be permitted to play, in a possible
future HPV vaccine decision depended largely on her age and perceived level of
maturity. The daughter’s age usually factored strongly into how urgent parents felt it was
to vaccinate their daughters, what types of information parents wanted to share with their
daughters about the vaccine, and how much of a decision-making role the daughter should have in the decision.

It is important to recall that I did not interview adolescent girls, and therefore cannot ascertain whether their own perceptions of vaccine participation mirror the accounts provided by their parents. What some parents might consider a joint decision, daughters might consider otherwise. Do daughters perceive that they truly have a choice in the vaccine decision, or believe that they will be forced to get the vaccine even if they refuse? In the case of the latter, can the daughter be said to have participated or simply acquiesced to something perceived as inevitable?
Chapter Twelve – Evaluating and Framing Risks and Benefits

In previous chapters, I described some of the salient risks and benefits framing vaccine decisions and the sources from which some of this information is derived. I introduced the notion of trust as a key mechanism through which competing and diverse sets of information are evaluated and described the role that mothers, fathers, and daughters play in assessing different types of knowledge to inform vaccine decisions.

In this chapter, I turn to the actual vaccine decisions that parents jointly or individually make to accept, defer, or refuse the Gardasil vaccine and the ways that latent but powerful culturally embedded values help to add additional frames through which other historical, structural, interpersonal, temporal, and individual are understood and positioned. As will become apparent shortly, there are no short answers to explain Gardasil vaccine decisions, no magic bullets to describe processes that unfold in constantly evolving temporal, social, political, and personal landscapes.

In this section, I begin with a discussion of key themes framing parental evaluations of the risks and benefits associated with HPV and the Gardasil vaccine. Notions of childhood, female vulnerability, and temporality emerge as salient threads relevant to the ways that parents conceptualize HPV and Gardasil. In the latter portion of the chapter, I further examine the temporal relationships between trust, sexuality, and risk. I attempt to elucidate the ways in which parents’ views toward technology, cancer, sexuality, and age intersect with multiple and competing levels of trust in different vaccine players (e.g., pharmaceutical companies, providers, daughters, etc.) to shape the
frames through which parents conceptualize the vaccine and make vaccine decisions. In the final section of the chapter, I suggest that three overarching vaccine frames are predominantly used by parents to situate the Gardasil vaccine within larger sociocultural milieus.

**Childhood, Femininity, Individuality, and Sexuality**

Gardasil decisions were not simply about preventing HPV-infection or considering the physiological risks associated with vaccination. At stake were meanings related to notions of childhood, femininity, expectations of individual responsibility, and morals and values associated with sexuality.

In this section, I discuss how these interrelated concepts often related to parents’ vaccine decisions. Often, notions of childhood and sexuality were coupled with concerns about vaccine safety and trust to inform parents’ decisions to delay, but eventually accept (or plan to accept) the Gardasil vaccine. Parents also drew upon notions of femininity and vulnerability to justify the need to vaccinate their daughters against HPV, despite beliefs that their daughters would not put themselves in positions of susceptibility.

**Vulnerability and Victimization**

Notions of childhood add an additional layer of meaning to vaccine decisions. In the United States, children are portrayed as vulnerable, dependent, and passive beings, but also as “active, knowing, autonomous individuals” (Jackson and Scott 1999:91) who from very young ages are granted relative autonomy and individuality. Two conflicting views of children thus emerge, whereby vulnerable, dependent, and passive individuals must also be given the space and relative freedom to develop their individuality and make
their own decisions. The contradictions inherent in this conception of childhood can create unique dilemmas for parents who attempt to shelter and protect their children from potential risks, while simultaneously encouraging the child’s individuality and autonomy.

Lucy explained her own struggle to find a balance between her urge to shelter and protect her daughter and the need to expose her daughter to the dangers of the real world. “In your mind you want your daughter to wear diapers for the rest of her life. But if you’re going to be that kind of a mom you’re really not going to help your daughter. I know parents [ . . . ] who won’t let their kids go to a party where there’s drinking for adults. I just want her to be exposed to as much life as she can, with me watching.

When understanding how many parents make HPV vaccine decisions, the relationship between vaccination, childhood, and sexuality cannot be overlooked. The fact that the vaccine protects against a virus that is generally sexually transmitted refocused the lens by which many parents assessed the need for and meaning of Gardasil. Many parents, especially those with younger daughters, envisioned them as existing in a state of asexual innocence. Few parents perceived their daughters as sexual beings, much less as sexually active beings. In fact, no parent, regardless of his or her daughter’s age, believed that his or her daughter was currently or ever had been, sexually active. Moreover, most parents (n=23) did not expect their children to become sexually active in the next few years, which made it difficult for those who had yet to make an HPV vaccine decision to contemplate the need for a vaccine that prevented a sexually transmitted virus.

It made little sense to some parents to vaccinate their sexually immature daughters against a disease that was sexually transmitted. In conceptualizing Gardasil as a vaccine
associated with sex, parents were led to think about vaccine need in similar terms, which led parents to think about their children as potentially sexual beings. In conjuring up images of sexuality, the vaccine represented to parents something adult, mature, and decidedly not childlike. In short, the Gardasil vaccine challenged the very notion of the child as a child, violating “[. . .] a strong cultural emphasis on marking the boundary between childhood and adulthood – on keeping children childlike” (Scott and Jackson 1999:96). Explaining why she was not presently considering the Gardasil vaccine for her 11 year old daughter, Victoria simply stated, “Right now [my daughter] is still very much a child.”

If parents associate receipt of Gardasil with sexuality, accepting the vaccine – and in some cases, simply discussing it – can challenge parents’ conceptions of their children as children. Moreover, because many parents associate the vaccine with the near onset of sexual activity, receipt of the vaccine is sometimes seen as an indicator of their child’s sexual and developmental status.

The association that parents make between sexual onset and the vaccine might help to explain why parents of younger girls – and who were generally supportive of vaccines – often appeared to be more resistant to the vaccine. Recall from Chapter Eight that providers repeatedly expressed difficulty discussing the vaccine with parents of young girls, whom, equating the vaccine with sexual activity saw Gardasil as a unique and unnecessary intervention. Associations between the vaccine and sex often stifled conversations, as Amelia observed: “Most of the moms are very uncomfortable about that. Saying she’s not sexually active. We don’t need to talk about that. We don’t need to worry about that.”
Even if parents understood that the vaccine was ideally administered well before sexual debut, some parents had a difficult time separating receipt of the vaccine from assumptions about impending sexual debut. In the following two examples, both women had previously described Gardasil as a prophylactic vaccine. However, in recounting their own reactions to the vaccine, it appeared difficult for them to conceive of the vaccine as something that could or would ideally be administered well before their daughters reached sexual debut. Marie, who was still undecided on the vaccine, first heard about it when her daughter was 14 years old. Recounting her early recollection of the vaccine, she explained: “[I remember] just that it was a new vaccine they were giving to children, you know, young girls, whatever the age was – [my daughter] was 14 at the time. And I thought that was a little ridiculous – wanting to vaccinate girls that early. I just thought that was just too young.” Theresa, who felt pressured into having her daughter vaccinated at 13 years of age, even though she was sure her daughter was not sexually active, explained her own hesitations about the vaccine: “I think if anything some parents may look at it like I did, as you know, do we need to do this when they’re only 13? And not sexually active? Or is it something that we can wait until they get into a high school level?”

The reaction that providers receive from parents of younger daughters might explain why some providers generally do not begin discussing the vaccine with parents until daughters are a few years older. Janet observed “Most of the refusals are ‘Oh, I just think that she’s too young. I don’t think she needs it yet.’” The “yet” here is significant, highlighting the fact that refusals to vaccinate daughters at one point in time cannot be taken as indicative of outright opposition to the vaccine.
Parents of early “teen” adolescents were more likely to consider the vaccine than parents of pre-teen girls. On one hand, parents tended to view their daughters as innocent, immature, and vulnerable and therefore often viewed the HPV vaccine as symbolic of a transition the girls (or, perhaps, the parents) were not yet ready to face. At the same time, parents recognized that their daughters would eventually transition out of childhood and into the realm of adulthood, at which point the vaccine could be protective.

While most parents grudgingly acknowledge that their daughters would eventually become sexually active, very few parents foresaw sexual debut as imminent. Nearly all parents, even those who anticipated that their daughters would become active in the relatively near future, often added that they hoped their daughters would remain abstinent for extended periods of time. Such addendums served to differentiate their moral position regarding their daughter’s sexuality from an acknowledged understanding that such expectations were perhaps unrealistic.

As Mark explained, “My hope is that my daughters wouldn’t be sexually active outside of the context of the man that they’re going to spend the rest of their lives within their marriages. But I know that that doesn’t always happen.” Faith, explaining her decision to vaccinate her daughter, added, “I’m hoping she wouldn’t go into sexual activity thinking I’m protected, because that’s not been the message we’ve given her. We told her, you know, that abstinence is really your only choice (laughs). And her dad reminds her – well, you’re 35 when you get married – so we joke about that.”

Such comments, expressed seriously or through humor, speak to a resignation that parents feel when imagining their daughters as sexual beings. Most parents did not want to imagine their daughters sexually active, yet many also recognized that hopes of
lifelong abstinence, abstinence until marriage, or even abstinence through high school were unrealistic. Lucy told her daughter, “I’d like to think that you’re going to be a virgin, but hello, I’m not that dumb to believe that it couldn’t very well happen”.

Perhaps because they saw their daughters as transitioning from childhood to young adulthood more clearly, parents of older girls were more likely to accept the idea of vaccinating their daughters against a disease that was sexually transmitted. From this perspective, parents tended to view HPV – rather than the vaccine or sexual debut itself – as the primary object of risk, often to marriage, reproduction, and overall health. Of course, this is not to say that parents did not continue to hope that their children would remain abstinent, at least a little bit longer. Gretchen conceded, “When I think about it, you know, I really don’t want my daughter to be active – sexually active at sixteen but I don’t want to be saying I wish I would have gotten that vaccine for her, if it had been available to me.”

In making Gardasil vaccine decisions, parents often consider two or more dimensions of time. Parents who had, or still were, deferring initiation of the series, balanced several risks simultaneously. Trust became an important way through which parents prioritized some risks over others in making vaccine decisions. As discussed previously (Chapters Eight and Ten), the newness of the vaccine, especially given distrust in Merck and the means by which the vaccine emerged onto the market, led some parents to fear that their children might be guinea pigs in a longitudinal experiment to discover the possible long-term effects of the vaccine. Some parents wanted to delay initiating the series as long as possible in order to hear more about the possible long-term adverse effects of the vaccine.
They reasoned that over the span of several years many more girls would be vaccinated; if there were rare or severe complications they would be more likely to appear as more girls received Gardasil. Additionally, parents concerned that Gardasil might lead to infertility of complications during pregnancy, believed that with the passage of time a greater proportion of vaccinated girls would have themselves reproduced. Again, if there were problems, it was more likely that they would be discovered with time.

While parents wanted to hold off on initiating the series as long as possible in order to allay their concerns regarding vaccine safety, they also recognized that they had a finite timeframe in which to operate. Countering concerns about the safety of the vaccine were concerns (or awareness) that their daughters would eventually become sexually active, and that to ensure that their daughters received the maximum benefit from the vaccine, they had to complete the series prior to sexual debut. The risk of sexual debut had to be measured against the risks of the vaccine, requiring parents to consider two dimensions of time simultaneously. As Figure 1 (below) illustrates, increasing trust (and diminishing risk) are inversely related – with time, trust in the safety of the vaccine increases (and the risk of adverse effects decrease), while trust in the daughter’s sexual abstinence diminishes (and the risk that she will be exposed to HPV increases).
Choosing the ideal time to administer the vaccine was, in some respects, a gamble, or “leap of faith” that parents based on balancing the diminishing trust they had in daughters with the growing trust they had in the vaccine. Parents knew that to ensure full coverage, they needed to begin the series six months before sexual debut. Some parents expressed anxiety and doubt that they would be able to accurately anticipate this window, and thus saw vaccine timing itself as a risky endeavor.

Vulnerability, Victimization, and Gender

Several studies have shown an association between perceived susceptibility to HPV and parental intentions to vaccinate (Brabin, et al. 2006; Friedman and Shepeard 2007; Marlow, et al. 2007a; Olshen, et al. 2005; Riedesel, et al. 2005; Waller, et al. 2006). Since many parents in this study vaccinated their daughters, despite strong
assertions that their daughters would not be sexually active in the near future, one might conclude that perceived susceptibility to HPV infection is unrelated to this sample’s vaccine decisions. Such a conclusion would be misleading.

Susceptibility was a key factor in many parents’ decision to vaccinate their daughters, but susceptibility was not indicative of daughters’ sexual behaviors or morality. Rather, young, immature women were viewed as vulnerable to social pressures and physical dangers that made them susceptible to HPV infection.

Gardasil not only hits upon cultural notions of childhood, but ideas about gender and sexuality. The fact that Gardasil was initially only approved for use in females should not be taken for granted. As several researchers (Mamo, et al. 2010; Prescott 2010; Thompson 2010) have convincingly argued, the decision to exclusively target females for vaccination is rooted in historical, assumptions about disease, responsibility, and sexuality. While a full discussion of these arguments in beyond the scope of this dissertation, the gist of the argument is that females have historically been burdened with the risks and responsibilities of protecting themselves and the public from males (e.g., contraceptive technologies) and that heterosexism led officials to dismiss the important benefits that Gardasil had demonstrated in the prevention of anal cancer – a disease primarily affecting gay men. During FDA hearings to approve Gardasil, Merck officials and key vaccine researchers recommended that the vaccine be approved for both males and females, not only because males play a primary role in transmitting the disease, but because of the benefits they stood to personally gain through protection (Thompson 2010).
As discussed in Chapter Nine, many parents valued sexual communication as a form of complimentary HPV prevention. A more latent thread underlying the heightened sense of importance in discussing sexuality with girls spoke to the deeply rooted and pervasive gender stereotypes. Cultural norms regarding the acceptability of premarital sex have historically been gendered. The “boys will be boys” adage speaks to a permissiveness – and expectation – that boys will (or should) engage in premarital sex. Girls on the other hand, are expected to remain chaste and pure. Boys are praised and girls stigmatized for engaging in premarital sexual activity (Crawford and Popp 2003; Schalet 2000).

Most of the parents who perceived sex education to be more difficult and important to communicate to daughters were mothers (n=5), four of whom had children of both sexes. These mothers were more open with their sons about the importance of practicing safe sex and did not (or would not) feel as comfortable having the same types of open conversations with their daughters. When mothers explained why they approached sex education with their sons and daughters differently, they noted that daughters were more likely than sons to suffer adverse effects from sex.

Theresa, for example, perceived the social and emotional risks associated with sex as being gendered and far more detrimental to girls. Theresa constantly reminded her daughter that boys who respected her would not pressure her into having sex, because “You’re worth more than that. You don’t want to put yourself in a position where you’re thought less of because of your choices.” While Theresa did not encourage her son to have sex, she was also less fearful that her son would suffer emotional consequences if he
chose to have sex in high school. The stakes were higher for her daughter, which caused Theresa to feel more anxiety discussing sex with her.

Bill tried to challenge gender norms with his girls, while also stressing that no matter how unfair, the double standard would be used by others to judge their actions. Bill explained, “I’ve taught my daughters to think for themselves, to be strong young women. But at the same time, let’s face it. I’ve talked to [my older daughter] about reputation and how it’s unfair that boys can [have sex] and girls can’t, but yet that’s the real world that we live in and that’s something she needs to be aware of.”

Victoria’s approach to sex education with her son, and the strategy she planned to adopt with her daughter, exemplify the important role that gender plays in shaping some parents’ sex communication methods. Victoria explained that since her son was 16 she and her husband would “always tease him not to leave home without his raincoat.” Victoria stressed the importance of using protection, pointing out the location of condoms to her son in the drug store. She did share with him her hope that he would have sex in the context of a meaningful relationship, then adding, “But come on. The reality of it is that an ounce of prevention is worth a pound of cure. And that’s my little foil wrapped ounce of prevention.” When she sent her son off to college with a box of condoms and joked, “Maybe you’ll get lucky and use a whole box!” When her son responded with embarrassment, she replied, “Take them. Give them to your friends if you don’t need them. You’re 18 years old now and for me to pretend that it’s not going to happen is ridiculous.”

While Victoria was very proactive and comfortable discussing sex with her son, she did not anticipate having such open and joking conversations with her daughter about
sex at any point, even when she was going off to college. She explained, “double standard wise, I’m sure I’ll be different with her.” Victoria knew that she would preach the importance of having protected sex every time as soon as she felt her daughter was “anywhere near that age,” but she also knew that she would be less “flippant” about it. Explaining why she would take the conversations more seriously, Victoria explained, “although an unwanted pregnancy would really change my son’s life, it would – it has much more of a devastating impact on the girls. Let’s face it.”

As illustrated in these sexual communication examples, and through provider and parent narratives throughout the dissertation, Gardasil risk perceptions are often tied up not only with issues of childhood, but with notions of sexuality. Gendered notions of risk become intertwined with neoliberal conceptions of individual risk mediation and responsibility adds additional layers of meaning to Gardasil vaccine decisions.

The potent belief that individuals are largely responsible for protecting their own health and well-being, and conversely, are responsible for putting themselves at risk of developing diseases, pervades discussions of the Gardasil vaccine. Because HPV cannot be transmitted by a child’s dirty hand, a sneeze, or a cough – but through what is often intentional, consensual sexual activity – creates an additional layer of consideration for the parent. Daughters themselves, rather than diseases, are perceived as the agents of risks. Good girls, who make good decisions, are not at risk, and therefore do not need the vaccine. Bad girls, who make immoral or irresponsible decisions, are the ones who would benefit from the vaccine.

The notion that the individual girl bears responsibility for her own HPV risk complicates parental decisions. Even if parents’ vaccination decisions have nothing to do
with their beliefs regarding their daughter’s current or imminent level of risk, parents feel compelled to explain the “real” reasons that they vaccinated, suggesting that they are aware of other perspectives. In describing their reasons to vaccinate their daughters, several parents went out of their way to explain that the decision did not in any way suggest that they lacked confidence in their daughters’ abilities to make responsible decisions regarding their own health. Similarly, some parents felt compelled to explain that their decision to vaccinate in no way diminished the high expectations that they had for their daughters to act responsibly, morally, and safely. In emphasizing the reasons to vaccinate their daughters, many parents reframed risk to position it beyond the daughter, thus protecting the daughter (and perhaps, themselves) from moral judgment.

While many parents felt uncomfortable confronting the notion of sexuality as a reason to consider the vaccine, the concept of “vulnerability” – associated with both childhood and femininity – was often invoked as a means to rationalize the need for the vaccine and provide an alternative means by which parents could weigh vaccine risks and benefits. By focusing on the child’s vulnerabilities – her inability to defend herself against unscrupulous predators or to make mature decisions, or the physical attributes that would make HPV infection more devastating– an alternative rational for the vaccine was proffered that avoided challenging the virginity, virtue, or moral standards of girls.

Sometimes, parents did not specifically identify the vulnerability from which they sought to protect their daughters. “That was my sole purpose in getting [the vaccine] for them. In the hopes that if they do – if something did happen, God willing it doesn’t, that they have a little bit extra protection.” Often times, however, parents and providers invoked fears of rape and sexual molestation as key reasons to vaccinate daughters.
One provider urged her sister-in-law to have her ten year old daughter vaccinated immediately. When her sister-in-law asked her why she should vaccinate her now, she replied, “Well the point is to do it before they ever become sexually active. And I don’t think that she’s going to be [sexually active soon] but you just never know and what if she’s molested? You still haven’t missed that window.” One father explained, “My wife was raped when she was in high school and certainly that wasn’t planned. . . .When I think about [vaccinating my daughter] that’s what factors into my mind. You have to [do it] before they’re sexually active. But in my wife’s case, you can’t always make that decision [for yourself]. So there’s a certain safety net that I think is provided by doing it at nine years old.”

While the notion of the “innocent child” is widely pervasive in parental descriptions of their own daughters’ character and virtue, it is also commonly believed that children – especially boys – are mischievous and unruly (Jackson and Scott 1999). Within parental and provider narratives, assumptions about the sexual and moral character of males are invoked to justify the need to vaccinate girls. One mother explained why she wanted her daughter to be protected, “I just think little boys are plain out horny. They’re horn-dogs. And from what I’ve seen of [my daughter’s] friends, you know, they’ll go with a boy for a month and, ‘Oh, I love you!’ And then [the girls] are giving it up and then the next month the [boy] is on to another friend and another friend and another friend.”

Parents often explained that they vaccinated their daughters to protect them from future partners, usually husbands, who might not have been as responsible. Tony based much of his decision to vaccinate his daughter on a family experience. One of his
cousins developed cervical cancer two years after she got married. He knew “for a fact” that she was a virgin prior to getting married. As a result she had a complete hysterectomy. “And she was 27! . . . [So with my daughter], if [her husband] doesn’t know he has it, even if he’s her first, he’s going to give it to her! So she’s done the right thing. She’s waited for sex for the person she plans to spend the rest of her life [with]. So she does everything right and she can get infected anyway?” For Tony, the risk of sexual immorality or disease was external to his daughter. He did not associate HPV-risk with his daughter’s own behavior, but with the behaviors of her future partner who could put her at risk.

Tony was not alone in framing sexual risk externally. Both parents and providers referred to their daughters’ future partners as risky agents from whom their girls needed protection. Sometimes parents and providers alluded to consensual future partners, and other times daughters needed to be protected from potential rapists.

If I can protect my daughter from a partner who isn’t –has had some bad habits in the past, I just think she needs to . . . I mean, she’s 14 and I think she’s a pretty sheltered 14 year old in some respects. I don’t know. I guess my fear is more that she will make good decisions for herself but as our doctor pointed out, sometimes unfortunate things happen. You know the trauma of a rape, I’m thinking date rape of something like that, is hard enough. You know you wouldn’t want to live with [HPV] consequences.

One mother explained to her daughter why she wanted her to be vaccinated, even though her daughter was not sexually active. She explained, “this is important to your health as a woman and even if you are not sexually active and don’t intend to be, things
happen that you don’t always intend to have happen and you can’t protect yourself from everything, but you should protect yourself from the things that you can.” In the mother’s explanation, she again positions sexual risk as existing externally.

A few parents (n=4) conceived of vulnerability as an inability to make wise decisions. As was discussed in Chapter Eleven on daughters’ roles in decision-making, many parents argued that even after age eighteen, their daughters were not capable of making fully informed, responsible decisions. Some parents believed that while their daughters would try to act responsibly, their naiveté and trusting disposition might lead them to make decisions that they would later regret. Lucy, who had recently had her 15 year old daughter vaccinated, worried that her daughter’s own insecurities might make her vulnerable to the advances of unscrupulous boys.

I just don’t want her to make a rash decision, you know? I want to cry, but you understand? I see her cheeks getting rosy and then on the other hand, she feels because she’s tall, or she’s ugly, that boys don’t like her. And if a boy did happen to be on the wrong side of the law or tracks, or whatever, and tell her ‘Oh, you’re so beautiful!’ I don’t want her to be one of those. But if she is, I want her to be prepared [by having been vaccinated].

Creeping into some parents’ narratives are not just concerns about the types of images, ideas, and values their children are constantly exposed to, but also fears that their own daughters might emulate the very behaviors and values that parents see as problematic. As parents envision a riskier and more hostile world, they see a greater need and responsibility to help their daughters successfully navigate it. Perceiving that fewer schools or parents are doing their jobs, parents – and particularly mothers- increasingly
impose upon themselves the burden of guarding and guiding their daughters. One mother expressed these sentiments candidly, “I know the world is going to hell and you know, people – especially here in Florida, there really aren’t any good parents anywhere. There’s just no good parents. No parent cares about their kids. And you know, I have to live in – I have to make [my daughter] smarter than her environment.”

The external risks confronting girls sometimes led parents to view the HPV vaccine not primarily as a technology to protect girls from a disease, but something to protect girls from a world beyond the control or knowledge of parents. From this perspective, parents felt obligated to protect their daughters from HPV not because they doubted their own daughters’ moral integrity or respectability, but their daughters’ abilities to remain unharmed and unaffected by the pressures, dangers, and immoralities of a degrading and dangerous society. The Gardasil vaccine became a means to counteract risks associated with society – a vaccine protecting against an immoral and unpredictable world as much as or more than, a virus.

One mother had confidence that her daughter would make good decisions for herself, but also worried about what types of diseases she might be exposed to given how prevalent she perceived them to be, and how common she perceived unprotected sex to be. She shared some of the issues she weighed when making a decision to vaccinate her daughter, “I mean, if on one hand you say, you have kids that are abstaining. But then you’ve got all these sexually transmitted diseases out there. I don’t know that kids are . . . one partner doesn’t seem to be, it doesn’t seem to exist anymore.
Providers were equally as likely to emphasize vulnerability when advocating that children be vaccinated. Sue intentionally tried to take the focus off of daughters when discussing the vaccine.

When parents hesitate I tell that the vaccine is very, very effective and that I really hope she’ll [the daughter] be one of the few girls that waits until she is married. But even then, the odds that her husband will do the same are pretty low. Putting it this way usually takes the pressure off of the parents . . . again, I think putting some of the burden on the boys, like I do when I talk to them, really helps.

Isabelle uses a similar approach:

I explain to them that really it doesn’t have anything to do with their sexual activity today and what we’re trying to do is protect them so when they become sexually active that they have immunities. And even if their daughters have, you know, never had sex until the day they’re married, that there just is no guarantee about the partner and how many partners [he’s] had.

In these types of discourses, two different ideas are being expressed. First, providers generally remove any kind of responsibility from the daughter by affirming parents’ assertions that their daughters will remain abstinent indefinitely. At the same time, providers emphasize the vulnerability of girls, creating a scenario in which parents might view the vaccine as a safeguard against the immorality of others (while leaving unchallenged the assumed morality of the girl and good parenting of the adult).

The desire to frame the need for the vaccine around notions of vulnerability was most pronounced among providers and parents who were making vaccine decisions for
younger girls. As girls approached the early and later teen years, discourses surrounding the need for the vaccine diversified.

In reframing HPV risk away from daughters, parents avoid questioning their own daughters’ virtue and perceive threats to her virtue existing not in her own sexual development or maturation, but in the abilities of others to forcibly or coercively take advantage of her. There are several ways in which this repositioning can be understood.

In viewing the vaccine as a means to protect girls from others, parents be seen as portraying their daughters as physically and emotionally vulnerable. Even when girls might engage in consensual sexual relations with boys, they are exempt from moral judgment or responsibility. They are seen as being the dupes of insincere boys who take advantage of the innocence, naïveté, and purity of girls. In this conceptualization, daughters remain the objects childhood and feminine virtue, whose purity and innocence make them vulnerable to threats. Boys are seen as immoral, unscrupulous, and cunning, willing to lie, coerce, and deceive in their dogged and singular attempts to deflower girls. One provider expressed this belief when explaining why boys should receive Gardasil: “Boys can get warts. I mean, what fun is that? (laughs). And they’re probably just as irresponsible, if not more so than girls. ‘Oh yeah, I’m using a condom.’ Yeah right. ‘Oh, I left it home.’ Or whatever. They definitely could use the protection.” These images portray girls as ignorant and powerless, incapable of being active, empowered, and informed sexual beings. At the same time, the script depicts boys as emotionless, one-dimensional, hormone-driven automatons incapable of intimacy or genuine feelings towards their partners.
In seeing risk as external to their daughters, parents simultaneously express trust and distrust in their daughters. The frame leaves unchallenged the belief that their daughters will make responsible decisions regarding their own sexual health. At the same time, in viewing their daughters as vulnerable to persuasion due to innocence or desires to fit in, parents also express a lack of trust in their daughters’ abilities to judge and evaluate situations and others carefully.

Notions regarding childhood, neoliberal individual risk mediation, and gender work in tandem to provide layers of meanings to Gardasil vaccine decisions. As children become young adults, the trust in their lack of sexuality diminishes at the same time that faith in the safety of the vaccine (over the course of years) increases. In another way, discourses of vulnerability alleviate discomfort with the meaning of vaccination in a world where individuals are expected to manage their own risk.

**Vaccine Frames**

In evaluating risks and benefits, parents consider Gardasil’s cancer preventing properties, the newness of the vaccine, notions of sexuality, time, and trust. Three overarching vaccine frames appear to shape the ways in which parents prioritize different issues, negotiate diverse trust relationships, and frame their vaccine decisions. These frames are not intended to be limiting or constraining. For example, it is absolutely the case that parents adopting the cancer frame expressed concerns about the newness of the vaccine and discussed sexuality issues during the interview. However, these concerns were peripheral to the major focus of their decision, which was to protect their daughters against a disease that could cause cervical cancer and that they trusted was sufficiently safe. In presenting vaccine frames or orientation, I try to explain some of the
commonalities interwoven throughout diverse and varying parental accounts, while highlighting where key differences exist.

**The “Cancer Frame”**

As was discussed in Chapter Eight, parents often viewed cancer prevention as a key benefit of the Gardasil vaccine. For some parents (n=7), the specter of cancer was so pronounced that few vaccine risks could be seen as significant enough to outweigh the benefits of reducing a child’s risk of cancer. When cancer was seen as a significant and severe risk of HPV disease, parents tended to downplay the possible risks associated with the vaccine.

Evidence that some parents were unalarmed by the newness of the vaccine or possible risks associated with it is exemplified by some parents’ inability to recollect any vaccine-related risks. One mother could not recall the specific risks associated with Gardasil, but was sure they could not outweigh the benefits of cervical cancer prevention. “I know for sure – I know that there wasn’t any risk that alarmed me. The benefits outweighed any risk that I obviously must have read and the benefits of it are long term prevention of cervical cancer. It was a no-brainer for me.” Another father took little time deciding that he wanted his daughter to receive the Gardasil vaccine: “Why risk getting an incurable disease when there’s no downside?” Another woman could not understand why any mother would not have her daughter vaccinated. “It’s not going to hurt her and it’s only going to help her, so why not?”

A strong sense of trust in the regulatory processes overseeing vaccine safety, and particularly in providers and their recommendations, contributed to the view that Gardasil was a “no brainer”. These parents did little research on the reported risks associated with
Gardasil, but deemed the risks to be minute or non-existent. They reasoned that an unsafe vaccine would not be available, and more importantly, that their providers would never recommend a vaccine that they did not believe to be safe. These parents often equated a provider recommendation with vaccine safety.

Parents who gravitated towards the “cancer frame” tended to view Gardasil in highly biomedical terms. They tended to view Gardasil, first and foremost, as a vaccine that, like all other vaccines, protects and safeguards children from contracting preventable diseases. From this position, parents focus on cervical cancer, not HPV, as the disease worth preventing. The cancer frame should sound familiar. It is the vaccine frame that Merck actively sought to convey to consumers through advertising. By touting Gardasil as a cancer-preventing vaccine (specifically, a vaccine to prevent cervical cancer and one originally only approved for use in females), Merck attempted to deflect attention from the fact that HPV is sexually transmitted and that HPV risks are not equal among all children.

The fear of cancer was so pronounced and central to some parents’ conceptualization of the vaccine that they seldom saw downsides to vaccinating their daughters. While many of these parents knew that HPV was sexually transmitted, they were unlikely to focus on the sexual aspects of the disease or implications that mode of transmission might have on vaccine need. Parents who gravitated towards this perspective shared a common trust not only in their individual healthcare providers, but in the benefits of vaccines and the processes by which vaccines are vetted, approved, and regulated. Perhaps as a result of their strong confidence in regulatory oversight processes
and the benefits of vaccines, these parents were early-adapters who expressed few hesitations about the newness of the vaccine.

Parents fitting within this frame still emphasized that their decision to vaccinate daughters was not in response to concerns about their daughter’s own sexual activity. Rather, parents underscored the protective benefits of the vaccine, viewing it as one way to provide their daughters with long-term protection against a disease they might be exposed to in the (usually) distant future: “I went out and got the vaccines for my daughters even though I’m hoping that they won’t be sexually active for quite some time. I just wanted to have them protected.” Tony, who had his daughter vaccinated, often had to explain to friends and colleagues that he did not think his daughter was sexually active. “I vaccinated my daughter not for what’s going to happen today, God forbid. But for what’s going to happen when she’s 26 or 27, or whenever it happens.” A nurse practitioner recounted an experience from a conference she attended where the guest speaker said, “My daughter just got her Gardasil shot – of course, she won’t be having sex until after 30. I’m just doing this to protect her”

In evaluating safety concerns and vaccine need, trust plays an important role. Parents who expressed high trust in the independence of governmental agencies and healthcare providers from pharmaceutical companies were more likely to have faith in the safety of the vaccine. Parents who doubted the motives of governmental agencies or healthcare providers, suspecting collusion with pharmaceutical companies, were less likely to see FDA approval as a sign of safety.
The “Sex Frame”

In the previous section “Vulnerability and Victimization,” I argued that parents often shifted their focus from daughters, and their individual sexual behaviors, to external sources of risk that could threaten the sexual health of their daughters. Regardless of which vaccine frame parents gravitated towards, most parents expressed sentiments that suggested they saw their daughters as vulnerable. The ways that sexuality and vulnerability were positioned in relation to Gardasil decisions, however, varied. Parents who adopted a sex frame (n=11) also tended to highlight the cancer-preventing aspects of the vaccine, but in the context of sexuality. The frame led parents to adopt one of three strategies.

One group of parents adopting a sex frame chose to have their daughters vaccinated, but re-conceptualized risk so that the vaccine decision was not associated with their daughters own moral character or sexual maturity. These parents recognized the benefits of the vaccine, but felt less comfortable with the thought that others might interpret their decision to vaccinate negatively. Parents stressed that they had high moral standards for their daughters, who they hoped and expected would not become sexually active in the near future. The vaccine, they often argued, was to protect their daughters from rape, or future partners who might not have been as sexually responsible as their own daughters. In deflecting blame from their daughters and onto others, parents position themselves as their daughters’ protectors, safeguarding their daughters from future threats beyond their daughters’ control. In shifting blame to external threats, parents also reaffirm their daughters as responsible and moral, yet vulnerable. This set of parents also highly valued provider recommendations and tended to trust in the vaccine’s
safety. While parents might have acknowledged some vaccine risks, concerns regarding the safety of the vaccine were not central to their decision if their healthcare practitioner recommended the vaccine.

The other group of parents adopting the sex frame simply deferred the decision until a later time when they thought their daughters might be approaching a stage when they were contemplating sexual activity. Unlike parents approaching the vaccine from the “safety frame” (discussed below), concerns with the vaccine’s safety were not paramount to their deferral decision. Providers note that many parents fall within this category. Providers expressed repeatedly that many parents expressed the view that Gardasil is “not something that the child needs until she’s older and maybe dating or thinking about, later on, becoming sexually active. I think a lot of parents just don’t think it’s a necessary thing until that point.”

A third frame focuses on sexuality, where beliefs about sexuality and need lead the parent to refuse the vaccine altogether. Unlike parents who simply defer the decision for a few years, this third group of parents refuse the vaccine and have no plans to revisit the decision in the future because they are adamant that their daughters will not be at risk for HPV before their eighteenth birthday. Rachel is the only parent who fits this profile among parents that I interviewed, but several providers described parents within their practice that also would fit into this category.

The “Safety” Frame

Parents who had not yet made a vaccine decision often weighed concerns about the newness of the vaccine and its possible long-term consequences against the risks associated with cancer. Among several undecided parents, the prospect of protecting their
daughters from cervical cancer was used to counterbalance fears they had about the vaccine itself. One mother did not want her daughter to experience any harm from the vaccine, but also did not want to leave her exposed to something she could prevent. She explained why she had not gotten her daughter vaccinated yet, but planned to in the future, “So I think that’s also part of my being leery of something that I feel is fairly new and untested, but you know, I just want to make sure that I’m not doing anything bad to her. But I want to help her as well. If it can prevent cervical cancer then I certainly want her to have that opportunity to not have that.”

Parents (n=8) who adopted this frame focused on the newness and cancer-preventing aspects of the vaccine. The section on “Childhood, Femininity, Individuality, and Sexuality” (Chapter Twelve) includes a discussion of issues most salient to this group. These parents tended to highly value the cancer-preventing benefits of Gardasil, but also were not overly trusting of vaccine manufacturers, regulatory oversight, or the safety of the vaccine. A trusted provider’s recommendation was critical to their decisions to eventually initiate the series, but would not on its own compel parents to act. Parents in this category were seldom early-adopters of innovative technologies. They took conservative approaches towards new treatments, developing confidence in the safety of a treatment over time. They reasoned that the longer a treatment was administered to the general population without incident, the more likely the treatment was safe. For these parents, sexuality also became a consideration, but in relation to vaccine timing. Parents wanted their daughters to receive Gardasil before they became sexually active, but also wanted to postpone initiating the series as long as possible in order to assess the safety of
the vaccine. Parents had to balance their trust in the vaccine with trust in their daughters’ sexual abstinence.

One parent explained this relationship, “it’s a new vaccine, has it been out long enough to really show if there are side-effects or risks? You know, and the longer it’s out the more comfortable you feel with that.” Marie had postponed the vaccine for more than a year and still felt she had some time assess the vaccine’s safety. “It’s still just too new as far as I’m concerned. I don’t feel my daughter is sexually active, I really don’t. So I just don’t think I want her to have it right now until I know more about the vaccine.”

Melissa, who was extremely distrustful of Merck and no longer had a trusting relationship with a healthcare provider, was finally considering the vaccine because of the amount of time the vaccine had been available and her concern that her daughter would soon become sexually active. In explaining why she was thinking about getting the vaccine, despite her safety concerns, she said, “Just the fact that if I vaccinate her before she’s sexually active I might be able to prevent cervical cancer for her.”

Another father had doubts about the safety and newness of the vaccine. He postponed initiating the series because of those concerns, and a lack of concern about his daughter’s sexual readiness. After a year, he felt more comfortable with the vaccine’s safety, and less confident that his daughter would delay sexual activity. In explaining why he was finally beginning the series he said, “I don’t anticipate [my daughter] having sex tomorrow. I just don’t think she has the opportunities right now. If I did, I would have gotten the vaccine sooner. That’s why I’m starting now, because it takes a few shots, a few months, to get it all there. So it’s time to start now.”

In explaining why he had postponed the decision, he recollected,
I was trying to wait and see if there were any [new] studies [on the HPV vaccine], and then try to balance that with, okay, well, I have to try and be realistic because she’s going to be sixteen in a few months. And in the next few years after that I would anticipate that she’ll engage in sexual activity of some sort . . . but you never know when they’ll start . . .

If she could do it over again, Theresa would have waited to vaccinate her daughter. She did not feel comfortable with the newness of the vaccine when she had her daughter vaccinated, but also felt pressured into getting it before she was really ready. In recalling that decision, she said, “That’s where I could kind of bop myself because I felt like I was a little railroaded into it. Because when [the pediatrician] was talking about it, it was so new and I still was not sure research wise if I felt comfortable saying yes, go ahead and give this.” Shortly after this visit, Theresa switched providers.

Many providers (n=9) reported that parents often weighed safety concerns against sexual onset when delaying vaccine decisions. One physician estimated that “If I could even give you a percentage, maybe, 80% [of parents of 11 and 12 year old girls] want to hold off, they want to wait until the child’s older and the vaccine has been around longer.”

Providers sometimes recommend to parents of younger patients that they postpone initiating the series for similar reasons. Victoria’s doctor advised that she wait until her eleven year old daughter was a little older to assess safety. “He said let’s just wait and see what happens. He won’t wait forever. But he said, at 11 we have plenty of time. But I wouldn’t want to wait much later than 15. You know . . . they have to get it before they’re sexually active.”
Chapter Twelve Summary

In this chapter, I described how latent but powerful culturally embedded values help to add additional frames through which other historical, structural, interpersonal, temporal, and individual factors relevant to vaccine decisions are understood and positioned. Notions of childhood, trust, and female vulnerability are recurrent themes that thread their way through parental conceptualizations of HPV disease and Gardasil. The temporal relationships between trust, sexuality, and risk are crucial to vaccine decision-making. Time can be seen as a modifier of other important themes; to a greater extent than other factors, time is heavily dependent upon other factors in order to gain its saliency. This might be an obvious observation, as time is nothing but a frame through which we conceptualize the relationship between other events.

Parents’ views towards technology, cancer, sexuality, and age are fused with notions of trust that operate at multiple and competing levels to focus the lens through which parents conceptualize the vaccine and make vaccine decisions. In suggesting that three lenses focusing on cancer prevention, sexuality, and safety help to frame vaccine decisions, I by no means imply that decisions can be understood solely through these frames. As I hope has been made clear throughout this dissertation, fears of cancer, desires to protect, issues of morality, and notions surrounding gender, morality, and trust imbue vaccine decisions with meaning and relevance. Furthermore, as these themes and frames gain or lose importance based on a temporal dimension (estimated time of sexual debut of daughter; number of years the vaccine has been out; number of years that vaccine study participants have been tracked), it is important not to hypostatize these frames as existing on their own, separate from peoples’ lives, actions and concerns.
Chapter Thirteen – Discussion

In Chapter Seven, I began this analysis by describing the historical, political, and cultural vaccine landscape, arguing that many of the tensions surrounding the HPV vaccine apply broadly to all vaccines, and at least partially stem from historical events and developments. The processes through which the Gardasil vaccine was approved and marketed both stymied and generated criticism about the vaccine and, as discussed in Chapter Ten, had significant effects on some parents’ perceptions of the vaccine’s safety. The events surrounding the development of Gardasil and subsequent public backlash exemplify the costs of institutional and industry interconnectivity: missteps taken by Merck and legislators left some parents with a diminished sense of trust in governmental agencies, public health campaigns, and healthcare providers, who they suspected to be in collusion with Merck. These findings mirror results reported by other anthropologists who have found that suspicious regarding government and pharmaceutical collusion lead to a sense of distrust in vaccines themselves (Casiday 2007; Cassell, et al. 2006; Poltorak, et al. 2005).

Despite initial concerns among women’s advocacy groups, public health officials, and health economists that the high cost of Gardasil would only serve to widen the disparity in cervical cancer rates, cost was not a significant factor motivating parent vaccine decisions in this study. Regardless of whether their children were publically, privately, or uninsured, parents agreed that cost alone would not deter them from
considering the vaccine, although in a few cases, paying out-of-pocket for the vaccine might influence when they gave their daughter the vaccine. Consistent with findings from several studies (Gerend, et al. 2007; Litton, et al. 2010), economic issues were of peripheral or no importance to parents’ vaccine decisions. However, few generalizations can be made regarding the role that insurance coverage and household income have on Gardasil vaccine decisions based on these dissertation findings given the lack of socioeconomic diversity among parents in the sample.

In explaining what factors were central to parents’ Gardasil vaccine decisions, there are no easy answers, no neat and clean conclusions to be drawn. The contextual landscapes that frame parental vaccine decisions are not painted in black and white, but splattered with shades of gray. Moreover, the landscapes within which decisions are made are constantly evolving. Time does not stand still. Daughters do not remain children forever; vaccines do not remain new indefinitely. The criteria upon which decisions are made exist not in isolation, but relationally and temporally. Changes regarding some aspects deemed pertinent to vaccine decisions require a reexamination of other potentially important considerations. Even though some deeply rooted culturally shared values regarding femininity, sexuality, and childhood are themselves pervasive, taken-for-granted, and largely unquestioned, the relative importance of these values both to parents in assessing their applicability to their own children, and to the vaccine decision, evolve with the passage of time.

Moreover, the trustworthiness of sources is contingent and tenuous. The sources of information deemed trustworthy one day, might be suspicious the next. Tony, for example, who planned to vaccinate his daughter as soon as Gardasil was available,
deferred the decision for a year after hearing about the political efforts to mandate the vaccine. A risk deemed unacceptably high two years ago, such as vaccine safety, might now be considered tolerable in light of other emerging or shifting risks, such as the likelihood of girls become sexually active in the near future. The findings presented here reflect the messiness, contradictions, and complexities of lives imbued with cultural, social, and personal meaning; similarly, these ambiguous manifestations can themselves be seen as evidence of shifting material and structural landscapes, or at least, of peoples’ perceptions of them.

To admit that vaccine decisions are complex is not suggest that efforts to understand them are futile or pointless. Quite the opposite – the complexity of such decisions requires complex research and complex analyses that provide perhaps incomplete, but realistic, assessments of decision-making that can meaningfully contribute to theory and practice. Despite the messiness of life, patterns – even if sometimes contradictory – emerge that shed light on the process through which people act in a world of uncertainty. In this chapter, I delineate some of these patterns in an attempt to flush out some of the key issues surrounding Gardasil uptake. I discuss the contributions and relevancy of this literature to anthropology and public health, while also noting the study’s limitations and areas for future research. Table 2 includes a summary of key findings, study strengths and limitations, practical recommendations, and directions for future research.

Well-designed contextualized research on HPV vaccine acceptance is needed, especially given the vaccine’s availability to boys (FDA approved in 2009) and the more recent (October 25, 2011) ACIP recommendation that all boys 11 and 12 years of age be
vaccinated. It is my hope that findings and implications described in this study can contribute to the development of more nuanced studies of HPV vaccine acceptance in the future.

Table 2. Summary of Key Findings, Limitations, and Recommendations

<table>
<thead>
<tr>
<th>The Nurse Practitioner (NP) Perspective</th>
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<tbody>
<tr>
<td><strong>Strengths</strong></td>
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<tr>
<td>One of few studies to include nurse practitioners in healthcare provider sample</td>
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<tr>
<td><strong>Findings</strong></td>
</tr>
<tr>
<td>Possible differences in NP and pediatricians’ views on, discussions of, and recommendations for Gardasil</td>
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<tr>
<td><strong>Limitations</strong></td>
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<tr>
<td>Small sample size makes it difficult to assess whether differences are significant</td>
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<tr>
<td><strong>Recommendations</strong></td>
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<tr>
<td>Future research that includes NP perspectives and compares potential pedagogical, structural, and ideological differences between NP and other healthcare providers’ clinical practices regarding the HPV vaccine</td>
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<tr>
<th>The Patient-Provider Interaction</th>
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<tbody>
<tr>
<td><strong>Strengths</strong></td>
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<tr>
<td>Qualitative methods and focus on service delivery provide valuable information on the provider-parent conversations that is largely absent from the current literature</td>
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<tr>
<td><strong>Findings</strong></td>
</tr>
<tr>
<td>Providers employ different strategies to discuss the vaccine, depending on child/parent characteristics, visit type, and other factors</td>
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<tr>
<td>Parental initiation of conversations could possibly alter the amount of information providers share about the vaccine</td>
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<tr>
<td><strong>Limitations</strong></td>
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<tr>
<td>Analysis of communication differences is based upon provider and parent recollections (subject to multiple biases) and not on observations of actual clinical visits</td>
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<tr>
<td><strong>Future Research</strong></td>
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<tr>
<td>Shadow healthcare providers and observe actual clinical visits for extended periods of time to document actual interactions and typical exchanges; consider alternative strategies to explore the service-delivery interface (e.g., conducting interviews directly following appointments) to minimize recall bias</td>
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<tr>
<td><strong>Practical Implications</strong></td>
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<td>Parents who initiate Gardasil conversations may not receive as much information about the</td>
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vaccine as parents whose doctors initiate conversations; this might alter the role that daughters play in the conversation (though future research is required to confirm whether this relationship with initiation actually exists)

**Vaccine Frames**

**Strengths**
The use of an open-ended, qualitative research design provided an opportunity to explore connections in parental decision-making processes that would be difficult to discover using more traditional models (e.g., The Health Belief Model and Theory of Reasoned Action)

**Findings**
While many parents shared similar views regarding risks and benefits of the vaccine, parents framed these risks and benefits differently. Three predominant frames were identified: the cancer frame, the sex frame, and the safety frame. These frames helped parents focus on specific attributes of the vaccine decision. Parents within the cancer frame tended to view Gardasil primarily in terms of its cancer-preventing benefits. For those using a sex frame, the sexual route of transmission was key in decision-making and framing. Parents using a safety frame focused on the temporal risks associated with the newness of the vaccine and sexual maturation.

**Limitations**
Identifying frames is time-intensive; not all parents easily fit within a single frame; the same parent might use a different frame depending on the individual child, point in time, etc.

**Future Research**
Attempt to operationalize variables relevant to the three proposed frames (and sub-frames) and conduct research to determine whether quantitative instruments can correctly classify parents into the same frames that they were assigned to based on qualitative analysis

**Practical Implications**
Understanding the different ways in which parents conceptualize the vaccine can help providers communicate with parents in relevant and meaningful ways.

**The Local Vaccine Culture (LVC) Approach**

**Strengths**
Allows for a nuanced, multi-level, holistic examination of healthcare decision-making; calls for examination of the service-delivery interface, which provides space to assess both structural and ideational factors through supply, demand, and delivery interfaces

**Limitations**
The LVC requirement to examine the patient-provider interface presents challenges in the United States given the structure of clinical visits (e.g., small examination rooms, presence of three individuals in the room during a typical visit, the problems of obtaining informed consent/assent from all parties involved, etc.)

Data collection and analysis are time consuming

The “Local” in the Local Vaccine Culture Approach requires definition

**Recommendations**
Rethinking the “Local” as the “Contextual” may more aptly describe the approach and require researchers to clearly articulate diversity within sample populations.

Encourage wider use of the LVC (or Contextual Vaccine Culture) approach to examine variations in vaccine acceptance.

### Issues of Trust

#### Strengths

One of few vaccine studies to examine the dynamic interaction between trust and risk, or to explore the role of trust itself in vaccine decision-making.

#### Findings

Trust worked at multiple and sometimes competing levels to help parents assess and compare risks and make temporally-situated vaccine decisions.

The significance of a provider’s vaccine recommendation is contingent upon the trustworthiness parents ascribe to the individual provider; Trust in providers has as much to do with affect as it does with medical competency.

Parents expressed distrust towards the pharmaceutical industry. Similarly, healthcare providers held differing views regarding the trustworthiness of Merck, the Gardasil vaccine, and FDA oversight. NPs were more critical of the pharmaceutical industry and less likely to widely recommend Gardasil to patients.

#### Recommendations

More detailed and in-depth studies of trust to better understand the relationship between risk, trust, and decision-making;

Theoretical advancement to explain the multilayered and competing ways in which trust can affect healthcare decision-making; this requires a reassessment of current models (e.g., HBM/TRA) that narrowly define risk.

#### Practical Implications

Public health practitioners and healthcare providers need to be aware of the perception some parents have regarding the relationship between pharmaceutical companies, public health campaigns, and provider recommendations.

Medical and nursing schools should stress the importance of interpersonal skills, empathy, and compassion in developing patient bonds and encouraging patient trust.

Providers can foster a sense of trust with patients if they can relate to parents using shared roles (e.g., as women, as parents, etc.) and are comfortable sharing their own healthcare decisions with parents.

### Adolescent Role in Decision-Making

#### Findings

Few parents felt their daughters would be capable of making a fully informed, autonomous vaccine decision, even after age 18.

It was important to some parents that their daughters take an active role in making an HPV
vaccine decision, despite the fact that parents did not typically involve daughters in vaccine decisions.

A few parents preferred to vaccinate against HPV at early ages to avoid discussions about HPV’s mode of transmission.

Most parents appreciated when providers included daughters in HPV vaccine discussions; parents appreciated when providers invited daughters to participate in the healthcare visit.

Limitation
Reports of daughters’ participation were based on parental and provider perceptions. Daughters might have different views on the role they played, or would like to play in such decisions.

Future Research
Pre-adolescents and adolescents have the potential to participate in health care decisions, but it is unclear if, when, and to what extent they actually contribute to their own healthcare experiences. There continues to be a dearth of theoretical and empirical literature on the role of adolescents in healthcare decisions; to fill this gap, adolescents must be included in qualitative studies to understand their perceptions.

Development of theories on healthcare decision-making and participation as a triad that includes the provider, parent, and adolescent; Establishment of shared working definition of autonomy within the healthcare and adolescent literature so that cross study comparisons can be undertaken.

Assessments of adolescent vaccine decision-making to understand the ethical dimensions of informed consent (e.g., can girls understand the short and long-term risks and benefits of HPV/Gardasil?)

Timing of Decisions

Strengths
By approaching vaccine decisions as processes, rather than dichotomous outcomes (e.g., accepted/refused), the importance of temporal factors emerged.

Findings
Parents’ HPV vaccine decisions often unfold through time. Factors associated with the vaccine (e.g., newness, safety), the daughter (e.g., individual health profile, age, sexual maturation), and the larger sociocultural context (e.g., debates to mandate the vaccine) can all influence parental choices. Some decisions to delay vaccine initiation relate to concerns about the long-term efficacy of the vaccine and desires to maximize protection.

Implications
Healthcare providers who begin discussing the vaccine with parents of younger girls should not consider a refusal at one point of time to be indicative of long-term resistance to the vaccine.

Future Research
Vaccine acceptance should be viewed as a process. Methods and instruments must be designed not only to assess vaccine outcomes, but to account for temporal changes in times and variations in decisions for individual children. Development of longitudinal study designs to better understand decision-making process among parents who defer and delay making a decision.
**Risk Communication**

**Strengths**  
Qualitative approach allowed for exploration of multiple communicative strategies used by providers to respond to specific parent concerns

**Findings**  
Some approaches can potentially damage the parent-provider relationship by challenging the validity of parental knowledge claims, such as the validity and relevance of a mother’s instinct.

**Limitations**  
Lack of observational data to validate parent and provider accounts of how risk communication unfolds

**Susceptibility**

**Findings**  
Some parents deferred making HPV decisions until their daughters were more sexually mature and thus, more susceptible to HPV. However, susceptibility was often seen as the effect of external threats (e.g., rape, male persuasion) rather than a daughter’s own lifestyle choice;

**Future Research**  
Studies using aspects of the Health Belief Model that measure perceived susceptibility need to account for different sources of susceptibility (e.g., daughter’s sexual behavior, rape/molestation, peer pressure)

**Monetary Concerns**

**Strengths**  
Using a qualitative approach allowed parents to explain if, and under what conditions, financial issues might influence vaccine decision-making

**Findings**  
Cost was not a significant barrier or deterrent to vaccination, although it is important to note that the majority of parents interviewed in this study were middle class and privately insured. A few parents would defer decision-making if the vaccine were not covered by insurance, either in order to save sufficient money to pay for the vaccine or to maximize the number of years of active coverage (i.e., delaying vaccination until a few months before their daughters became sexually active)

Some providers were unaware of governmental vaccine programs available to Medicaid insured, under insured, and uninsured youth

**Recommendations**  
Expand qualitative approach to include a more diverse parent sample to determine whether socioeconomic status and insurance type influence views on vaccine cost

**Implications**  
Provide healthcare providers with county-level information on the Vaccines for Children program and vaccine availability to adolescents who are publically insured, under insured, or uninsured.
The Importance of Timing

Study findings underscore the fact that Gardasil vaccine decision cannot be understood outside of their temporal dimension. In keeping with calls to situate analyses of meaning with the unfolding of peoples’ lives (Ortner 1984); that is, in analyzing meaning attribution and the processes through which meanings gain significance, it is essential to understand the impact that temporal distance of a series of events (vaccination, insurance coverage, sexual debut) may have on the saliency of the meanings under discussion.

In the clearest example of why time matters, consider some parental concerns regarding long-term vaccine efficacy. Several parents were supportive of Gardasil, but suspected that future booster shots would be needed to help protect their daughters. Parents balanced concerns regarding the limited duration of vaccine coverage with other factors, including insurance coverage, parental authority, and HPV susceptibility. These parents – two of whom were (or had been) nurses – chose to defer vaccination for several years, not because of vaccine safety concerns, but because they wanted to maximize the protective benefits of the vaccine and ensure that their daughters were protected from HPV at the period in life when they were most likely to be exposed to it. These parents recognized that after age eighteen, their daughters would be able to make their own vaccine decisions and might not consent to vaccination, so immunizing before this age was important. At the same time, parents doubted that their daughters would become sexually active at age thirteen or fourteen, and therefore saw no reason to waste valuable years of protection,
In this study, as in others (Brownlie and Howson 2005:228; Casiday 2007), parents described that the ability to “bracket out uncertainties fluctuates over time”. This fluctuation characterized parents subscribing to the “safety” vaccine frame. Parents’ distrust in medical systems, pharmaceutical motives, and vaccine safety compelled them to delay initiating the vaccine series, despite their general support for vaccines and desire to protect their children from cancer. Over the course of time, however, (and in the absence of information to cause parents to question the safety of the vaccine further), trust in the vaccine’s safety increased, what at the same time, trust in their daughters’ insusceptibility diminished.

Few parents with whom I spoke were against their daughters ever receiving the vaccine. Rather, parents were hesitant to have their daughters vaccinated before it was necessary. And “necessary”, for most parents, was when daughters become interested in dating or sex, or when they turn a certain age. These findings suggest that short-term or snapshot studies of HPV vaccine uptake that only account for dichotomous decision outcomes likely overestimate the actual percentage of vaccine refusals and uptake. It is likely that the same parents who were classified as vaccine resistant at one point in time, might actively demand the vaccine in the future.

These findings have important implications for the ways in which vaccine acceptance is measured. Recall that Nichter (1996c:330) originally saw active demand as “adherence to vaccination programs by an informed public which perceives the benefits of and need for specific vaccinations” while passive acceptance denotes compliance by a “public which yields to the recommendations and social pressure, if not prodding, of health workers and community leaders.” Streefland and colleagues (1999), in developing
the Local Vaccines Culture approach, questioned the sensitivity of Nichter’s original concepts of active demand and passive acceptance to assess actual vaccine behavior. They argued that acceptance was best seen in gradations, pointing to cases in which a parent might fully vaccinate one child, partially vaccinate another, and choose not to vaccinate a third. In response, they proposed the concept of “social demand” to account for vaccine demand that is associated with general vaccine benefits or general trust in biomedicine, rather than the vaccine’s biomedically-defined therapeutic effects.

In conceptualizing acceptance in gradations, it is necessary to emphasize that parental vaccine acceptance must be understood as processual, contingent, and ongoing. Again, parents classified as “non acceptors” of Gardasil one visit may very well, even at the same visit, be planning to “actively demand” the vaccine in four years’ time.

**Trust and Knowledge**

Earlier, in my review of risk theories (Chapter Two), I posed the question, “Does risk matter?” Based on an analysis of parental narratives in this study, the answer is yes. While parent risk evaluations are unquestionably critical to parents’ Gardasil vaccine decisions, to suggest that risk defined Gardasil decisions would be inaccurate. Further, the concept of “risk” needs to be unpacked in order to avoid reifying it as a static, universal category; as mentioned previously, risk cannot be understood outside of a temporal dimension. Adding further variation to this issue is the fact that risk assessments used by parents were “construed differently from the probabilistic framework of epidemiological risk” that was used by many providers in this study to evaluate risk (Casiday 2007:1061).
Although it is true that parental concerns regarding the relevance and weight of some risks, such as the risks of sexual debut, promiscuity, cervical cancer, and vaccine side effects, were central to the ways that parents understood Gardasil, decisions were as much informed by ways that parents chose to frame and interpret specific “unknown” risks through trust. Thus, while risk does matter, its role in vaccine decision-making cannot be understood separate from trust. As I have tried to demonstrate throughout this dissertation, trust is central to the ways in which parents conceptualized the Gardasil vaccine, evaluated risks related to vaccines, sexuality, and HPV-infection, and ultimately made vaccine decisions. These findings are consistent with those reported by Brownlie and Howson (2005). In their study, parents, rather than focusing on risk, turned their attention to questioning “the trustworthiness of the institutions in charge” (2005:224). Based on these results, the authors suggest that vaccine decisions are best understood by examining how parents deal (i.e., trust) with “unknowns” (i.e., risks). To understand risks one must study trust, for as Misztal argued, “To trust is to believe despite uncertainty” (Brownlie and Howson 2005:223). Trust and risk, rather than existing separately, form a conceptual whole that must be viewed as such.

In Chapter Two, I provided an outline of Giddens’ main argument regarding the trust-risk relationship; here I discuss how his argument can be applied to make sense of some of the ways in which vaccine narratives are situated. Central to my analysis is Giddens’ argument that social relationships are positioned within abstract, expert medical systems through which knowledge is legitimized and validated irrespective of the particular healthcare clinicians or patients who rely upon it. Giddens (1993:292) argues that because the knowledge contained in the system exists beyond any one individual,
trust – “a leap of commitment, a quality of ‘faith’ which is irreducible” – is required for the system to function.

Vaccines like Gardasil are highly technical innovations developed based on expert knowledge contributed by biochemists, virologists, biostatisticians, and medical doctors. Parents are so far removed from these expert systems that affirmation in their safety and efficacy largely has to be taken on faith. Some parents had little trouble taking a leap of faith, vaccinating their daughters without questioning the safety or efficacy of the vaccine. Sarah had her daughter vaccinated without much consideration because in her words, “I don’t have time to worry about it. I just have to take the faith of the system.” While Sarah and several other parents felt comfortable taking a leap of faith, other parents, who eventually also had their daughters vaccinated, had less faith in expert systems – expressing a degree of distrust in governmental vaccine oversight, in biomedicine as a capitalist system, and in the separation between healthcare providers and pharmaceutical companies (see Chapter Ten).

Trust in expert systems is largely unconscious and taken-for-granted; when expert systems work the results generally go unnoticed. In the case of vaccines, which prevent disease, no news is good news. The lack of trust in expert systems occurs when these systems fail and as a result, harm befalls the public (Giddens 1993).

Parental trust in expert systems is built upon ever-changing and cumulative experience, illustrating, once again, the relevance of time and context to decision-making. This also suggests the importance of shifting perceptions of relationality: between parents and children; between medical consumers and the public health establishment; between relations of governmental oversight and pharmaceutical lobbying. Parents in this study
who doubted the safety of Gardasil, pointed to past cases in which regulatory oversights failed; as a result of those failures, children died from vaccines (e.g., polio) and mothers gave birth to stillborn or severely deformed children (e.g., thalidomide). Both parents and providers recalled the recent recall on Vioxx in describing their distrust of Merck, and in the ability of expert agencies such as the FDA to protect the public. I argue that the attempted efforts of legislators, in alleged collusion with Merck, to mandate Gardasil for school entry were interpreted by some parents as ethical failure of expert systems to prohibit that a mandate be issued for a brand new vaccine.

Decisions to trust are not made in isolation, but within relationships and networks. Fundamental to the Local Vaccines Culture approach is the service-delivery interface, which is characterized by provider-patient interactions. Such interactions play a pivotal role in vaccine decisions because it is through these institutional relationships, in which providers are positioned both as symbols of medical expertise and as individuals, that trust in expert systems is largely defined. At the same time, the parent-provider interaction is located within other relationships – “including those between health professionals, those within the organizational context of the health provider and those between parents, professionals, health systems and society in general” (Brownlie and Howson 2005:225). The role of providers, and their positionality vis-à-vis parents, other healthcare providers, and expert systems, is significant, especially in times of expert failure.

As Lupton (1999) and Taylor-Gooby and Zinn (2006) note, when expert systems fail, people turn to face-to-face relationships in an effort to re-establish trust, and turn away from the unseen, unknown, and abstract entities (i.e., expert systems) to obtain
knowledge. In response to failures, individuals also increasingly associate
trustworthiness with likeness. Parents, for example, feel a strong sense of collective
interest, common identity, mutual understanding, and trust with one another based on
their shared roles as parents. Conversely, trust becomes more difficult to establish
between people of different social groups, such as parents and providers.

Both of these responses can be seen in the ways that parents explained provider
trust relationships. As was described extensively in Chapter Ten, parents did not express
a high degree of trust in healthcare professionals as an expert group of practitioners; to
the contrary, parents tended to view the average healthcare professional with skepticism
or ambivalence. While trust in providers as an expert group was low, trust in individual
healthcare providers was exceptionally high. In explaining why they trusted individual
providers, parents emphasized exceptionality. The behaviors, approaches, and
characteristics that made the provider trustworthy were also perceived to be unique.

When parents described the qualities, characteristics, or behaviors that led them to
strongly trust (or distrust) their providers, they often emphasized the provider’s attributes
as personable, kind, and caring human being. It is worth noting that none of these
characteristics are directly associated with provider knowledge, skill, or competency to
practice medicine (though one could argue that an unkind, uncaring, or impersonal affect
could make it difficult for a patient to feel comfortable sharing health concerns, which
could then affect treatment). These qualities were important not because they were signs
of medical competence, but because they were signs of social competence or a sense of
shared humanity. Kind and personable providers were the types of people that parents
could relate to, who they might be friends with, who they could trust. They were not
unknown representatives of an abstract system, but friends and confidants who would treat their children as individuals and not cases.

Parents also granted a high degree of validity to provider recommendations when the providers were themselves parents. When providers had children, parents felt more confident that providers would make careful, thoughtful, individualized decisions, rather than approach treatment from a removed, depersonalized, and objectified position. Parents, who approached healthcare as a highly involved, highly personalized, highly subjective experience, felt comfort and communalism knowing that their child’s healthcare clinician also took on that role with his or her own children. Providers who establish personal, kind, and caring relationships with parents – whether it is as parents themselves, by valuing parental knowledge, or by sharing personal vaccine decisions – can foster a sense of trust that strengthens parental confidence in provider expertise and professional recommendations.

**Childhood, Sexuality, and Risk**

Like trust, notions of gender and childhood are largely absent from theoretical discussions of risk and risk anxiety; moreover, theoretical discussions have largely been devoid of ethnographic grounding. Jackson and Scott (1999) argue that risk management may in fact be central to our understanding of childhood. Risk anxieties directed at children are viewed as unique, and thus are central to the concept of childhood as a demarcated phase of life imbued with specific characteristics, expectations, and vulnerabilities. The cultural expectations regarding the management of risk during this phase of life are equally relevant to the construction of childhood. So strongly engrained are our cultural notions regarding the vulnerability and innocence of children that few
would argue the ‘rightness’ or obvious need to ‘protect’ children. At the same time, competing cultural values compel parents to cultivate a sense of individuality within their children, which is associated with a degree of child autonomy and agency. Parents’ efforts to balance child autonomy and parental surveillance are informed by notions of vulnerability, maturity (or lack thereof), and assessments of a child’s ability to think and act competently.

In this study, deeply held cultural assumptions regarding childhood and adolescence were expressed in parent and provider perspectives of adolescent autonomy and decision-making. In describing whether adolescents can and should take part in Gardasil decision, both parent and providers questioned their ability to make informed healthcare decisions – even after age eighteen. If in fact young adults are indeed incapable of making fully informed healthcare decisions (a question well beyond the scope of this study), their incompetence might itself be the result of the cultural notions of childhood that assume an inability to make well informed decisions. If not permitted to participate in healthcare decisions during childhood and adolescence, then it should not be so surprising that such competencies are not fully developed by adulthood – as marked by the eighteenth birthday.

Adolescents are largely perceived as being incapable of making informed and responsible healthcare decisions, and yet, adolescents – especially boys – have a fair degree of sexual freedom. Adolescents exist in a space of contradictions. On one hand, they have a tremendous degree of physical freedom to engage in the physical act of sex. On the other hand, the act itself is culturally taboo to speak of (intergenerationally) and many adolescents are actively discouraged from becoming informed about reproductive
health. In other words, adolescents are largely free to engage in sex, while being largely misinformed, under informed, or uninformed about the risks and responsibilities of having sex.

There is an interesting contradiction at play in vaccine decision-making when adolescents, who generally have little autonomy in healthcare decision-making, are simultaneously asked to participate in one specific vaccine decision because of their perceived autonomy in another area of life. For other parents, a perceived lack of control in limiting their children’s sexual behavior – and the belief that children are incapable of making informed and responsible sexual health decisions – compels parents to exercise control in an area where they still have it: vaccine decision-making.

The socially constructed period of childhood becomes a locus of risk. As vulnerable, inexperienced, fragile beings, children need to be protected from external risks. Risks threaten not only children, but childhood. Just as children must be protected, so must the stage of childhood be preserved. The familiar idiom, “to be robbed of one’s childhood” assumes that there are specific qualities or markers (e.g., vulnerability, sexual naïveté, and innocence) of childhood that must be protected (Jackson and Scott 1999). Risk anxiety directed at children, and responses to it, simultaneously serve to “construct childhood and maintain its boundaries – the specific risks from which children must be protected help to define the characteristics of childhood and the ‘nature’ of children themselves” (86-87). Jackson and Scott (1999) argue that there is perhaps no other area of life in which childhood risk anxiety is more pronounced than when considering sexuality.
When considered together, childhood and sexuality are viewed as mutually exclusive categories. Sexuality is seen as antithetical to the state of innocence that is a defining cultural characteristic of the “normal” child (Jackson and Scott 1999:87). There are countless examples of the symbolic, temporal, and spatial boundaries used to separate childhood from sexuality, from providing warning labels about a television show’s sexually-explicit content, to limiting soft pornography to late night, to prohibiting individuals under 18 years of age from purchasing pornography, to the use of euphemistic terms to refer to genitalia (and critical reactions and protest when parents refuse to use such euphemisms). Recent controversies regarding the availability of thong underwear in pre-teen sizes and the acceptability of childhood beauty pageants (Jackson and Scott 1999) were controversial because these actions transgressed an invisible boundary demarcating childhood and protecting the phase from becoming sexualized.

Sexual or otherwise, it is the parent’s role to protect children from danger. Jackson and Scott (1999:97) argue that there is a strong cultural emphasis on delineating the boundaries between childhood and adulthood. The state of childhood itself is seen as vulnerable and in need of protection from pressures towards early sexual maturity and precocious sexuality. Simultaneously, childhood is seen as a natural state but also a state of being perpetually threatened. As a result, “constant vigilance is required in order to protect, preserve and manage childhood for the sake of the children” (Jackson and Scott 1990:97). The strong cultural focus on individual responsibility in the management of health risk, coupled with the sexual mode by which HPV is transmitted, forces parents to confront issues that may challenge their own conceptions of their children as children. Jackson and Scott (1999:90) argue that “Increasing anxiety about risk has been
superimposed upon an older ‘protective discourse’ within which children are located as vulnerable innocents to be shielded from the dangers of the wider social (implicitly adult) world.”

The fusion of risk anxiety with protectiveness engenders a preoccupation with prevention, a need for constant vigilance in order to anticipate and guard against potential threats to children’s wellbeing.” As I argued in Chapter Twelve, one way in which parents deflect risk away from their daughters, and simultaneously maintain their image of their daughters as children, is through reference to social disorder and external threat. From this perspective, a girls’ sexual wellbeing is in need of protection, not from HPV-infection itself, but the people who might expose their daughters to it. Daughters are repositioned as vulnerable innocents; Gardasil emerges as a means to protect them from “all-pervasive, global social ‘ills,’” sexual predators, and immoral peers (Jackson and Scott 1999:88).

While parents are responsible for protecting their children from risk, they are also criticized if they are overly protective and too sheltering. Jackson and Scott (1999:103) argue that “Parental risk anxiety is heightened by particular discursive constructions of responsibility. Parents are not only responsible for the care of their children, they are also held responsible for their children’s wellbeing and conduct.” Parents are expected to manage their children’s transition to sexual awareness, but only once they have been deemed to have reached some undefined but socially appropriate age of awareness. Until that transition is completed, parents also need to keep young children free from the “taint of sexuality” (103) that could threaten their innocence.
Such concerns help to explain why parents stress the importance of sex education and shared vaccine decision-making, while simultaneously expressing anxiety about how much information to share with daughters, how much autonomy to grant them, and at what stages in their maturation process. Moreover, parents’ responsibilities to simultaneously protect their children from sexuality, while preparing them for it, illuminate ambivalence in explaining to their daughters the role of Gardasil vaccine. Parents wanted their children to understand the individual responsibility they had in protecting themselves from HPV, but did not want to have that conversation (or vaccinate) until they felt their daughters were at an age to have a conversation about sexual responsibility.

Parents, especially mothers, internalized vaccine responsibility and healthcare decision-making. As has been found in other studies (Flanagan-Klygis et al. 2005; Leask et al. 2006), parents not only internalized vaccine responsibility, but cast moral judgment upon other women (and themselves) based on Gardasil vaccine decisions. The two women who would not vaccinate their daughters with Gardasil saw their own decisions as reflections of their desire to protect their daughters and fulfill their own duties as responsible mothers. Mothers who did (or would eventually) vaccinate also saw their decisions as reflections of their desires to protect daughters and act responsibly, describing non-vaccinating mothers as ignorant, oblivious, irresponsible, or selfish.

Limitations

Like all studies, this study is not without limitations. Although the purpose of this study was not to draw sweeping or widely generalizable conclusions about vaccine acceptance and decision-making, I still attempted to obtain vaccine perspectives from a
diverse group of parents. Despite efforts to do so, the majority of parents with whom I spoke self-identified as White, were privately insured, and reported household incomes above state averages (by household size). Only two of the parents that I interviewed were uninsured and only two parents had children enrolled in publically-funded programs. It is unclear how significant ethnic, socioeconomic, and insurance variations might have been in this study.

The same limitations apply to the provider sample. As previously discussed, only one male healthcare provider (chiropractor) participated in the study, despite the fact that a greater percentage of total research fliers were sent to males. While several large studies of healthcare provider practices and attitudes vis-à-vis HPV vaccination failed to show an association between provider sex and vaccination practices (Roberto et al. 2011; Vadaparampil et al. in press), another national study reported that female providers were more likely than male providers to report administering the vaccine in their offices (Daley et al. 2010). Even if one supposes that there are no gender differences in the likelihood that providers will recommend the HPV vaccine, there could be variations in the ways that they approach the topic, the information they share or withhold, to whom they direct conversations, and the level of comfort they feel when discussing the vaccine.

For example, Burd and colleagues (2006) reported that both male and female physicians felt significantly higher levels of discomfort when recording sexual health histories of patients of the opposite sex. In a study of physician gender and patient-centered communication, Roter and Hall (2004) found that female primary care physicians tended to spend more time with their patients and engage in more patient-centered forms of communication. On the other hand, Miller and colleagues (2008)
found no gender differences in the practices through which pediatricians provided
guidance to parents about sexual risk reduction. Research using qualitative methods can
meaningfully contribute by exploring some of the potential variations in vaccine
communication by gender.

While the Local Vaccine Culture (LVC) approach provides an integrated and
dynamic approach to explore vaccine acceptance that connects individual practices to
larger community processes, the term “local” in the Local Vaccine Culture approach
requires unpacking. How is “localness” defined? The LVC approach was developed
with an overarching international lens in mind. From my reading of the literature, it
appears that the term “local” was used to emphasize the importance of local – or perhaps
more aptly, “contextual” landscapes and the relevant laws, policies, politics, and cultural
beliefs that shape vaccine uptake and decision-making in a particular place. If the
essence of the approach is to capture contextual factors relevant to vaccine decision-
making, then what is “local” will vary not only geographically, but temporally.

Although I cannot speak for the main proponents of the approach, my own sense
is that from a global health perspective, “local” can be narrowly or broadly defined
depending on the specific field site. Many authors using the approach appear to use the
term “local” to describe regional or national-level vaccine program. Of course, defining
“local” at either such level can easily be problematized. In the U.S., there are clear and
pronounced differences in vaccine uptake (e.g., Colorado vs. Connecticut). Thus, despite
the varied uses of the term “local”, my decision to include parents from two regionally
distinct areas of the U.S. within the sample necessitates some level of explanation.
Pennsylvania and Florida are different in important ways (see Chapter Five). At the same time, there are a broad set of shared cultural values regarding individual autonomy, governmental regulation, choice, and sexuality that are generally shared among individuals across the U.S. I contend that Pennsylvania and Florida do share some defining features that are markedly different from features defining vaccine uptake in, for example, the U.K., the Netherlands, Cameroon, or China. The term "local" thus, (again, from my reading), can be flexibly defined.

To describe the landscapes in which Floridians and Pennsylvanians make vaccine decisions, I attempted to couch state-level differences in rates of vaccine uptake, coverage, and laws within a larger historical discussion of shared cultural values related to vaccine decision-making (Chapters Five and Six). Throughout the analysis process, I actively looked for regional variations in vaccine decision-making. The absence of regional variation suggests that, at least among this small sample of participants, there is a unifying level of "sameness" that the term "local" might not adequately convey, but that was adequately captured by using the LVC approach.

From my perspective, ambiguity that can arise in trying to create limits or boundaries on “localness” arises from the usage of the term “local”, rather than the approach itself. Based upon my own reading of studies using the approach, the framework could more accurately be called the “Contextualized Vaccine Culture” approach. The need to provide a contextualized, rather than local, description of vaccine decision-making more precisely captures, in my mind, the essences, benefits, and "point" of the approach.
Public Health and Clinical Practice Implications

Results from this study reveal the important role of healthcare providers as sources of HPV-related information and Gardasil recommendations. These results are consistent with past studies reporting the importance of provider recommendations on Gardasil uptake (Kahn, et al. 2005; Klein and Wilson 2002; Mays and Zimet 2004; Millstein, et al. 1996; Raley 2004; Riedesel, et al. 2005; Sussman, et al. 2007; Torkko, et al. 2000). However, parents in this study also made it clear that the value, impact, and credibility of provider recommendations is typically provider-specific. A specific recommendation for the HPV vaccine was a significant motivator for many parents to get the vaccine, but only among parents who also had faith in their provider.

This study can help public health professionals and clinicians better understand how to cultivate and maintain trusting relationships with parents. While most parents trusted their children’s healthcare providers, parents did not always express trust in providers as sources of information. Consistent with other findings (Evans et al. 2001; Smailbegovic; Sporton and Francis 2001), some parents questioned the objectivity of information presented by healthcare professionals. In order to foster a sense of trust with patients, it is important that providers communicate the benefits and risks of Gardasil with parents, including its association with genital warts.

Most parents I spoke with had not known that Gardasil would provide their daughters with protection against genital warts. While most parents were not angry that their providers had not shared this information with them, they did feel that having known about the additional protections would have furthered their support for the vaccine. One mother, however, was upset that her provider did not disclose this
relationship, interpreting it as a sign that providers did not present objective information or trust parents to make informed decision when presented with sensitive information.

Aside from the ethical obligations providers have to fully inform parents of the benefits and risks associated with vaccination, one recent study suggests that equipping parents with information increases vaccine rates. Litton and colleagues (2011) found that caregivers who received HPV-related information from a healthcare professional were more likely to intend to vaccinate their daughters against HPV in the next six months compared with caregivers who did not report this source of information.

Another way clinicians can foster trust is through risk communication. For some parents, trust in expert systems has much to do with a sense of reciprocal trust from experts. Parents trust providers who recognize and value parental abilities to notice slight variations in children as signs of illness or health. Most importantly, parents have confidence in providers who acknowledge and understand that making healthcare decisions for one’s own child is a qualitatively different experience than making decisions for populations. Parents seek providers who respect their efforts to make careful, responsible, and informed decisions about their children’s healthcare.

As has been discussed in various sections of the dissertation, and has been reported in other studies (Casiday 2007; LeBlanc 2007; Leask 2002), providers and parents use different sets of criteria to evaluate the trustworthiness and validity of knowledge. Providers tend to rely upon a narrower set of criteria in exclusively (or primarily) legitimating scientific knowledge, while parents validate more diverse ways of knowing (e.g., motherly embodied knowledge; personal, family, and peer vaccine experiences, etc.).
Providers frame vaccine evaluations using a cognitive science understanding of risk. Parents do not. Providers in this study often made implicit and explicit statements that indicated a heightened belief in the superiority of scientific ways of knowing. While some providers were more likely than others to recognize the validity of other ways of knowing, many providers, especially physicians, made comments to suggest that they too perceived some parental concerns to be irrational, selfish, or inaccurate and that they viewed parental decisions to refuse (and in some cases, defer the decision) as based on lack of education, awareness, or worldliness.

Clinicians often tried to respond to parental concerns using statistics derived from scientific risk assessments. In responding to parents’ assertions that their daughters did not need to be vaccinated because they were not sexually active, providers sometimes presented statistics on ages of sexual debut to suggest that sexual activity might occur earlier than parents anticipated. Parents likely do not view these statistics as relevant to assessing their individual daughter’s risk because their daughter is not normal, she is not a statistic, and she is not sexually active. If the provider argues that sixty percent of girls become sexually active during high school, the parent responds that her daughter is part of the forty percent who will not. If the provider raises the risk, arguing that ninety percent of girls become sexually active during college, the only conclusion a parent might draw from this is that her daughter is more exceptional in being part of the ten percent who will not. While providers are no doubt well-intentioned in presenting these statistics, such responses could undermine parent trust in the provider, who might be perceived as doubting the daughter’s moral compass, or as questioning (i.e., distrusting) the parent’s own knowledge of his or her daughter’s character.
Some healthcare providers found paradoxical the association between increased education and higher observed rates of vaccine refusal. As argued earlier, this association is founded upon an assumption that educated individuals are more likely than others to use scientific information to assess risk, and that through assessments, parents will conclude that vaccine is the appropriate choice. However, in this study, most of the parents who worked within the medical system or had advanced degrees themselves had made decisions to defer vaccination.

While the risk appraisal is absolutely essential to scientific, medical, and public health understandings of the relative merits of vaccination, there is less evidence to suggest that parents use the same process to consider the relative merits of vaccination for their own children. In fact, studies that examine risk communication between providers and parents indicate that the relative importance of the scientifically understood risk appraisal has little relevance for most parents (Hobson-West 2003; Hunt, et al. 2006; Rapp 2000). As Hunt and colleagues (2006: 193) note, parents often have to translate providers’ general risk information into relevant data; “while clinicians discuss risk in clinically meaningful terms, patients must translate the clinical notion of risk into personally meaningful terms, in order to apply to their own situation”.

Casiday (2007) argues that parents and clinicians often speak different epistemological languages of risk. Communicating across this divide requires translation; the challenge for clinicians is to acknowledge other forms of knowledge and take personal experiences seriously, while also interpreting epidemiological knowledge (Casiday 2007). Expanding notions of risk communication, and what falls within the purview of legitimate risk knowledge, can foster parent trust in providers while also
heightening the credibility parents ascribe to provider recommendations. Epidemiological findings and risk assessments lack the richness and meaning of narratives presented through media stories or personal anecdotes and are therefore sometimes more difficult for parents to appreciate. Several researchers have recommended that clinician’s use their own narratives as bridges to imbue epidemiological information with meaning (Casiday 2007; Fitzpatrick 2004). Some parents and providers in this study felt it was beneficial when clinicians shared their own vaccine decisions with parents because it established a shared identity and link between them.

Establishing trust in providers is a process that generally takes time to build. Recall that Alice’s daughter was publically-insured and though her daughter was initially treated by a resident, her primary care provider always followed-up. Alice was clear that she would not make a vaccine decision based on the recommendation of residents because she did not have a long-term, trusting relationship with them. However, Alice’s trust and confidence in her primary care provider’s recommendation was so resolute that Alice had her daughter vaccinated with Gardasil without having previously heard of it or knowing what it prevented. Melissa felt similarly. If her daughter’s previous pediatrician (who lived in another part of the country) recommended Gardasil, Melissa would get it, yet because Melissa did not have a trusted provider in Florida, she was unable to know whether she could trust a random provider’s professional opinion.

These findings have implications for health policy. Several studies report variations in vaccine uptake among girls enrolled in different types of publically insurance programs (Staras, et al. 2010b; Staras, et al. 2010). The authors of these studies
suggest that differences in plan policies – specifically differences in rules regarding consistency in the provision of primary care – likely explain some of these disparities. They noted that girls more likely to be vaccinated are also enrolled in public insurance plans that require that preventive and primary care is consistently administered by the same individual, which is key in developing a trusting, long-term relationship. Given the importance that trust can have in fostering positive healthcare relationships, and in allaying parental fears, it appears beneficial to encourage these types of long-term relationships. Most parents in this study not only accepted when providers included their daughters in HPV vaccine conversations and discussions of sexuality, but actually expected that providers would comfortably engage in these types of interactions.

Several studies have compared rates of uptake among privately and publically insured girls, but rates among under-insured and uninsured girls are less clear (Chao, et al. 2010; Staras, et al. 2010b; Staras, et al. 2010). As described in Chapters Five and Six, federal and state-funding programs exist to ensure that these girls have access to the Gardasil vaccine, yet from provider narratives, it appears that neither parents nor providers are always aware of these options. Several providers lacked awareness of available resources through which their under-insured and uninsured patients could receive Gardasil. This is concerning given that (according to three providers) some parents would vaccinate their children if they were aware of low or no cost means by which to do so. Demands placed on clinicians are already high; it would behoove county-level public health officials to ensure that healthcare practitioners in their communities are trained on the local vaccine options available to girls, criteria for
seeking different options, and information about locations through which vaccines can be obtained.

From their own clinical experiences, most healthcare providers in this study described many parents’ HPV vaccine decisions as ongoing processes. While many parents accepted Gardasil vaccination when it was originally recommended to them, other parents preferred to wait – for various reasons – to make a vaccine decision. All but two of the parents in this study had, or eventually planned to have their daughters vaccinated. To ensure that parents have adequate time to make a vaccine decisions without feeling pressured, providers might consider introducing the vaccine before the eleventh and twelfth year exams, not with the intention of vaccinating girls during those visits, but with the goal of informing parents about the vaccines potential future use.

**Anthropological, Public Health, and Practice Contributions**

Results from this dissertation study have practical and theoretical anthropological, public health, and practice implications. In this section, I describe some of these key contributions. This dissertation study is one of few anthropological studies of parental HPV vaccine decision-making in the United States, thus providing valuable information about the cultural, social, and experiential context in which HPV vaccine decisions take place. It is also one of the few studies to examine both provider and parent perspectives regarding HPV vaccine decisions with attention to the service-delivery interface. Perhaps most importantly, it is, to my knowledge, one of only three studies (Sussman et al. 2007; Tisset et al. 2007) to obtain clinicians’ own narrative accounts regarding their perceptions, interactions, and delivery of the HPV vaccine. Of equal importance, it is one of few studies to obtain perspectives of nurse practitioners’ perspectives on
recommending vaccines against sexually transmitted infections (Mays and Zimet 2004) and one of even fewer that explicitly seeks to understand their attitudes and perspectives regarding the HPV vaccine (Sussman 2007).

The American Academy of Nurse Practitioners estimates that as of 2011, there are nearly 150,000 nurse practitioners currently practicing medicine in the United States; NPs comprise more than one-sixth of the health care workforce (AANP 2011; ACP 2009). Approximately two-thirds (68%) of NPs practice in at least one primary care site and 88% of NPs are trained in primary care (AANP 2011). Aside from physicians, nurse practitioners are the largest group of primary care providers, with more than 600 million patient visits annually. NPs are more likely than physicians to provide care to younger patients with few co-morbidities and to see patients with only acute minor illnesses (Hooker and McCaig year). They also play a critical role in providing care to individuals seeking care in rural communities: an estimated 18% of NPs work in rural or frontier settings (ACP 2009; AANP 2011).

Unlike some other types of analyses of healthcare choices that focus on values, behaviors, and beliefs as discrete units of measure, an anthropological analysis begins with the assumption that the values, behaviors, and beliefs associated with healthcare choices are embedded within larger cultural contexts that cannot be understood in isolation (Helman 1990). The approach highlights the limits of using the Health Belief Model or Theory of Reasoned Action as exclusive theoretical frameworks for understanding vaccine acceptance. While these theories offer helpful heuristic categories to think about factors that might be relevant to decision-making, they are also limiting. While they can identify specific factors, such as provider recommendations or perceived
susceptibility, associated with a vaccine outcome, they do not inform the process through which these variables become significant, or how interplay among factors can affect decisions.

As I have argued throughout this dissertation, parents’ vaccine decisions are embedded within complex webs. To isolate one strand of the web as central without explaining its interconnectedness and relationship to the whole is to largely miss the point of the web itself. In reducing vaccine decisions to discrete variables we run the risk of losing sight of the goal – which is to understand the processes through which vaccine decisions gain saliency. Parental understandings of vaccine risks are embedded in an “evolving cultural process which resists categorizations within the static abstractions of ‘grand theory’” (Wilkinson 2001:14). Attempting to explain all risk decisions according to one grand theory requires reducing complexities to such an extent that we run the risk of developing frameworks “so far removed from the reality of lived experience that we are left building castles in the air” (Wilkinson 2001:14).

The Local Vaccine Culture (LVC) approach provides an excellent framework to holistically examine the historical, political, economic, and sociocultural milieu within which providers and parents interact and through which parents’ temporally-situated values, beliefs, and experiences are made meaningful. Attending to the role of social context, temporality, and experience in examining vaccine decisions helps to make sense of variations in vaccine decisions by viewing the within – rather than apart from – the social fabric in which they are embedded.

The use of a more open-ended, qualitative research methodology provided the opportunity for parents to express and articulate perceptions, values, beliefs, events, and
characteristics that they deemed important to vaccine decision-making. The approach also allows space for decisions to be viewed as processes rather than discrete events or outcomes, which revealed the importance of social context and temporality on decision-making processes. Through narratives, it became clear that some parental evaluations of risks associated with vaccine safety and sexual debut evolve through time, leading to different perceptions regarding the Gardasil vaccine.

**Future Research**

Few studies examine issues of autonomy and agency in adolescent healthcare decision-making. Though researchers have called for more adolescent participation and autonomy in healthcare decision-making (Dickey and Deatrick 2000), few studies have actually examined the role that young people play in making decisions about their health. Several small studies suggest that children and adolescents do not participate in healthcare decision-making to the extent that they might (Runeson, et al. 2002; Runeson, et al. 2007).

One area in need of further theoretical and ethical development relates to the concept of childhood and adolescent autonomy and its relationship to healthcare decision-making. In a review of existing literature on adolescent autonomy in healthcare decision-making, Spear and Kulbok (2004) found little consensus regarding the definition or measurement of autonomy.

Although pre-adolescent and adolescent girls have the language and cognitive capabilities to engage in some level of discussion about vaccines, the literature tells us little about what role, if any, girls actually play in Gardasil vaccine conversations and decisions. McRee and colleagues (2010) asked parents to rank, using a scale of 1 to 4
(from no involvement to high involvement), what role their daughters played in HPV vaccination decisions and who was the primary person involved in making the decision. Similar to this study, parents of older girls reported that their daughters were more involved in decisions, but again, reports come from parents’ perceptions of involvement.

Mathur and colleagues (Mathur, et al. 2010) surveyed 170 Californian high school girls about whether they, someone else, or no one was involved in the HPV vaccine decision-making process. Because girls used their own definitions (which were not recorded) of what participation meant, it is impossible to assess how levels of participation might vary, or to determine whether girls made decisions along or jointly. While the study is a good start towards understanding how girls themselves understand participation in healthcare decision-making, more open-ended, qualitative methodologies lend themselves to a more thorough and nuanced analysis of what participation means to adolescents, which can subsequently contribute to a discussion of autonomy.

Although it is impossible to know whether providers described in this study actually shared less information about HPV vaccines with parents who initiated the conversation, the possibility deserves further exploration, especially given that parents seem unaware of the limited protections of vaccines to protect against all types of cervical cancer. To my knowledge, there are no studies of vaccine communication that examine the provider-patient-adolescent triad; such studies, that incorporate the use of observational methods to record these interactions can provide fertile ground for theoretical development and prove helpful in parsing out the dynamics through which information is offered, vetted, and withheld from and by parents, providers, and adolescents.
Studies in this area can also reveal how parents conceptualize their children’s roles in healthcare decision-making, and how these perspectives vary according to the types of interventions and technologies in question. It was clear from this study that many parents who did not give their daughters any decision-making authority in relation to other vaccines were not only willing, but insisted that their daughters take a more active role in making a Gardasil vaccine decision. Studies can help to identify what role parents will allow their children to play in their own healthcare, while identifying strategies and techniques that foster greater participation and inclusion of adolescents in making healthcare decisions.

Additionally, studies on the provider-parent-adolescent triad can also help public health and clinical practitioners understand the ethical dimensions involved in informed decision-making. In this study, some providers and parents doubted that adolescents were capable of weighing short-term consequences (such as injection pain or in the case of Depo-Provera, protection against pregnancy) with long-term benefits (e.g., protection against some types of cervical cancer) or risks (e.g., osteoporosis). Parents in another study of HPV vaccine acceptance also expressed similar concerns; some parents chose to vaccinate their daughters because they questioned their daughters’ judgment (or lack thereof) vis-à-vis sexual decision-making (Perkins et al. 2010).

One key finding from this study was that parents conceptualize susceptibility to HPV infection in multiple ways. Few parents believed that their daughters would be susceptible to HPV because of their own sexual decision-making; rather, parents saw their daughters – as females, as adolescents, as youth growing up in a changing world – as vulnerable to external threats (e.g., rape, peer pressure, unscrupulous boys) that could
put them at risk of acquiring HPV. It is important that researchers using theories and instrument (e.g., the Health Belief Model) to assess susceptibility account for the multiple meanings and associations that parents hold regarding vulnerability.

Additional research is needed to understand the role that trust plays in risk assessments and vaccine decision-making. The amorphous, abstract, and competing ways that parents and providers described trust, and the importance of trust in shaping broader attitudes and perceptions regarding the pharmaceutical industry, public health, healthcare providers, their daughters, and others, need to be better understood. Using mixed method approaches to delineate such relationships will contribute to our understanding of the processes through which trust work, at multiple levels, to inform both parents and providers’ views toward vaccines can have important theoretical and practical implications.

More qualitative research designs are needed to add balance and context to the existing vaccine acceptance literature. The systematic, but flexible nature of qualitative data analysis allows us to rework questions and methods as we go, to adjust our focus and sharpen our view of a problem. While statistical analysis gives us a snapshot, qualitative analysis allows us to explore other dimensions as well – to add layers and depth and nuance to contextualize findings. Statistical analyses are of limited utility if practitioners do not understand how specific relationships gain saliency. Unfortunately, within the current literature, the meaningfulness of behaviors, such as vaccination, is often overlooked or stripped down to a quantifiable essence. To strip meaning from behaviors – to suggest that behaviors are simply guided by physical events or conditions – is to deny the complexity of human action. The processes through which people attach
meaning to events are not static nor mechanical, but creative, contextual, and experience-based.

Anthropologists are well positioned to provide their own meaningful contributions to the vaccine acceptance literature. Anthropology is not merely about identifying patterns or associations; rather, anthropological analyses move beyond reports of statistical correlations among variables to understand the relationships of patterns to the complex whole. In focusing on the meaning of observations (both to individuals and more broadly), the normality (or uniqueness) of specific behaviors and beliefs and their relationships to other beliefs and behaviors, and in attending to the ways in which behaviors might change if represented differently, anthropologists can provide a more holistic and complex understanding of phenomena.
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VHPB, Viral Hepatitis Prevention Board

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Warren, Carol A.B.


Weinstein, Neil D.


WHO

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Zimet, Gregory D., and Susan L. Rosenthal
## Appendix One: Additional Tables

### Table A1. Association between Demographics and Vaccine Uptake

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>Association</th>
<th>Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent Education Level</td>
<td>Positive (as education level increases, acceptance increases)</td>
<td>Gust, et al. 2003; Luman, et al. 2003; Marks et al., 1979; Mays and Zimet 2004</td>
</tr>
<tr>
<td></td>
<td>Negative</td>
<td>Allen 2007; Constantine and Jerman 2007; Davis, et al. 2004; Marlow, et al. 2007; Salmon et al. 2005</td>
</tr>
<tr>
<td>Income</td>
<td>Negative Correlation (as income level increases, vaccine acceptance decreases)</td>
<td>Hopenhayn, et al. 2007; Salmon, et al. 2005</td>
</tr>
<tr>
<td></td>
<td>None</td>
<td>Brabin 2006; Slomovitz, et al. 2006</td>
</tr>
<tr>
<td>Family Size</td>
<td>Negative Correlation (as family size increases, vaccine acceptance decreases)</td>
<td>Dombkowski, et al. 2004; Marks et al. 1979</td>
</tr>
<tr>
<td></td>
<td>Positive Correlation</td>
<td>Casiday, et al. 2006; Tickner et al. in press (first-time mothers expressed less confidence in vaccines than other mothers)</td>
</tr>
<tr>
<td>Single Parent</td>
<td>Positive Correlation</td>
<td>Liddon 2005</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td>Hispanic mothers more accepting of vaccines than other mothers</td>
<td>Constantine and Jerman 2007; Scarinci, et al. 2007</td>
</tr>
<tr>
<td></td>
<td>African American parents less accepting of vaccines than other parents</td>
<td>Constantine and Jerman 2007; Litton, et al. 2011; Luman, et al. 2003; Scarinci, et al. 2007; Fazekas, et al. in press</td>
</tr>
<tr>
<td></td>
<td>Non-white more willing to accept vaccinations than white parents</td>
<td>Liddon 2005</td>
</tr>
<tr>
<td>Parent Age</td>
<td>As age increases, acceptance decreases</td>
<td>Hopehayn, et al. 2007; Sperber, et al. in press</td>
</tr>
</tbody>
</table>
Table A2. Cognitive Biases associated with Vaccine Decision-Making

<table>
<thead>
<tr>
<th>Type of Bias</th>
<th>Definition</th>
</tr>
</thead>
</table>
| Amplification   | Risks are amplified depending on the type of risk. Risk perceptions are amplified when the risk is associated with a deliberate human act, rather than a natural, random event. Voluntary risks are more acceptable than non-voluntary risks (Kimmel and Wolfe 2005)  
  - Parents are more likely to accept vaccine scenarios when the vaccine was voluntary, but recommended, as opposed to mandatory (ibid) |
| Omission        | The preference to accept a harmful consequence from inaction, rather than a harmful consequence from doing something (Baron and Ritov 2004)  
  - Parents would rather withhold a vaccine because they believe that taking actions are more harmful than inaction. Parents would feel more responsible if their child died from a vaccine than from a vaccine preventable disease (Asch, et al. 1994; Dannetun, et al. 2005; Kimmel and Wolfe 2005; Meszaros, et al. 1996; Ritov and Baron 1990) |
| Control Bias    | Parents are more likely to refuse a vaccine if they perceive greater control over their own abilities to control their child’s exposure to the disease (Kimmel and Wolfe 2005; Meszaros, et al. 1996; Sporton and Francis 2001)  
  - Parents thought vaccine-preventable diseases were largely determined by environmental factors and associated with low income, poor nutrition, and poor sanitation (Niederhauser and Markowitz 2007)  
  - Parents believe they have sufficient control over their child’s sexual or moral behavior (Mays, et al. 2004)  
  - Parents ascribed control to God, out of anyone else’s hands (Princeton 1988; Sporton and Francis 2000) |
| Compression     | People over-estimate the frequency of a rare risk, such as vaccine death, and underestimate the frequency of a more common risk, such as influenza (Ball et al. 1998)  
  - Compressions biases reported in (Hilton, et al. 2006b; Smailbegovic, et al. 2003) |
| Availability Bias | Easily accessible, widely publicized, and easily imaginable risks are likely to be over-emphasized.  
  - Bias particularly used to understand the role of media coverage about adverse vaccine effects and the effect it has on parental vaccine risk perceptions (Ball, et al. 1998; Leask 2002) |
Table A3. Selected HPV Vaccine Studies by Methods and Sample Population

<table>
<thead>
<tr>
<th>Authors</th>
<th>Methods</th>
<th>Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brabin et al. 2006</td>
<td>S</td>
<td>Parents</td>
</tr>
<tr>
<td>Brabin et al. 2007</td>
<td>S/I</td>
<td>Parents</td>
</tr>
<tr>
<td>Chan et al. 2007</td>
<td>S</td>
<td>Mothers</td>
</tr>
<tr>
<td>Constantine and Jermain 2007</td>
<td>TS</td>
<td>Mothers</td>
</tr>
<tr>
<td>Davis et al. 2004a</td>
<td>S</td>
<td>Parents</td>
</tr>
<tr>
<td>Dempsey et al. 2006</td>
<td>S/V</td>
<td>Parents</td>
</tr>
<tr>
<td>Dinh et al. 2007</td>
<td>S</td>
<td>Mothers</td>
</tr>
<tr>
<td>Friedman and Shepeard 2007</td>
<td>FG</td>
<td>Males/Females</td>
</tr>
<tr>
<td>Gerend et al. 2007</td>
<td>S</td>
<td>Mothers/Females</td>
</tr>
<tr>
<td>Giles and Garland 2006</td>
<td>S</td>
<td>Females</td>
</tr>
<tr>
<td>Hopenhayn et al. 2007</td>
<td>TS</td>
<td>Mothers/Females</td>
</tr>
<tr>
<td>Kahn et al. 2003</td>
<td>S</td>
<td>Females</td>
</tr>
<tr>
<td>Lascano-Ponce et al. 2001</td>
<td>S</td>
<td>Mothers/Females</td>
</tr>
<tr>
<td>Lenselink et al. in press</td>
<td>TS</td>
<td>Parents</td>
</tr>
<tr>
<td>Marlow et al. 2007</td>
<td>S</td>
<td>Mothers</td>
</tr>
<tr>
<td>Moraros et al. 2006</td>
<td>S</td>
<td>Mothers</td>
</tr>
<tr>
<td>Ogilvie et al. 2007</td>
<td>TS</td>
<td>Parents</td>
</tr>
<tr>
<td>Olshen et al. 2005</td>
<td>FG/I</td>
<td>Parents</td>
</tr>
<tr>
<td>Scarinci et al. 2007</td>
<td>FG</td>
<td>Females</td>
</tr>
<tr>
<td>Slomovitz et al. 2006</td>
<td>S</td>
<td>Mothers</td>
</tr>
<tr>
<td>Sperber et al. in press</td>
<td>S</td>
<td>Females</td>
</tr>
<tr>
<td>Waller et al. 2006</td>
<td>FG/V</td>
<td>Parents</td>
</tr>
</tbody>
</table>

FG – Focus groups  
I – Interviews  
S – Surveys  
TS – Telephone surveys  
V – Vignettes
Table A4. Selected non-HPV Studies by Vaccine, Methods, and Sample Population

<table>
<thead>
<tr>
<th>Vaccine</th>
<th>Authors</th>
<th>Methods</th>
<th>Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>MMR</td>
<td>Casiday 2007</td>
<td>FG</td>
<td>Parents</td>
</tr>
<tr>
<td>MMR</td>
<td>Casiday et al. 2006</td>
<td>ES</td>
<td>Parents</td>
</tr>
<tr>
<td>MMR</td>
<td>Guillaume and Bath 2004</td>
<td>I</td>
<td>Parents</td>
</tr>
<tr>
<td>MMR</td>
<td>Hilton et al. 2007b</td>
<td>FG</td>
<td>Parents</td>
</tr>
<tr>
<td>MMR</td>
<td>Hilton et al. 2007a</td>
<td>FG</td>
<td>Parents</td>
</tr>
<tr>
<td>MMR</td>
<td>McMurray et al. 2004</td>
<td>I</td>
<td>Mix</td>
</tr>
<tr>
<td>MMR</td>
<td>Petts and Niemeyer 2004</td>
<td>FG</td>
<td>Parents</td>
</tr>
<tr>
<td>MMR</td>
<td>Poltorak et al. 2004</td>
<td>PO/I/FG/B</td>
<td>Parents/Providers</td>
</tr>
<tr>
<td>MMR</td>
<td>Smith et al. 2007</td>
<td>S</td>
<td>Mothers</td>
</tr>
<tr>
<td>MMR</td>
<td>Raithatha 2003</td>
<td>I</td>
<td>Parents</td>
</tr>
<tr>
<td>MMR</td>
<td>Smailbegovac et al. 2003</td>
<td>S/I</td>
<td>Parents</td>
</tr>
<tr>
<td>OPV</td>
<td>Kishore et al. 2003</td>
<td>FG/PO</td>
<td>Mix</td>
</tr>
<tr>
<td>MIX</td>
<td>Hak et al. 2005</td>
<td>S</td>
<td>Parents</td>
</tr>
<tr>
<td>POL</td>
<td>Yahya 2006</td>
<td>PO/I/FG</td>
<td>Mix</td>
</tr>
<tr>
<td>RAB/HEPa</td>
<td>McCombie 1989</td>
<td>I</td>
<td>Providers</td>
</tr>
<tr>
<td>STI</td>
<td>Mays et al. 2004</td>
<td>I/S</td>
<td>Parents</td>
</tr>
<tr>
<td>VAR</td>
<td>Marshall et al. 2005</td>
<td>TS</td>
<td>Males/Females</td>
</tr>
<tr>
<td>Sin1</td>
<td>Niederhauser 2001</td>
<td>S</td>
<td>Parents</td>
</tr>
<tr>
<td>GEN</td>
<td>Tickner in press</td>
<td>I</td>
<td>Parents</td>
</tr>
<tr>
<td>GEN</td>
<td>Meszaros et al. 1996</td>
<td>S/V</td>
<td>Parents</td>
</tr>
<tr>
<td>GEN</td>
<td>Benin et al. 2006</td>
<td>I(LGT)</td>
<td>Mothers</td>
</tr>
<tr>
<td>GEN</td>
<td>Fairhead et al. 2004</td>
<td>B/I/FG/ES</td>
<td>Mix</td>
</tr>
<tr>
<td>GEN</td>
<td>Fowler et al. 2007</td>
<td>I/FG</td>
<td>Mothers/Grandmothers</td>
</tr>
<tr>
<td>GEN</td>
<td>Jegede 2005</td>
<td>S</td>
<td>Mix</td>
</tr>
<tr>
<td>GEN</td>
<td>Kamara 2005</td>
<td>FG/I/PO/B</td>
<td>Mix</td>
</tr>
<tr>
<td>GEN</td>
<td>Keane 2005</td>
<td>S</td>
<td>Parents</td>
</tr>
<tr>
<td>GEN</td>
<td>Millimouno et al. 2006</td>
<td>I/B/F/A/PO</td>
<td>Mix</td>
</tr>
<tr>
<td>GEN</td>
<td>Niederhauser and Markowitz 2007</td>
<td>FG</td>
<td>Parents</td>
</tr>
<tr>
<td>GEN</td>
<td>Sporton and Francis 2001</td>
<td>I</td>
<td>Parents</td>
</tr>
<tr>
<td>GEN</td>
<td>Wilson 2000</td>
<td>S/I</td>
<td>Mothers</td>
</tr>
<tr>
<td>GEN</td>
<td>Wroe 2004</td>
<td>S(LGT)</td>
<td>Pregnant women</td>
</tr>
<tr>
<td>GEN</td>
<td>Zimet 2005</td>
<td>S/V</td>
<td>Parents</td>
</tr>
<tr>
<td>GEN</td>
<td>Hinds and Cameron 2004</td>
<td>FG</td>
<td>Parents /Adolescents</td>
</tr>
<tr>
<td>GEN</td>
<td>Rosenthal 1995</td>
<td>S</td>
<td>Parents /Adolescents</td>
</tr>
</tbody>
</table>

A – Archival research
B – Vaccine biographies
FG – Focus groups
I – Interviews
LGT – Longitudinal

PO – Participant observation
S – Surveys
TS – Telephone surveys
V – Vignettes
Table A5. Studies of Vaccine Acceptance using Focus Group Method

<table>
<thead>
<tr>
<th>Authors</th>
<th># of Groups</th>
<th>Grouped By</th>
</tr>
</thead>
<tbody>
<tr>
<td>Casiday (2007)</td>
<td>NA</td>
<td>Vaccine acceptance only</td>
</tr>
<tr>
<td>Coreil et al. (1994)</td>
<td>4</td>
<td>Program sector coverage rate/child’s immunization status</td>
</tr>
<tr>
<td>Fairhead et al. (2006)</td>
<td>13</td>
<td>Mothers in toddler groups, by country</td>
</tr>
<tr>
<td>Fowler et al. (2007)</td>
<td>16</td>
<td>Mothers and grandmothers only</td>
</tr>
<tr>
<td>Friedman and Shepeard</td>
<td>35</td>
<td>Sex; ethnicity; rural/urban</td>
</tr>
<tr>
<td>Hilton et al. (2006a)</td>
<td>18</td>
<td>Vaccine acceptance; single moms/dads; parents w/partner; first time parents;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>non-first time parents; income level; autistic child</td>
</tr>
<tr>
<td>Hinds and Cameron (2004)</td>
<td>8</td>
<td>Parents; adolescents; school attended</td>
</tr>
<tr>
<td>Houseman et al. (1997)</td>
<td>6</td>
<td>Head Start; homeless shelter; WIC; inner-city program; teen mothers program;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Navy wives group; privately insured</td>
</tr>
<tr>
<td>Kishore et al. (2003)</td>
<td>NA</td>
<td>Family members of a child who got polio; community members in villages</td>
</tr>
<tr>
<td></td>
<td></td>
<td>where a child got polio; government physicians; private doctors</td>
</tr>
<tr>
<td>Leask et al. (2006)</td>
<td>6</td>
<td>Middle class; vaccine supporters only</td>
</tr>
<tr>
<td>McCormick et al. (1997)</td>
<td>12</td>
<td>Ethnicity; language; urban/rural</td>
</tr>
<tr>
<td>Millimouno et al. (2006)</td>
<td>NA</td>
<td>Unspecified</td>
</tr>
<tr>
<td>Niederhauser and Markowitz (2007)</td>
<td>13</td>
<td>Parents whose children were not fully immunized</td>
</tr>
<tr>
<td>Olshen et al. (2005)</td>
<td>6</td>
<td>Parents</td>
</tr>
<tr>
<td>Petts and Niemeyer (2004)</td>
<td>8</td>
<td>By vaccine acceptance; sex; ethnicity (Asian/White)</td>
</tr>
<tr>
<td>Scarinci et al. (2007)</td>
<td>8</td>
<td>Ethnicity</td>
</tr>
<tr>
<td>Waller et al. (2006)</td>
<td>4</td>
<td>Education</td>
</tr>
</tbody>
</table>