HPV Vaccine Distribution: An Ethical Tug-of-War

Perceptions Among Latina Mothers Living in Durham, NC

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# Table of Contents

TABLE OF CONTENTS ............................................................................................................. 3
FIGURES AND TABLES ........................................................................................................... 4
ABSTRACT ................................................................................................................................. 5
INTRODUCTION ......................................................................................................................... 6
  PUBLIC HEALTH OR INDIVIDUAL RIGHTS? ........................................................................ 6
CONTEXT AND LITERATURE REVIEW ..................................................................................... 10
  THE ETHICAL DILEMMAS OF HPV VACCINE DISTRIBUTION: ........................................... 10
    Ethical Dilemma #1: A School Mandate ............................................................................ 10
    Ethical Dilemma #2: Vaccinating Males as well as Females .......................................... 12
    Ethical Dilemma #3: Vaccination of Children Under 18 without Parental Consent ....... 13
    Ethical Dilemma #4: Mandating the HPV Vaccine for Immigrants ................................ 14
  THE LATINO PERSPECTIVE: ............................................................................................... 16
  KNOWLEDGE GAPS TO BE ADDRESSED: .......................................................................... 17
METHODOLOGY ......................................................................................................................... 19
DATA ANALYSIS AND FINDINGS .............................................................................................. 22
  DEMOGRAPHICS OF SAMPLE .............................................................................................. 22
  DURHAM LATINA MOTHERS’ PERSPECTIVES ON ETHICAL HPV VACCINE DISTRIBUTION... 24
    A. Initial Knowledge and Perceptions of HPV and the Vaccine ....................................... 26
    B. Perceptions of the Four Ethical Dilemmas ................................................................... 29
    C. Age and Cost of HPV Vaccination ............................................................................. 38
    D. Other Issues of Importance to Latina Women ......................................................... 40
CONCLUSIONS: .......................................................................................................................... 43
  HPV VACCINE ACCEPTANCE AMONG LATINOS ................................................................. 43
  THE FOUR ETHICAL DILEMMAS ......................................................................................... 44
    I. School Mandate Issue .................................................................................................. 44
    II. Vaccinating Males ........................................................................................................ 46
    III. Parental Consent Issue .............................................................................................. 47
    IV. Immigrant Mandate .................................................................................................... 48
  THE POTENTIAL FOR THE HPV VACCINE TO REDUCE CERVICAL CANCER AMONG LATINA
  WOMEN: .............................................................................................................................. 49
  SUGGESTIONS FOR FUTURE RESEARCH ........................................................................... 50
APPENDIX A: PRELIMINARY SURVEY .................................................................................. 52
APPENDIX B: FOCUS GROUP QUESTIONS ............................................................................ 53
APPENDIX C: CDC VACCINE INFORMATION SHEET (TRANSLATED) .............................. 54
WORKS CITED .......................................................................................................................... 56
Figures and Tables

TABLE 1. THE SIX FOCUS GROUPS.............................................................................................................19
TABLE 2: DEMOGRAPHIC CHARACTERISTICS OF STUDY PARTICIPANTS..............................................22
FIGURE 1.1: CHILDREN’S HEALTH ISSUES OF CONCERN TO PARTICIPANTS .................................26
FIGURE 1.2: PARTICIPANTS’ INITIAL HPV KNOWLEDGE ....................................................................27
FIGURE 1.3: PARTICIPANTS’ INITIAL HPV VACCINE KNOWLEDGE .................................................28
FIGURE 2.1: PARTICIPANTS’ VIEWS ON MANDATING THE HPV VACCINE FOR SCHOOL ENTRY ...29
FIGURE 2.2: REASONS CITED IN OPPOSITION OF A SCHOOL MANDATE ........................................31
FIGURE 2.3: REASONS CITED IN SUPPORT OF A SCHOOL MANDATE ...............................................32
FIGURE 3.1: REASONS CITED IN SUPPORT OF MALE VACCINATION .............................................33
FIGURE 4.1: PARTICIPANTS’ VIEWS ON VACCINATING CHILDREN Without PARENTAL CONSENT: ...............................................................................................................................34
FIGURE 4.2: REASONS CITED IN SUPPORT OF REQUIRING PARENTAL CONSENT FOR HPV VACCINATION ........................................................................................................................................35
FIGURE 5.1: PARTICIPANTS’ VIEWS ON REQUIRING THE HPV VACCINE FOR IMMIGRANTS ......36
FIGURE 5.2: REASONS CITED IN OPPOSITION OF THE IMMIGRANT REQUIREMENT .....................38
TABLE 3. PARTICIPANTS’ PERCEPTIONS OF THE APPROPRIATE AGE OF VACCINATION ..........39
FIGURE 6.1: PARTICIPANTS’ VIEWS ON HPV VACCINE COSTS ..............................................................40
TABLE 4. SCHOOL MANDATE ISSUE: DURHAM MOTHERS’ VIEWS AS COMPARED TO LITERATURE .................................................................................................................................45
TABLE 5. MALE VACCINATION ISSUE: DURHAM MOTHERS’ VIEWS AS COMPARED TO LITERATURE .............................................................................................................................46
TABLE 6. IMMIGRANT REQUIREMENT ISSUE: DURHAM MOTHERS’ VIEWS COMPARED TO LITERATURE .................................................................................................................................48
Abstract

This research project examined the views of Latina mothers living in Durham, North Carolina on four major ethical dilemmas surrounding HPV vaccine distribution: mandating the vaccine for school entry, vaccinating males as well as females, allowing adolescent access to the vaccine without parental permission and requiring the vaccine for new female immigrants to the United States. Forty-five self-identified Latina mothers living in Durham, NC participated in six focus groups conducted in Spanish between September – October 2009. Latina mothers showed high acceptance of the vaccine in general, but voiced low desire to vaccinate their own daughters. Participants also favored conservative approaches to its distribution. Mothers opposed a school mandate, believing parental and individual autonomy should be respected, but were in favor of vaccinating males to protect them from HPV and related diseases. Participants also believed parental consent should be required for adolescent vaccination, because parents have a right and responsibility to be involved in the decision. Lastly, Latina mothers disagreed with the immigrant requirement, calling it a form of discrimination and racism. Cultural factors did influence some of participants’ views; however, the majority of opinions expressed were similar to those encountered in the literature for other groups. The HPV vaccine has the potential to reduce cervical cancer incidence among Latinos; however, mothers must be better informed about the vaccine, which could increase their desire to vaccinate their own daughters. The vaccine’s affordability within the Latino community must also be considered.
Introduction

Public Health or Individual Rights?

Should the government prioritize vaccine distribution policies that result in the highest levels of immunity achievable within a population? Is mandating a vaccine against a sexually transmitted infection (STI) for adolescent girls an intrusion on parental rights? Such questions were of paramount importance in February 2007, when Texan Governor Rick Perry issued an executive order requiring a newly released vaccine to be administered to all girls entering the sixth grade (Blumenthal, 2007). The vaccine in question was Gardasil, which protects against the cervical-cancer causing human papillomavirus (HPV).

HPV is the most common sexually transmitted infections in the United States (CDC, 2009). At least half of Americans will become infected at some point in their lives (CDC, 2009) and most contract the virus during their first five years of sexual activity (Reisinger, et al., 2007). Transmitted through genital contact, HPV exists in over 70 strains (CDC, 2009). All HPV infections are classified as either low-risk or high-risk. Low-risk strains can cause genital warts in both men and women, and are often eradicated from the body without medical attention (CDC, 2009). However, high-risk strains of HPV can cause cervical cancer in females, which in 2005 affected 11,999 women in the United States, killing 3,924 of them (CDC, 2009). Though cervical cancer is the second most common cause of female death worldwide, the majority of the disease burden falls on those who do not have access to Pap tests (Swingle, 2000), a screening tool that can detect abnormal changes in cervical cells before cancer develops.

In June 2006, the US Food and Drug Administration (FDA) approved a vaccine to prevent cervical cancer. Gardasil, manufactured by the pharmaceutical company Merck,
protects against two high-risk strains of HPV (types 16 and 18), which cause 70% of cervical cancers (Watts, 2009). The vaccine also offers protection against two low-risk HPV infections (types 6 and 11), which are responsible for 90% of genital warts (American Cancer Society, 2009). Gardasil was cleared for use in females aged 9 – 26 when it was first approved, and in October 2009, the HPV vaccine became the first preventative measure against genital warts to be approved for males (FDA, 2009). Though another HPV vaccine, GlaxoSmithKline’s Cervarix, also offers protection against the two cervical cancer-causing HPV strains 16 and 18, it was not approved in the United States until 2009 (FDA, 2009) and has therefore not been included in this thesis. Further discussion on the HPV vaccine will therefore refer solely to Gardasil.

Following the FDA approval of Gardasil, the vaccine’s distribution stirred a great deal of controversy, as access to the vaccine became “more a political than a public health question” (Charo, 2007). Gardasil is only effective if administered to girls and women before they are exposed to HPV, and there has consequently been a push to vaccinate girls before they become sexually active. Given that 29% of American ninth grade students are sexually active (Zimmerman, 2006), most of the HPV vaccine debate has centered around the ethics and consequences of distributing a vaccine against an STI to young adolescents. Though certainly not alone in considering such policy, Texas was the first state to pass a law requiring HPV vaccination for girls entering the sixth grade (National Conference of State Legislatures, 2009). The Texan legislation allowed females between the ages of 9 – 21 who are eligible for public assistance to receive the $360, three-dose series of Gardasil for free (Blumenthal, 2007). Parents were also permitted to opt out of vaccination for their children based on “reasons of conscience, including religious beliefs” (Blumenthal, 2007).
State vaccine mandates have existed for more than a century (Charo, 2007). Even the Hepatitis B vaccine, which protects against the largely sexually transmitted HBV virus, is required in most states for school entry (Haber, 2007). According to Texas’s Governor, the HPV vaccine mandate was “responsible health and fiscal policy” (Blumenthal, 2007) and “an incredible opportunity to effectively target and prevent cervical cancer” (Forsyth, 2007). Despite these assurances, the HPV mandate law sparked public outcry. Many parents worried about condoning sexual activity among their children (Blumenthal, 2007). Some doctors were also concerned universal vaccination would give teenage girls a false sense of protection, causing them to forgo yearly Pap tests (Rubin, 2007). Merck was also criticized for their lack of long-term studies and questionable ethics behind HPV vaccine promotion, or as one activist called it, the “Help Pay for Vioxx” vaccine¹ (Saul and Pollack, 2007).

Due to the strong reactions from parents, health care workers, and interest groups, Texas’s HPV requirement was removed before it could take effect (Showdown in Texas over HPV vaccine order, 2007). Discussions surrounding compulsory HPV vaccination were tabled around the country while policy makers waited for the uproar to subside. Now, two and a half years after the HPV vaccine was released onto the market, Gardasil is universally recommended by the CDC Advisory Community on Immunization Practices (ACIP) for females aged 11 – 26 and is available in all 50 states. However, discussions on the most ethical and effective distribution policy are far from over.

In the following sections of this thesis, a review of published literature will detail perspectives on the ethical dilemmas surrounding HPV vaccine distribution. Next, the methodology used to gather information on these ethical dilemmas in North Carolina’s Latino

¹ Vioxx was a painkiller manufactured by Merck that was associated with cardiovascular problems. It was taken off the market in 2004.
population will be explained. Findings from six focus groups conducted with Latina mothers in Durham, NC will then be described. Conclusions from this research will be presented and the results of the focus groups will be compared with perspectives encountered in the literature review. Finally, suggestions for future research will be proposed.
Context and Literature Review

**The Ethical Dilemmas of HPV Vaccine Distribution:**

The following ethical dilemmas were found to be associated with HPV vaccine distribution debates documented in the literature:

I. The Ethics of a School HPV Vaccine Requirement
II. The Ethics of Vaccinating Both Males and Females
III. The Ethics of Vaccinating Children Under 18 Without Parental Consent
IV. The Ethics of Requiring the Vaccine for New Immigrants

In the subsequent sections of the literature review, a spectrum of opinions on each dilemma will be explored. Few studies, either qualitative or quantitative, have been carried out on HPV vaccine distribution, especially within the context of the last two ethical dilemmas: vaccination without parental consent and the immigrant requirement. Therefore, much of the literature review is informed by newspaper articles and opinion papers.

**Ethical Dilemma #1: A School Mandate**

Controversy surrounding requiring the HPV vaccine for entry into sixth grade has not been confined to Texas. More than 20 states considered bills that would require HPV vaccination in schools (National Conference of State Legislatures, 2009), and this ethical dilemma has been discussed more extensively than any of the other three. Proponents of compulsory vaccination have constructed their arguments within the ethical frameworks of beneficence, utilitarianism, justice and non-maleficence (Field and Caplan, 2008; Zimmerman, 2006).
Beneficence implies an obligation to help others (Field and Caplan, 2008) by preventing the physical and psychological suffering associated with cervical cancer (Balog, 2009; Colgrove, 2007). Utilitarianism relates to the public health benefits that would result from widespread vaccination; school entry laws have been shown to increase vaccine coverage rates (Colgrove, 2007). The justice argument calls for fair distribution of scarce resources (Field and Caplan, 2009). By mandating the HPV vaccine in schools, populations that have traditionally had limited access to vaccines, will be protected (Tissot, et al., 2007; Charo, 2007). Finally, the principle of non-maleficence and a need to protect those who would not get vaccinated if Gardasil were not mandated from HPV and cervical cancer have been used to support the requirement in schools (Ubesky, 2007).

Opponents of the school mandate cite more arguments than its proponents; however, this is not proof that one view is preferred over the other. According to mandate opponents, the fact that HPV is transmitted sexually and not by casual contact makes it different from other vaccines traditionally required for school entry (Gostin, 2007; Javitt, 2008). This has lead to concerns over an unwarranted government intrusion on parents and adolescents’ right to autonomous decision-making (Smith, 2007; Haber, et al., 2007; Charo, 2007). Some also believe compulsory vaccination in schools will condone promiscuity and increase sexual disinhibition among adolescents (Smith, 2007; Zimet, et al., 2008, Vamos, et al., 2008).

Furthermore, funding is an issue. The inability of lower socioeconomic groups, who bear the largest burden of cervical cancer, to afford the HPV vaccine suggest a mandate may not be the optimal policy (Ubesky, et al., 2007; Vamos, et al., 2008). As well, many believe the lack of long-term studies leaves too many lingering questions about Gardasil’s safety and efficacy to mandate it in schools (Balog, et al., 2008; Vamos, et al., 2008; Haber, et al., 2007). Lastly, other
opponents believe it is unfair for a vaccine to be targeted at females only (Haber, et al., 2007) and still more worry universal vaccination will cause women to decrease their use of Pap tests to screen for cervical cancer (Zimmerman, 2006). Finally, some who oppose requiring the vaccine in schools feel the prevalence of HPV-associated cervical cancers in the US is too low to warrant such an intrusive policy (Gostin, 2007).

**Ethical Dilemma # 2: Vaccinating Males as well as Females**

The majority of sources reviewed supported administering the HPV vaccine to boys and young men, although most were hypothetical arguments given that Gardasil was only approved for males in October 2009 (FDA, 2009). Vaccinating males would reduce disease transmission and increase a population’s immunity to HPV (Kubba, 2008; Hann and Peckham, 2008). This would protect women (including men’s future partners), from HPV and cervical cancer (Olshen, et al., 2005; Rome, 2009; Sanderson, 2009). Gardasil could also protect men from genital warts and possibly some head and neck cancers caused by HPV type 16 (Kubba, 2008). Lastly, some proponents of male vaccination believed men and boys should be included in immunization programs to show that responsibility for sexual health should not fall solely on women (Ubesky, 2007; Rome, 2009).

Some studies, however, have found that vaccinating males would not be a cost-effective public health strategy, as it would only slightly reduce HPV infections and cervical cancer cases (Tair, et al., 2004; Javitt, et al., 2008). Critics believe limited healthcare resources should be directed first toward vaccinating females, who are directly at risk for cervical cancer (Taira, et al, 2004). Lastly, those who oppose the vaccination of men and boys reason that vaccine acceptance in males is unknown (Javitt, et al., 2008) and if vaccine uptake were high among women, HPV
transmission would be slowed or stopped, indirectly protecting men as well as women (Hann and Peckham, 2008).

**Ethical Dilemma # 3: Vaccination of Children Under 18 without Parental Consent:**

Though adolescents’ rights to access the HPV vaccine without their parents’ permission has been a topic of debate, this dilemma is not well documented in the literature. Those who support requiring parental authorization believe parents have a right (Zimet, et al., 2008) and a duty (Brabin, et al., 2007) to take responsibility for the health of their sons and daughters (Brabin, et al., 2007). Some also feel that involving the parents in the HPV vaccination choice would demonstrate respect for cultural family values (Kleifgen, 2009). Others reason that children under 18 years of age are not mature enough to decide on their own (Brabin, et al., 2007), and vaccinating children only if they have parental permission could promote conversations about sexual health between parents and children (Brabin, et al., 2007). Other proponents of requiring parental authorization worry about the safety of children and the possibility that they might have dangerous reactions to the vaccine after being inoculated, which the parent would need to know about. Lastly, some parents worry about the type and completeness of information children would receive about the vaccine from the clinic or doctor’s office where they chose to receive the vaccine (Brabin, et al., 2007).

Those opposed to requiring parental consent for HPV vaccination argue that adolescents are permitted to seek treatment for STIs without parental consent, and should therefore be able to do the same with the HPV vaccine (Farrell, et al., 2007). These sources cite a need to protect children whose families would not have them vaccinated (Farrell, et al., 2007), possibly because the parents are ill informed, have unrealistic perceptions about their children’s sexual activity or object to vaccination against STIs in general (Kleifgen, 2009). Others believe a policy allowing
adolescents access to the HPV vaccine without parental consent could encourage teenagers to behave responsibly (Kleifgen, 2009). Furthermore, these sources say that adolescents are educated about STI-related vaccines and are capable of making their own decision (Farrell, et al., 2007). Finally, some believe children have the right to decide about their vaccination (Brabin, et al., 2007) and adolescent rights to confidentiality and privacy should be respected (Brabin, et al., 2007).

Ethical Dilemma # 4: Mandating the HPV Vaccine for New Immigrants

The final ethical dilemma lies in the US Center for Disease Control and Prevention’s support of the HPV vaccine. In July 2008, The CDC Advisory Committee on Immunization Practices (ACIP) updated their list of recommended vaccines to include Gardasil for females between the ages of 11 and 26 (Golberson, 2008). However, a 1996 immigration law requires any individual seeking immigrant status or permanent residency in the United States to have been immunized with all the vaccines on this list (“HPV Vaccine mandated for green card applicants,” 2008). In universally recommending Gardasil, the ACIP essentially mandated the HPV vaccine for female immigrants within the specified age range. Furthermore, there was no opt-out clause associated with the immigrant requirement; in order to claim exemption from the HPV vaccine, prospective immigrants had to demonstrate that their beliefs prohibited them from receiving any kind of vaccination (Golberson, 2008).

Citizen and Immigration Services (CIS) personnel supported the immigrant mandate, arguing that medical exams and vaccines have always been required for green card applicants and the HPV mandate is no different (Immigrant, Women's Rights Advocates Call New HPV Vaccine Requirement for U.S. Citizenship Discriminatory, Costly, 2008). CIS staff also claimed that containing the spread of contagious diseases justifies the immigrant mandate (Immigrant,
Women's Rights Advocates Call New HPV Vaccine Requirement for U.S. Citizenship Discriminatory, Costly, (2008) and proponents of the policy said vaccination of immigrants would contribute to high levels of immunity within the US population (Golberson, 2008).

Immigrant advocates and women’s rights groups opposed the immigrant requirement, believing it would exert social and cultural barriers on green card applicants (HPV vaccine mandated for green card applicants, 2008). Given that HPV does not pose an immediate threat to public health (Chung, 2009), many were against applying such a requirement to only one population, accusing the United States of using immigrant women as “clinical test subjects,” (Garay, 2009) since the long-term effects of Gardasil are not well-known (Shreyn, 2009). Some (Golberson, 2008) also cited financial barriers to both HPV vaccination and exemption (the opt-out waiver costs more than the vaccine) as unjust. Others felt it was unethical to vaccinate immigrants without also educating them about HPV (Harutyunyan, 2008), and worried mandating Gardasil would not address the disproportional impact cervical cancer has on immigrant populations, particularly Latinos (Shreyn, 2009). Due to pressure from interest groups, who cite many of the above arguments, the Gardasil immigrant mandate will be removed on December 14, 2009 (Garay, 2009).

The population the immigrant mandate most affected was the Latino community. As of 2005, Latinos made up 14% of the total US population (Pew Hispanic Center, 2008). This figure is expected to grow to 29% by 2050 (Pew Hispanic Center, 2008). About 400,000 people from Mexico alone enter the US legally each year (Pew Hispanic Center, 2005) and would have to comply with the Gardasil requirement if they met the criteria for vaccination. Furthermore, cervical cancer incidence is twice as high in the Latino population as it is among Whites (Byrd, et al., 2007). Latinos are also the least likely to have access to Pap tests due to financial,
language and cultural barriers (Byrd, et al., 2007). Therefore, Latino views on the HPV vaccine and its distribution are important to explore, as vaccination policies will have a large effect on this community.

**The Latino Perspective:**

A few published studies have investigated Latino views on the HPV vaccine; however, most have focused on acceptance, not distribution. Latinos tend to have high acceptance of vaccines against STIs in general (Blair, 2008) and are more likely to want their children vaccinated against infectious diseases than Whites and Asians (Rose and Ayad, 2008). Studies conducted within the United States found that Latino parents were more likely to say they would vaccinate their daughters before the age of 13 than non-Latino parents (Constantine, et al., 2006). Latina mothers said they would vaccinate their daughters, to protect them against HPV, genital warts, and cervical cancer, and their sons, to protect them from genital warts and anogenital cancers (Watts, 2009). Barriers to vaccine acceptance included worries about condoning sexual activity (Podolsky, et al., 2009), the possible side effects of the vaccine (Gaylord, et al., 2008) and the cost (Sanderson, et al., 2009). Furthermore, some Latino parents simply did not believe their children were at risk for HPV and felt vaccination was unnecessary (Podolsky, et al, 2009).

The few studies that did look at distribution showed that Latina women supported the vaccination of males as well as females to prevent the virus’s transmission to women (Gaylord, et al., 2008) and to prevent cervical cancer in their partners (Sanderson, et al., 2009). One study (Sanderson, et al., 2009) found that 85% of Latino women were in favor of the Texas vaccine mandate; however, some participants cited worries about the potential for Gardasil to be mandated in schools as barriers to their acceptance of the vaccine (Gaylord, et al., 2008). Parents felt they needed more information about the vaccine (Podolsky, et al., 2009; Gaylord, et al.,
2008), which they said should come from credible sources such as doctors, TV or churches (Scarinci, et al., 2007).

Though there is limited information available on Latinos’ opinions, a comprehensive review of the literature on HPV vaccine perceptions reveals a spectrum of views on each of four ethical dilemmas surrounding vaccine distribution: mandating Gardasil for school entry, vaccinating males as well as females, vaccinating children without parental consent and requiring the vaccine for immigrants. The studies that do examine Latino perceptions show women are in favor of vaccinating males to protect women (Gaylord, et al., 2008). Views on the school mandate issue differ between studies (Gaylord, et al., 2008; Sanderson, et al., 2009). Finally, Latinos demonstrate high acceptance of STI-related vaccines (Blair, 2009) and are likely to want Gardasil to be administered to their children (Constantine, et al., 2006).

**Knowledge gaps to be addressed:**

Both qualitative and quantitative studies have focused on measuring acceptability of the HPV vaccine, with some commenting on one or more of the ethical dilemmas surrounding its distribution (most often, the school mandate issue). Some sources additionally explore the reasoning behind the views presented; however, few studies exist in which data were actually gathered on vaccine distribution views. Furthermore, the literature presented on some of the ethical dilemmas is biased toward one side, most notably in the immigrant mandate debate where almost all sources opposed the requirement. Lastly, there is limited information available on the views of Latinos and other minority groups in relation to the HPV vaccine. This thesis aimed to fill some of these knowledge gaps, by exploring views on HPV vaccine distribution and focusing on one particular population: Latina mothers living in Durham County, NC.
North Carolina has the fastest growing Latino population in the United States (NC Latino Health, 2003). Durham County alone is home to over 30,000 Latinos (US Census Bureau), who make up approximately 11.7% of the County’s population (U.S. Census Bureau, 2006-2008). Understanding the opinions of this community on ethical and effective HPV vaccine distribution could provide information on Gardasil’s potential role as a cervical cancer prevention tool, especially since financial, cultural and language barriers limit Latinos’ access to Pap tests (Byrd, et al., 2007). The information from this research project will also help situate the Latino perspective in the current debate over Gardasil’s distribution, and could provide information on ways to improve HPV vaccine education targeted at this population. This study will therefore explore Latino views on each of the four ethical dilemmas encountered in the literature: the school mandate, vaccinating males, requiring parental permission for adolescent vaccination, and the immigrant requirement.
Methodology

Six focus group discussions were conducted with a total of 45 self-identified Latina mothers (see Table 1) over a one-month period (September – October 2009). In order to attend the focus groups, participants were required to be Latina mothers over 18 years of age, live in Durham County, NC and have at least one child under the age of 18. The study focused on mothers based on the assumption that they would have the largest influence on whether or not a child was administered the HPV vaccine. The literature indicates that mothers are primarily responsible for the children in most Latino cultures (Diffily, 2004). Participants were required to have a child under the age of 18, because most of the ethical issues surrounding HPV vaccine distribution relate to the vaccination of minors.

Table 1. The Six Focus Groups

<table>
<thead>
<tr>
<th>Group #</th>
<th>Participants Recruited from:</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Baby Clothes Donation Program</td>
<td>11</td>
</tr>
<tr>
<td>2</td>
<td>Latino Health Fair</td>
<td>8</td>
</tr>
<tr>
<td>3</td>
<td>Church Mothers’ Group</td>
<td>11</td>
</tr>
<tr>
<td>4</td>
<td>ESL Program Tutees</td>
<td>5</td>
</tr>
<tr>
<td>5</td>
<td>Church Food Service</td>
<td>3</td>
</tr>
<tr>
<td>6</td>
<td>Domestic Violence Support Group</td>
<td>8</td>
</tr>
</tbody>
</table>

The use of a convenience sample limits the extent to which these findings can be generalized. After Institutional Review Board (IRB) approval was obtained, Latina women were recruited from various locations around Durham County. Participants were recruited through word of mouth, churches, local social service agencies, a health fair, and an ESL tutoring program.

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2 This restriction was placed to facilitate the IRB approval process; it is more difficult to get permission to work with minors
3 Some of the focus groups included participants who did not meet the three criteria; however, the views of these individuals are not included in this thesis
program. Participation was voluntary and those who chose to attend the focus groups may differ in some way from those who chose not to. For example, it is possible that undocumented Latina mothers were less likely to choose to attend a discussion out of fear of being discovered and deported. The focus group discussions lasted about one hour each and were conducted in Spanish to allow participants who were not comfortable with English to freely express themselves. The groups were conducted in community locations that were convenient and familiar to participants, and most of the discussions were held during their regular meetings. Participants were offered childcare and refreshments as compensation, and those who participated in Group 1 were also given items of clothing from the organization’s donation closet.

Focus group participants were first asked to fill out a one-page survey (in Spanish), which collected general demographic information (see Appendix A). All participants possessed at least basic literacy skills and were able to fill out the survey independently. The survey responses indicated that participants had understood the majority of the questions, though some misinterpreted the questions “how many daughters do you have” and “how many sons do you have” to be asking for the same response. Each participant was assigned a number that linked the information in the survey to the views they expressed during the discussion to protect their confidentiality.

After the survey was completed, participants were read a two-page document on the HPV vaccine that was produced in Spanish by the CDC (see translated version in Appendix C). All groups indicated high comprehension of this information; after the reading was completed, many participants asked questions that other mothers in their group were able to answer. Participants were then asked a series of open-ended questions on how they thought the vaccine should be distributed (see Appendix B). The discussions were recorded using an iPOD and microphone and
were transcribed following each focus group. Written notes were also taken. The focus group methodology produced data and insights that would not necessarily have emerged in a non-group setting (Morgan, 1988), revealing a range of opinions (Casey & Krueger, 2000) on ethical HPV vaccine distribution. Furthermore, after six focus groups, a reasonable level of saturation was reached; by then new ideas were no longer emerging in significant quantity from discussions (Casey & Krueger, 2000).

However, the focus group method limited the ability to quantify results and state with confidence the number of women who preferred a particular view. Using 1:1 interviews would have facilitated quantifying categorical answers about vaccine distribution views; however, using interviews would have significantly limited the sample size due to the time and resource constraints of the researcher. One-on-one interviews would also have lacked the group interaction that was necessary to stimulate debate over the different ethical dilemmas and help participants think through their reasoning and views.

An open-ended survey could also have been more effective in obtaining quantifiable responses; however, this method would have excluded women with a limited ability to read or write, who comprised a large part of the study population. Finally, the Latino community is a hard-to-reach population. Many of the mothers in the sample did not have email addresses or even working telephone numbers. They also had limited access to transportation and were busy taking care of their children. Given these constraints, it would have been extremely difficult to get participants to fill out long surveys on their own time and return them at a later date.

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4 Though information on participants’ ability to read or write was not directly collected, it was evident from the surveys that although many mothers possessed basic literacy skills, they would not have been able to independently complete a lengthy, in-depth survey.
Data Analysis and Findings

Demographics of Sample

The background information surveys collected during five\(^5\) of the focus groups were compiled to produce a demographic profile of both the sample as a whole and each group individually. The number of participants who self-identified with each characteristic is listed in Table 2. Blank responses or questions that were clearly misunderstood (ex. multiple boxes checked for one question, same answer for question about daughters and question about sons) were not included in the analysis. Though single questions were disregarded, entire surveys were not excluded due to an invalid response to one or more questions.

Table 2: Demographic Characteristics of Study Participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Overall Sample</th>
<th>Group 1</th>
<th>Group 2</th>
<th>Group 3</th>
<th>Group 4</th>
<th>Group 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants:</td>
<td>38</td>
<td>11</td>
<td>8</td>
<td>11</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Work outside of house</td>
<td>10</td>
<td>N/A(^5)</td>
<td>N/A</td>
<td>4</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Children</td>
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<td>Have only daughters</td>
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<td>2</td>
<td>3</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Have only sons</td>
<td>9</td>
<td>-</td>
<td>3</td>
<td>3</td>
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<td>1</td>
</tr>
<tr>
<td>Have both daughter and sons</td>
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<td>5</td>
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<td>3</td>
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<td>Mexico</td>
<td>28</td>
<td>8</td>
<td>8</td>
<td>7</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>El Salvador</td>
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<td>-</td>
<td>-</td>
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<td>Honduras</td>
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<td>2</td>
<td>-</td>
<td>1</td>
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<td>Colombia</td>
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<td>-</td>
<td>-</td>
<td>1</td>
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<td>Uruguay</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>1</td>
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<td>-</td>
</tr>
</tbody>
</table>

\(^5\) Background information surveys were not collected for Group 6 due to time constraints. Group 6 was composed of 11 participants who were attending a domestic violence support group

\(^6\) This question was not asked on the Group 1 or Group 2 surveys
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Overall Sample</th>
<th>Group 1</th>
<th>Group 2</th>
<th>Group 3</th>
<th>Group 4</th>
<th>Group 5</th>
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<tbody>
<tr>
<td>Length of time in US</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>0-5 years</td>
<td>6</td>
<td>4</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>6-9 years</td>
<td>13</td>
<td>4</td>
<td>1</td>
<td>5</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>10+ years</td>
<td>17</td>
<td>3</td>
<td>5</td>
<td>5</td>
<td>1</td>
<td>3</td>
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<tr>
<td>Highest level of education attempted</td>
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<td></td>
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<td>3</td>
<td>1</td>
<td>5</td>
<td>-</td>
<td>-</td>
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<td>4</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>1</td>
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<tr>
<td>High School</td>
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<td>2</td>
<td>4</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>University</td>
<td>3</td>
<td>2</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Religiosity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not religious at all</td>
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<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>A bit religious</td>
<td>23</td>
<td>7</td>
<td>7</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Fairly, but not too religious</td>
<td>9</td>
<td>2</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Very religious</td>
<td>2</td>
<td>1</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Political Preference</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conservative</td>
<td>5</td>
<td>3</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>In the middle</td>
<td>13</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>5</td>
<td>-</td>
</tr>
<tr>
<td>Liberal</td>
<td>13</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Other/Not Interested in politics</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

The demographic trends observed in the sample were as follows. Most participants were from Mexico and had been living in the United States for more than five years. Very few mothers had reached university-level education, though the majority had begun middle or high school. The majority of mothers were only “a bit religious,” with very few self-identifying as “very religious” or “not religious at all.” Finally, few mothers cited a conservative political preference; most identified either as “in the middle” or “liberal.” Few notable differences existed between the groups. The only observed variations were that Group 1 had the highest proportion
of participants who had been living in the United States for less than five years and Group 3 had the highest proportion of participants stating they were more than “a bit religious.”

**Durham Latina Mothers’ Perspectives on Ethical HPV Vaccine Distribution**

In order to investigate the perspectives of Latina mothers living in Durham on the ethical dilemmas surrounding HPV vaccine distribution, transcripts from the six focus group discussions were analyzed for patterns. Participants’ initial knowledge and perceived importance of HPV and the vaccine are first presented. Subsequently, Latina mothers’ views are reported for each of the four ethical dilemmas observed in the literature:

1. **School Mandate Issue**
2. **Vaccinating Males as well as Females**
3. **Vaccinating Adolescents Without Parental Consent**
4. **Immigrant Requirement**

Finally, the opinions of focus group participants on the appropriate age of HPV vaccination and who should pay the cost of the vaccine are described. Other issues of importance to Latina mothers are also presented.

The relative importance participants ascribed to different issues was represented by the number of groups across the total sample who mentioned a particular view or supporting reason. Only verbal responses were included in this analysis; participants who nodded in agreement, for example, were not counted. There are several limitations to this method of data analysis:

a) Importance of a particular view or reason within a group is not represented.

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7 Initial knowledge includes responses to questions asked before participants were read the CDC information sheet on the HPV vaccine
b) Many participants changed their opinions throughout the discussion; however, all opinions voiced in a particular group are represented.

c) A few mothers inevitably dominated each focus group. The views of the women who did not contribute to the discussion are not known, and it is possible that they had completely different opinions to the rest of the group.

d) Some of the information conveyed by the participants was inevitably lost in translation. Certain nuances expressed in Spanish during the focus groups are not expressed in the English report.
A. Initial Knowledge and Perceptions of HPV and the Vaccine

I. Perceived Importance of HPV

HPV was not high on the list of diseases mothers worried about for their children (see Figure 1.1). Across the five groups asked what health issues concerned them, only one participant mentioned HPV. Sexually transmitted infections, however, were mentioned in three groups, with AIDS being specified in two of them. Contagious diseases were also mentioned in three groups and the flu was cited in two. Fevers and cancers were each mentioned in one group.

Figure 1.1: Children’s Health Issues of Concern to Participants

Graphs with a maximum y-value of 5 represent answers to questions only asked of 5 focus groups.

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8 Graphs with a maximum y-value of 5 represent answers to questions only asked of 5 focus groups
II. Initial HPV Knowledge

Although at least ten of the women in the sample knew nothing about HPV, the six groups were able to mention several things about the virus (see Figure 1.2) Four of the groups knew the virus could cause cervical cancer and three knew HPV was sexually transmitted. Three of the groups also knew that the virus could be present without symptoms, and two groups linked it to women, with some participants believing it to be more severe in females. None of the groups mentioned that HPV could cause genital warts.

Figure 1.2: Participants’ Initial HPV Knowledge
III. Initial HPV Vaccine Knowledge

At least five mothers in the sample did not know anything about the HPV vaccine. Some women had heard about it on TV or through clinics. Four groups knew that the vaccine prevented cancer, and two groups specifically cited cervical cancer (see Figure 1.3). Three groups believed the vaccine was for adolescents and two of the groups thought it was for girls. One group had heard of the vaccine being given in schools. Mothers whose daughters had been vaccinated were better informed; one such participant knew that the vaccine existed in three injections, which were administered at 0, 2 and 6 months.

Figure 1.3: Participants’ Initial HPV Vaccine Knowledge
B. Perceptions of the Four Ethical Dilemmas

I. Should the HPV Vaccine Be Mandated in Schools?

Most of the mothers in the sample were against requiring the HPV vaccine for entry into sixth grade\(^9\) (see Figure 2.1). These mothers felt that HPV vaccine distribution should be “much less like a law,” and more about raising awareness.

**Figure 2.1: Participants’ Views on Mandating the HPV Vaccine for School Entry**

![Bar chart showing support and opposition to the mandate]

The most cited reason for opposing a school mandate was a belief in parental, family and/or individual autonomy (see Figure 2.2). Participants stated that vaccination should be a parental or personal decision, not one made by the government. They believed that the need for

\(^9\) The views of Group 1 on the four ethical dilemmas were inconsistent with those of the other groups. The reason for this difference is unknown; however, it is possible that sample bias (possibly the shorter length of time the women in this group had been in the US) played a role.
the vaccine “depends on each person, on each girl [and] on each family,” adding that girls who are not yet sexually active should not be forced to get the vaccine. Of those in favor of the mandate, participants in three groups countered that a school requirement would protect girls from cancer (see Figure 2.3). One participant thought it was good to look for alternate methods of prevention and another said, “If they do not make us [vaccinate our children], we will not do it.”

Mothers in three groups also believed not enough is known about the HPV vaccine to mandate it, worrying about possible secondary effects and the lack of long-term studies. Two of the groups believed it would be better to inform parents about the vaccine than to require it in schools. They said if parents were aware of the vaccine’s benefits, they would “want to protect their daughters.” Those who were in favor of requiring the vaccine in schools, however, argued that a mandate would force parents to inform themselves, as a Gardasil fact sheet would be sent home with their children.

Two groups worried that mandating the vaccine would encourage promiscuity. Those who favored a school requirement countered that vaccinating girls is not inciting them to have [sexual relations]…instead the vaccine is to prevent a disease in the future.” Some of the mandate supporters also believed that girls were already sexually active at 11-12 years of age and the vaccine could protect them. Others said irresponsible behavior could be prevented with sound sexual education. One of the groups against the mandate also talked about the fact that the HPV vaccine does not prevent 100% of cervical cancers. Finally, women in one group against the school mandate stated that HPV was not contagious in the classroom. One group in favor of the requirement, however, believed that the HPV vaccine was similar to any other medical

10 All quotations were stated in Spanish by the focus group participants and were translated by the author
procedure required for school entry and should be placed on the vaccination schedule for children.

**Figure 2.2: Reasons Cited in Opposition of a School Mandate**

![Bar chart showing reasons cited in opposition of school mandates. The chart indicates the number of groups for each reason.

- Autonomy: 4
- Too many unknowns: 3
- Better to inform than require: 2
- Would encourage promiscuity: 1
- Doesn't prevent 100% of cervical cancers: 1
- HPV vaccine not for general health: 1]
II. Should Males Be Vaccinated?

None of the women in the sample expressed opposition to vaccinating males as well as females. Four groups favored male vaccination to protect boys and men from HPV and related diseases (See Figure 3.1), while three groups reasoned that males should be vaccinated to protect their female partners. Two groups believed “both women and men have the same rights” and should therefore be given equal opportunity to the HPV vaccine. One group felt men should also
take responsibility for sexual health, especially since machismo\textsuperscript{11} is so prevalent among Latino men.

Figure 3.1: Reasons Cited in Support of Male Vaccination

III. Should Children Under 18 Be Vaccinated Without Parental Authorization?

Most participants were against administering the vaccine to children under 18 without their parents’ permission (see Figure 4.1).

\textsuperscript{11}Machismo is a cultural belief often observed in Latino cultures; it emphasizes the expression of masculinity by aggressiveness, control over the woman, and hyper sexuality (Ingoldsby, 1991).
Four of the focus groups supported a parental consent requirement. They felt parents had a right to be informed about their children’s medical care and a responsibility to educate them about HPV before they were vaccinated (see Figure 4.2). They also thought allowing adolescents to access Gardasil without parental authorization would promote children engaging in activities “they don’t want their parents to know about.” One group who opposed to requiring parental permission, however, said girls who keep their sexual activity a secret must still be protected from HPV, especially if their parents would not authorize their vaccination. Furthermore, they said some fathers are very machista and might not permit their daughters to get the vaccine.

---

12 Act in accordance with a machismo ethos
Two groups believed children under 18 were not mature enough to make the decision to receive the vaccine alone and parental consent should therefore be required. One group countered that girls over the age of 15 would be capable of deciding for themselves, and another said children needed to be able to make such decisions, because if their parents were to die the next day they would need to be informed enough to reach a conclusion alone. Finally, one group cited safety in support of requiring parental consent, saying that a girl who was vaccinated without her parents’ knowledge could have a dangerous reaction to the vaccine while walking home and the parent would be unable to help.

Figure 4.2: Reasons Cited in Support of Requiring Parental Consent for HPV Vaccination
IV. Should the HPV Vaccine be Required for Immigrants?

Most participants opposed the HPV vaccine requirement for US green card applicants (see Figure 5.1).

Figure 5.1: Participants’ Views on Requiring the HPV Vaccine for Immigrants

Discrimination was the main reason cited in opposition to a requirement that forces immigrants, but not US citizens, to receive the HPV vaccine (see Figure 5.2). Participants in three of the six groups believed immigrants and Americans should be treated equally. One group in favor the immigrant mandate, however, said the policy should be viewed as an opportunity, not discrimination. These mothers said they would be unable to receive the vaccine in their home countries due to the high cost of new vaccines and the lack of an advanced health system.
Other reasons for opposing the immigrant requirement included those previously cited in the school mandate controversy. One group said Gardasil is “a preventative vaccine, not a vaccine that falls under general health,” although one participant countered that the HPV vaccine was like all other medical citizenship requirements. One group opposed the immigrant mandate because Gardasil does not prevent 100% of cervical cancers. Another group felt there were still too many unknowns about how long Gardasil would protect against HPV and how it would affect children of different ages. One mother feared the vaccine was being tested on immigrants. Participants in one group opposed the immigrant requirement because they believed in personal autonomy. These mothers thought it was unjust that immigrants who needed to live in the United States should be forced to get a vaccine they did not want to, especially since “there are other ways of protecting yourself” against HPV. Finally, one group worried about encouraging promiscuity and “giving…children the option to do many things that they should not have done if they hadn’t gotten the vaccine.”
C. Age and Cost of HPV Vaccination

I. What is the Appropriate Age for Vaccination?

Three of five groups believed the vaccine should be administered after development, because girls would know more about STIs by then through school and friends (see Table 3). Participants disagreed, however, on what constituted development. Two groups preferred that girls be vaccinated after the onset of sexual activity, which these women felt was at the age of 12-13 years. Participants in two groups also said the vaccine should be administered at the age of 15, while one group mentioned the onset of menstruation as an indication of development.
Two groups talked about the vaccine being administered “as early as possible.” The HPV vaccine can only be given to girls nine years of age and older. Participants thought it was important to look early on for as many ways as possible to protect against cervical cancer. The women in the domestic violence support group (Group 6) also talked about protecting children who could be abused at an extremely young age. Two groups mentioned vaccinating girls after the age of 18, at which point they could decide to receive the vaccine themselves based on their level of sexual activity. One participant also mentioned that Latina mothers strive to keep their daughters conservative, and vaccinating them before the age of 18 could make these girls more liberal.

Table 3. Participants’ Perceptions of the Appropriate Age of Vaccination

<table>
<thead>
<tr>
<th>View</th>
<th>Reasoning</th>
</tr>
</thead>
<tbody>
<tr>
<td>After development → after onset of sexual activity, age of 15, after menstruation begins</td>
<td>• Girls would understand sexual health aspect of HPV vaccine</td>
</tr>
<tr>
<td>As early as possible → 9 years of age</td>
<td>• Protect girls, including victims of abuse</td>
</tr>
<tr>
<td>After age of 18</td>
<td>• Girl could decide for themselves about vaccination • Keep daughters conservative</td>
</tr>
</tbody>
</table>

II. Who Should Pay the Cost of Vaccination?

The majority of women believed “whoever wants the vaccine to be administered should pay.” If the vaccine was mandated, four of six groups thought the government should pay for it (see Figure 6.1). If vaccination was voluntary, five groups felt the family of the child in question should pay if they were able to. These mothers believed “parents are responsible for the health of [their] children” and “shouldn’t always say that the government should pay,” especially since Latinos are often perceived as draining public resources. Two groups, however, said insurance or Medicaid should pay for the vaccine and one group wanted the government to fund the entire
cost, since Gardasil is administered to adolescents. Three groups believed “the cost of the vaccine will be an obstacle to the Latino community.” Four groups mentioned that some sort of subsidy should be available.

Figure 6.1: Participants’ Views on HPV Vaccine Costs

D. Other Issues of Importance to Latina Women

I. Vaccine Acceptance:

Most participants had high acceptance of the vaccine in general. Though there was controversy over the optimal method of distribution, those who opposed a mandate did so largely
because they thought a voluntary vaccination program was a better option. The majority of those who said they would not give the vaccine to their daughters also said Gardasil should continue to be distributed. These mothers reasoned that it is good to explore ways to prevent cancer, vaccine manufacturers have already spent millions of dollars on research and someone is always going to want to get vaccinated. Women in one group also brought up that the vaccine should be available for women over 26 years of age, because some people believe in virginity until marriage and some have simply not had any sexual partners before then. Mothers in two of the focus groups mentioned that women with only one partner should not need to be vaccinated; however, other participants convinced them that nobody can be sure their partner is not having an affair.

II. The Need for Information

A major theme across groups was a need for more information. Participants worried about vaccine safety, including potential side effects and the risks of vaccinating girls at different stages of development. Two groups felt that if parents were given more information about the HPV vaccine, controversies like vaccinating males and vaccinating children without parental consent would become non-issues, as parents would want their sons and daughters to be protected. Mothers in two groups also stated that their parents had never talked to them about sexual health issues. They therefore felt a responsibility to educate their children on such topics.

III. Sources of Information

When asked where they would look for advice about vaccinating their children, women in all six groups cited doctors as the best source, with three groups specifying a pediatrician and two indicating clinics. When asked about other sources, most women still said the best information would come from a doctor. Three groups also said their husbands’ insight would be
important, although many of those participants said the final decision would be the mother’s, because the father was not as well-informed about the children. One woman said her husband’s permission would be necessary to vaccinate her daughters, and another said her husband’s opinion would be of equal importance since vaccination was the responsibility of both parents. Many women said they would also look for information on TV and in newspapers, though one woman said she would be wary of these sources, because the media can manipulate information.

IV. Vaccinating own daughters

Participants were not asked if they would vaccinate their own daughters; however, three groups raised this issue on their own. Women in all three of the groups said they would not vaccinate their own daughters yet, because Gardasil does not protect against 100% of cervical cancers, worries about encouraging promiscuity and a fear that the vaccine has harmful secondary effects. Furthermore, many preferred to educate their daughters about STI prevention instead of vaccinating them. Mothers in two groups said they would vaccinate their daughters to prevent disease. One mother worried about the vaccine’s side effects also, but felt “there is nothing worse than my daughter getting cancer. Everything else would be less risk.”
Conclusions:

Two major conclusions can be derived from this study. First, this research adds to the very limited body of literature that currently provides information on Latino and minority groups’ perceptions of HPV vaccine distribution. Second, this project demonstrates the need to talk to members of populations like the Latino community before enacting policy that will affect them. Research aimed at understanding their views and the reasoning they use to arrive at these views, will be important. This is not to say that Latino or any other group’s views should sanction or prevent the implementation of a certain form of distribution (such as a school mandate); however, policy makers must be able to predict the concerns that will arise from these populations if a particular legislation is drafted.

In order to provide some insight on how this research fits into the greater debate of ethical and effective Gardasil distribution, the Latino mothers’ views expressed in this study will be compared to findings from previously published research. The following sections will first discuss HPV vaccine acceptability in Latino populations, and subsequently perceptions of the four ethical dilemmas across cultures. I will then offer some hypotheses as to why discrepancies exist between this study and preexisting literature. Finally, the potential for the HPV vaccine to play a role in reducing cervical cancer incidence in the Latino community will be discussed, and suggestions for future research will be presented.

**HPV Vaccine Acceptance Among Latinos**

The findings from this study (in Durham, NC) concurred with previously published data showing high acceptance of STI vaccines in the Latino community (Blair, 2009). Though the participants in Durham, NC supported the general availability of the HPV vaccine, they
demonstrated significantly lower desire to vaccinate their own daughters. Previous studies, however, indicated Latina women were more likely than Whites to express an intention to vaccinate their daughters (Constantine, et al., 2006; Watts, 2009). It is possible that the type of information each sample of women received about the HPV vaccine influenced their views. Women in the Durham focus groups were read a CDC-issued two-page long information sheet about the HPV vaccine. The Watts (2009) paper does not mention providing information on the vaccine to participants and the Constantine, et al. (2006) study only read survey participants a short paragraph on the HPV vaccine.

The Four Ethical Dilemmas

I. School Mandate Issue

The majority of Latina mothers in the Durham, NC sample opposed a school requirement for HPV vaccination. Many of those in favor of the mandate also supported voluntary vaccination, arguing that they could simply elect to vaccinate their own daughters. The reasons Durham focus group participants cited in opposition of compulsory vaccination were closely aligned with the literature (see Table 4). Latina women in Durham most frequently referred to autonomy, which was also mentioned most in the literature review (10 out of 14 studies cited this reason). Furthermore, the argument that too many unknowns surround the HPV vaccine was cited in three Durham focus groups and appeared in eight studies from the literature.

Worries about a school mandate encouraging promiscuity appeared in five studies, but only one Durham focus group. As well, the fact that the HPV vaccine is not for general health or casually transmitted diseases was cited in nine studies, but only in one Durham focus group. Latina mothers in Durham also mentioned it was better to inform parents about Gardasil than
require the vaccine (two focus groups); however, this view was only cited in one previous study. Finally, Durham Latina mothers mentioned the fact that Gardasil does not protect against 100% of cervical cancers to oppose a school mandate in one focus group; however, none of the studies examined throughout the literature review cited this.

<table>
<thead>
<tr>
<th>Reason for Opposing a School Mandate</th>
<th>Number of focus groups cited in</th>
<th>Number of studies in the literature review cited in</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autonomy</td>
<td>4</td>
<td>10*</td>
</tr>
<tr>
<td>Too many unknowns</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Better to inform than require</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Would encourage promiscuity</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>HPV vaccine not for general health</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>HPV vaccine does not protect against 100% of cervical cancers</td>
<td>1</td>
<td>-</td>
</tr>
</tbody>
</table>

* 14 studies were examined on the school mandate issue throughout the literature

Given the similarity of views cited by Durham Latina mothers to those expressed in the literature, it does not appear that cultural factors play a large role in perceptions of the school mandate issue. This might be explained by the fact that the majority of Latina mothers in the Durham sample had been in the US for over five years, and had perhaps modified their views during the process of assimilation. Mothers in the Durham sample never mentioned the disparity in cervical cancer incidence that exists between ethnic groups; it is possible they did not know Latinos bear the highest burden of disease. Finally, religious arguments were not cited in the Durham focus groups to oppose the idea of an HPV vaccine mandate. The majority of women in the Durham sample were only “a bit religious,” though 14 of them were recruited through churches.
II. Vaccinating Males

Participants in all of the Durham focus groups favored the availability of Gardasil to both males and females. Protecting men was the most cited reason among Durham Latina women; however, this argument only appeared in two out of the 12 studies examined in the literature review (see Table 5). Protecting women was cited in three Durham focus groups and six studies, and the fact that both men and women should be responsible for sexual health was cited in one focus group and three studies. Latina women stated in two Durham focus groups that both genders should be afforded an equal right to vaccination; however, the literature did not mention this argument. Finally, the cost-effectiveness of a male vaccination campaign was discussed in the literature (mostly by academics), but was not discussed in the Durham focus groups.

Table 5. Male Vaccination Issue: Durham Mothers’ Views As Compared to Literature

<table>
<thead>
<tr>
<th>Reason for Supporting Male Vaccination</th>
<th>Number of focus groups cited in</th>
<th>Number of studies in the literature review cited in</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protect men</td>
<td>4</td>
<td>2*</td>
</tr>
<tr>
<td>Protect women</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Both genders should have equal opportunity to protection from HPV</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Both sexes should take responsibility for sexual health</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

* 12 studies were examined on the issue of male vaccination throughout the literature

Durham Latina mothers’ views on male vaccination were similar to the arguments referenced in literature. Latino views on this ethical dilemma may relate somewhat to cultural factors. Though it was also cited in the literature (where most studies did not focus on Latinos), the Durham mothers’ argument that vaccinating both sexes would imply equal responsibility for sexual health was partly influenced by the machismo they had experienced. Mothers mentioned
that men often wanted women to take sole responsibility for the couple's sexual health and felt that vaccinating boys could teach them from a young age that men and women should be treated equally.

III. Parental Consent Issue

Most women in the Durham sample believed parental consent should be required for adolescent access to the HPV vaccine. Latina mothers in four focus groups and two previously published studies (out of the four examined) stated parents are responsible for the health of their children. Mothers in two Durham focus groups also believed children were not mature enough to decide about their vaccination, a view that was cited in one study. Concern for the safety of children immediately following vaccination was cited in one focus group and one study.

Once again, as the issues raised by Durham Latina women were similar to those broached in the literature, cultural factors seemed to play a small role in mothers’ views on the parental consent issue. Latina mothers in Durham emphasized feeling a responsibility to inform and protect their children, partially due to the fact that sexual health issues are not as openly discussed in their home countries and their parents had not informed these women when they were young. Furthermore, on the maturity issue, one Durham group mentioned that children over the age of 15 would be capable of making the decision and should therefore be able to consent to vaccination without their parents’ authorization. The age of 15 marks the transition from childhood to womanhood in Latino cultures, suggesting that mothers’ views were somewhat influenced by cultural factors.
IV. Immigrant Mandate

The majority of Durham Latina mothers were against the immigrant requirement. The most cited reason (in three focus groups) was a belief that the mandate was a discrimination of immigrants, a view also cited in three of the five studies examined on this ethical dilemma (see Table 6). The other five reasons cited by participants in the Durham focus groups were the same as the arguments referenced in opposition to the school mandate. In the literature, autonomy was cited in one study, the fact that there may be too many unknowns about the HPV vaccine was cited in two and the fact that Gardasil is not for general health was also cited in two studies. The Durham Latina mother arguments that an immigrant mandate could encourage promiscuity and is unjust because Gardasil does not protect against 100% of cervical cancers were not cited in the literature.

Table 6. Immigrant Requirement Issue: Durham Mothers’ Views Compared to Literature

<table>
<thead>
<tr>
<th>Reason for Opposing the Immigrant Requirement</th>
<th>Number of focus groups cited in</th>
<th>Number of studies in the literature review cited in</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discrimination toward immigrants</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Autonomy</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Too many unknowns</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>HPV not a general health issue</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Encourage promiscuity</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Vaccine does not protect against 100% of cervical cancers</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Injustice of cost barrier</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Immoral to vaccinate without educating</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Gender discrimination</td>
<td>-</td>
<td>1</td>
</tr>
</tbody>
</table>

* 5 studies were examined on the issue of the immigrant mandate throughout the literature
It is possible some of the discrepancies between the literature and participants’ views relate to the fact that Durham Latina mothers and their daughters actually form part of the population that is affected by this requirement. The increased promiscuity argument could also relate to culture, as some mothers mentioned Latina women prefer to keep their daughters conservative. Furthermore, Latina mothers did not mention the cost of the vaccine being an unfair barrier to immigrants, though three of the five studies in the literature review did. This could relate to the disempowerment the focus group participants showed at times. For example, one mother stated immigrants who need to be in the US would have no choice but to get vaccinated, even if they did not want to receive the HPV vaccine.

**The Potential for the HPV Vaccine to Reduce Cervical Cancer among Latina women:**

Though Durham Latina mothers showed high levels of general acceptability toward the HPV vaccine, the majority of participants said they would not vaccinate their daughters at this point. Most mothers also favored conservative distribution policies, such as opposing mandates and believing parental consent should be required for adolescents to receive the vaccine. Latina mothers did, however, support the continued distribution of Gardasil and thought it should also be available to males.

If education campaigns or other programs can increase Latina mothers’ acceptability of the vaccine for their own children, Gardasil could play a role in lowering cervical cancer incidence in this community. Since many Latina women do not have access to Pap tests for cervical cancer screening (Byrd, et al., 2007), the HPV vaccine has the potential to reduce the disease burden that currently falls disproportionately on minority populations, and especially Latinos (Byrd, et al., 2007). Increasing the amount of information and education about the HPV
vaccine targeted at the Latino population, taking into account cultural and language barriers that may exist, could have a large impact on Latina mothers’ views. Participants in the Durham focus groups stated that if mothers knew more about Gardasil, they would want their daughters to be protected. This would make some of the ethical dilemmas discussed in this paper non-issues.

If this view holds true for parents not included in the Durham sample, a voluntary distribution system could result in widespread and accepted HPV vaccination within the Latino community. However, the affordability of the vaccine will need to be explored further. Some sort of subsidy will likely be needed if the vaccine is to be administered on a large scale to Latinos, as mothers in the Durham focus groups said the vaccine was too expensive, especially for women who have multiple daughters. Affordability will be central to Gardasil’s use among Latinos; if Latinos cannot afford to be vaccinated, the HPV vaccine cannot be used to reduce cervical cancer in this population, even if Latina mothers believe it will protect their daughters.

**Suggestions for Future Research**

Additional studies are needed to clarify which findings and consequently conclusions from this study hold true in other sample populations. Future research should attempt to secure a larger sample size and quantitatively test the significance of some of the factors indicated to influence Latino perceptions of the ethical dilemmas surrounding HPV vaccine distribution. Such factors could include migratory status, length of time living in the US and age at which one immigrated. The results could provide insight on how Latino views may change as immigrants assimilate and acculturate\(^{13}\) to life in the US. Furthermore, the role of having lost relatives to cervical cancer should be explored, as two of the women in the Durham focus groups mentioned

\(^{13}\) Acculturation is “the process of incorporating aspects of the mainstream (host) culture into each individual’s repertoire of behaviors” (Aguirre-Molina, et al., 2001).
this when talking about why they supported a school mandate to protect girls. Additionally, Latino parents’ perceptions of their children’s risk for cervical cancer could be investigated. Finally, examining Latino access to information on the HPV vaccine and the role this plays in views on ethical Gardasil distribution could provide some indication on where to target educational efforts.

Finally, further research should expand the scope of this project by investigating HPV vaccine perceptions among other populations who would be affected by distribution policies. For example, the African American perspective will be particularly important in Durham, given that this group makes up close to 40% of the County’s population (US Census Bureau, 2006-2008). Furthermore, incorporating the views of other stakeholders, such as children, healthcare personnel, and policy makers, could contribute to the growing body of literature of perceptions on ethical and effective HPV vaccine distribution.
Appendix A: Preliminary Survey

1. How many sons do you have? How old is each one?

2. How many daughters do you have? How old is each one?

3. What country are you from?

4. For how long have you live in the US?

5. How many years of education have you completed?

6. How religious are you?

□ Very religious
□ Fairly, but not too religious
□ A bit religious
□ Not at all religious

7. Is your political preference:

□ Liberal
□ Conservative
□ In the middle
□ Other

8. Do you work outside of the house?\textsuperscript{14}

□ No
□ Yes

\textsuperscript{14} This question was not included for Groups # 1 or # 2.
Appendix B: Focus Group Questions

1) Let’s introduce ourselves – tell us a bit about your family and yourself.

2) What health conditions are you most concerned about for your children?

3) What do you know about the human papillomavirus (HPV)?

4) What have you heard about the HPV vaccine?

Pass out handouts and read CDC vaccine info sheet

5) Who do you think should receive this vaccine and why?
   PROBE:
   A. Boys, if it is shown to be safe and effective for them?
   B. Girls without the permission of their parents?
   C. At what age should the vaccine be administered?

6) Should anyone be required to receive the vaccine? Why?
   PROBE:
   A. Should it be required for school entry?
   B. Should immigrants be required to get the vaccine (even if American citizens are not required to)?
   C. Should anyone be able to opt-out of vaccination if the vaccine is mandated? For what reasons?

7) Who should pay for the vaccine? If it is mandated? If it is optional?
   PROBE:
   A. Parents
   B. Insurance
   C. Public funding

8) Where would you look for information about whether or not your child should receive the HPV vaccine?
   PROBE
   A. Doctor
   B. Teachers
   C. Spouse
   D. Other family members
   E. Media: TV/radio/newspaper/pamphlets

9) After participating in the discussion today, if you could recommend a policy to the Governor of North Carolina terms of who should be able to or be required to receive the HPV vaccine, what would you recommend? What reasons would you use as support for your recommendation?

10) Is there anything else you would like to discuss about this topic?
What is HPV and how does it affect health?

HPV is a virus commonly sexually transmitted. There are 40 strains of HPV that can infect the genital regions of men and women. Almost all of sexually active adults contract HPV sometime in their lives, though in the majority of cases, they don't know because in general, HPV does not cause symptoms and goes away on its own. Nevertheless:

- Some strains of HPV can cause cervical cancer in women
- Other types of HPV can cause genital warts

The American Cancer society estimates that in the US, more than 9,700 women were diagnosed with cervical cancer in 2006, and 3,700 died of the disease.

It is estimated that around one million sexually active people in the US have visible genital warts.

- The HPV vaccine is recommended for girls between 11-12 years of age, and it can also be administered to girls aged 9 years and older. This vaccine is also recommended for girls and women between 13 and 26 years of age, who have not received the 3 doses.
- Ideally, girls should be vaccinated before initiating sexual activity, as the vaccine is more effective in girls or women who have not contracted any strains of HPV against which the vaccine protects.
- In girls and women who have not been infected with any of these 4 strains of HPV, the vaccine has shown almost 100% effectiveness in preventing precancers of the cervix, vulva and vagina, as well as genital warts that are caused by these strains of HPV.
- The vaccine is administered in 3 injections over a period of 6 months. Once your daughter has received the first injection, she must return after 2 months and 6 months to receive the second and third doses, respectively. It is very important that your daughter receive the 3 doses, as it is not known to what extent she will be protected if she only receives one or two injections.
- The vaccine does not cause serious secondary effects. The most common side effect is pain at the injection site.
- Each dose of the HPV vaccine costs $120 ($360 for the three doses). It is possible to receive the vaccine at a lower price or for free through your medical insurance or federal or state programs. Your doctor’s office or the local health department has more information about these programs.
Girls who have received this vaccine still need to get regular pap smears during the 3 years after initiating sexual activity (or after turning 21 years old), as the vaccine does not protect against all cervical cancers. Also, once initiating sexual activity, girls need to protect themselves through responsible sexual health behaviors, as the vaccine does not prevent all types of genital warts or sexual transmitted infections (STI).

**Other ways to prevent HPV and related diseases**

- The vaccine prevents against the strains of HPV that most commonly cause cervical cancer and genital warts. However, the only certain way to prevent all strains of HPV is abstaining from all sexual activity.
- Condoms can reduce the probability of contracting HPV or related diseases if used correctly every time one engages in sexual relations. However, condoms do not protect completely against HPV, as HPV can infect areas that the condom does not cover. Even people with a single sexual partner can contract HPV in their lifetime, if their partner is infected.
- Regular pap smears and the following required treatments can prevent the majority, but not all, cervical cancers.

**Is there a vaccine for boys, men or women over 26 years of age?**

It is still unknown if this vaccine is effective and safe for boys and men, or for women over 26 years of age. Clinical studies are currently being conducted with men and women over 26. The FDA will consider approving the vaccine for these groups when it is shown to be safe and effective.

Centers for Disease Control (CDC): 1-800-CDC-INFO (1-800-232-4636) and 1-888-232-6348 (line for people with hearing problems) where they can answer your questions in English or Spanish 24 hours a day, 7 days a week.

The National Cancer Institute's Cancer Information Service (CIS, because of its English abbreviation): 1-800-4-CANCER (1-800-422-6237) and 1-800-332-8615 (line for people with hearing problems) where information specialists can answer your questions in English or Spanish from 9:00am to 4:30pm.

Spanish version approved by CDC Multilingual Services


should be vaccinated. (POINT/COUNTERPOINT)." *Skin & Allergy News* 40(6): 18(1).


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