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# **Divergent Discourses: Medical and Cultural Understandings of Latina Reproductive Health in the Era of Gardasil**

**Cindy Camacho**

**Advised by Professor Daphne John**

## **Abstract:**

In 2006, the vaccine Gardasil was distributed in the United States. Gardasil was created to block four strains of human papilloma virus (HPV), two of which cause about 70% of cervical cancer, and two others that cause 90% of genital warts. Although the Gardasil vaccine is an advance in the fight against cervical cancer, reports show that Latinas have low vaccination rates of Gardasil, disproportionately higher rates of cervical cancer and that cervical cancer screening rates are much lower for Latinas than women of other ethnicities. I argue that there is a disconnect between the Latina and medical discourses and the lack of integration of these discourses potentially contributes to the disparity of cervical cancer for Latinas. I have identified the groups that have produced the most influential discourses in the debate around Latina reproductive health: medical communities and Latina communities. To test this hypothesis, I collected data related to each of these discourses in the Lorain County area employing surveys and in-depth interviews. My work focuses on what the discourses say about the problem of reproductive health care for Latinas and how each community can enter into communication with each other in order to reduce the number of Latinas whose lives are directly affected by cervical cancer.

## **INTRODUCTION**

In 2006, the vaccine Gardasil was distributed in the United States. Gardasil was created to block four strains of human papilloma virus (HPV), two of which cause about 70% of cervical cancers and two more that cause 90% of the cases of genital warts (Merck & Co., 2009). This advance in medicine seemed to be a great step forward to combat cervical cancer. However, the Centers for Disease Control (CDC) report that only 1.1% of Latinas have used Gardasil.

The CDC shares that cancer is a disease in which cells in the body grow abnormally and that the main cause of cervical cancer is the human papilloma virus (HPV) (CDC, 2010). This is a disease that is highly preventable with cervical cancer screenings such as a papanicolaou test, a pap smear, or the vaccine Gardasil<sup>1</sup>. Though in the past 40 years the number of cases and deaths for cervical cancer have decreased, CDC shares that 12,280 women in the United States were diagnosed with cervical cancer and that 4,021 women in the United States died from cervical cancer in 2007 (CDC, 2010). Though these numbers may not seem large, they are a reflection of the larger problem of unequal access to reproductive health care. Reports show that rates of cervical cancer are 65% higher among Latina women than White women and that death rates are 42% higher among Latina women than White women (American Cancer Society, 2006, 2009). In addition, Latinas are screened for cervical cancer much less than White or Black women. The American Cancer Society reports, “In 2001, 83.4% of Hispanic women reported having had a Pap test in the last 3 years compared to 87.2% of non-Hispanic White women and 88.8% of Black women” (American Cancer Society, 2003 in Allison, Duran, & Pena-Purcella, 2005). Moreover, “[r]ates of ever having a pap test are lower among Hispanic women age 18 and over

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<sup>1</sup> Cervarix is the other cervical cancer vaccine. It was approved by the U.S. Food and Drug Administration on October 16, 2009. The vaccine protects against strains 16 and 18 which cause 75% of cervical cancers (HealthDay, 2009). I have decided to only focus on Gardasil because it has been out for longer and has a larger discourse surrounding it.

(85%) when compared to non-Hispanic White women (93%)” (United States Department of Health and Human Services, 2000 in Allison et al. 2005). With these statistics, my research question is: why is it that Latinas’ rates of cervical cancer screenings and Gardasil vaccination are lower than other women?

In order to begin addressing this problem, I have identified the groups that have produced the most influential discourses in the debate around Latina reproductive health: the medical communities and Latina communities. My work focuses on what these discourses say about the problem of Latina reproductive health care, specifically cervical cancer; how structural factors constraint women’s reproductive health choices, what each communities’ understanding of Latinas’ culture and faith are and how that plays out into their actions that either facilitate or hinder reproductive healthcare for Latinas.

I argue that there is a disconnect between the Latina and medical discourses and the lack of integration of these discourses potentially contributes to the disparity of cervical cancer for Latinas. To reduce the racial disparity in usage of reproductive care, it is necessary to bring these communities into communication with integrative and culturally sensitive models of health care and dispersal of culturally appropriate health education. Doing so will pave the way to reducing the number of Latinas whose lives are affected by cervical cancer.

## **LITERATURE REVIEW**

In assessing the current state of reproductive health care for Latinas, it is important to acknowledge that these barriers exist and that there is a need to improve accessibility for this population. In previous research scholars have identified *language* (Anders, Belcazar, & Paez, 2006), *culture* (specifically norms of communication regarding sexuality) (Allison et. al. 2005, 2005; Zavella & Castañeda, 2005), *acculturation* (Allison et al., 2005; Anders et al., 2006), *insurance* (Fernández-Esquer, Eugenia & Cardenas-Turanza, 2004; Frost, 2008; Sambamoorthi & McAlpine, 2003), *socioeconomic status* (Sambamoorthi & McAlpine, 2003), *education* (Anders et al., 2006; Sambamoorthi & McAlpine, 2003), and *faith* (Ayala, 2006; Zavella & Castañeda, 2005) as barriers for Latinas accessing health care. It is also important to analyze what factors influence Latinas' choices and some of the research that shows the disparity in access to resources.

## **SOCIOECONOMIC STATUS AND INSURANCE**

Research indicates that from 1995 to 2002, contraceptive services, preventative gynecological care, pregnancy-related care and STD- related care of HIV testing increased among women with private physicians, while reproductive care remained unchanged for women visiting clinics or hospitals (Frost, 2008:1814). For routine gynecological care, 80.9% of women visited private doctors and 16.8% visited a publicly funded clinic (Frost, 2008:1815). This research indicates that insurance can be a barrier to accessing healthcare. Additionally, Latinas are less likely than White non-Latinas to receive preventative care services such as pap smears; (Guendelman and Wagner, 1999 in Sambamoorthi and McAlpine, 2003) although once poverty and education are controlled for, the disparity between White and Latina women receiving pap smears closes. Furthermore, a study conducted by Sambamoorthi et al. (2003) finds that

including pap smears, uninsured women had the lowest rates of use across all services measured – suggesting that socioeconomic disparities and lack of insurance are fundamental factors to understanding reproductive health care disparities. This body of research is useful in assessing barriers such as insurance and socioeconomic status however culture and religion are not addressed in these studies.

One of the barriers to access to health care is insurance. In order to make health care more accessible to people of low income, the federal government and states have funded Medicaid. Medicaid is the largest provider of health insurance for people of low-income. The National Latina Institute for Reproductive Health (NLIRH) explains, “Medicaid is a means-tested entitlement program, which means that it is only guaranteed for individuals who meet certain qualifications” (NLIRH, 2005). These requirements are based on income and specific categories such as pregnant women, parents and of low-income children (NLIRH, 2005). Most of the funding for Medicaid is ran by the state and each state has different requirements. Though most states try to accommodate people, these requirements do deny coverage to some that are just above the cut off point and are still needy families, which leaves many people uninsured. The importance of Medicaid to reproductive health care is that it does cover health screenings for cervical and breast cancer, testing for some sexually transmitted infections, prenatal care, and delivery services. Additionally, NLIRH report that, “Latinas have the highest uninsured rate (37%) of any racial or ethnic group, and more that 50% of low-income Latinas lack insurance” (NLIRH, 2005). If 50% of low-income Latinas are uninsured, their chances of having consistent and preventative health care are significantly decrease which becomes a barrier in the fight against cervical cancer.

## SEXUALITY, CULTURAL NORMS AND RELIGION

To explore the factors of how culture and religion affect Latinas' experience with reproductive health care, the work of scholars Zavella and Castañeda (2005) sheds light on the importance of virginity, the ritual and meaning of marriage, and how both translate into value, honor and respect for Chicanas. The discussion of how these cultural norms intersect with faith can influence women's choices about reproductive healthcare.

*"Some religious authorities stigmatize even the provision of information about sexuality that includes sexually transmitted infections, and they see such information as a way of encouraging experimentation outside the institution of marriage. Local priests and preachers identify, condemn and equate sexual pleasures even with divine punishment, which sinners deserve for having done "what God forbids" (Zavella and Castañeda, 2005:236).*

If women see an illness or symptoms of illness as punishments sent from God, they may be reluctant to search for reproductive healthcare. The views of virginity and the messages that religious authorities send are influential voices for some Chicanas. When the message is that women ought to be afraid of their sexuality, it is hard to get sexual education and resources to these women.

Ayala (2006) finds that "mothers frame sexuality within a discourse of danger, violence, and victimization" (Ayala, 2006:34). These teachings frame men as sexual predators for Chicanas, yet the men in their own family – their brothers or fathers – are portrayed as guardians against the predators. These contradictions shape adolescent females' interpretations of sex and sexuality, and may influence reproductive health care choices by inculcating either a fear of male doctors or a fear of their own sexuality. These messages of fear can be passed down from mothers to daughters making it difficult to distribute sexual education and resources to Latinas.

Ayala (2006) uses her work to highlight some contradictions and moments of disruption of this binary through Latinas contestation of spaces of gender/culture.

In her analysis on Latina's sexuality, Ayala (2006) explains the virgin/puta (virgin/whore) dichotomy as a way to understand the cultural and structural scripts within which women understand their sexuality. She describes that the virgin/puta dichotomy explains the power component implicit in sexuality. The dichotomy explains that Latinas should be self-sacrificing and beholden to the needs of men. She lays out the binary in order to be able to understand how this ideology is being negotiated and transformed by the second generation Latinas.

Zavella (2003) describes the virgin-puta dichotomy as one in which proper and shameful sexual practices for women are set as oppositional. Zavella (2003) explains states, "In this patriarchal logic there are culturally sanctioned discourses or practices of repressing women's sexual desires, whereby women should experience pleasure only in the context of institutional approval: through Church-sanctified marriage" (Zavella, 2003:229) Zavella's work provides an historical analysis to explain why this cultural practice has persisted for both Mexicans and Chicanas. She explains that traditional gender roles for men and women were the norm in rural Mexico and social control of women was highly enforced. Additionally, she explains that female chastity was an indicator of social class and she cites research that confirms that the Catholic ideology in repressing women's desires and supporting the double standard for women is still present for Mexican and Chicana women (Sanchez, 1993:33 in Zavella 2003). Taking into account the importance of family order, class and religion, the virgin/puta dichotomy as a cultural practice has a lot of strength in for Mexicans and Chicanas.



It is important to understand where the logic of the virgin/puta binary comes from as well as understanding why Latinas believe in, contest or abide to the dichotomy. Understanding the way that Latinas think about and negotiate cultural practice on sexuality, and what affects this has on reproductive health care choices, is one of the aims of this research.

Another aim in my research is to explore the relationship between faith discourse and medical discourse. Gillum and Dupree (2007) state that, “analysis of NSFG data [data from CDC’s National Center for Health Statistics follow-up] have confirmed the important role religion plays in determining reproductive behavior in women” (Gillum and Dupree, 2007:160). Additionally, an analysis on data from the National Longitudinal Study of Adolescent Health by Hollander (2003) reveals that women’s involvement in a religious community increased, as their number of partners decreased and fear of pregnancy and HIV increased. Findings when measuring women’s personal devotion parallel the trend seen in women’s involvement in a religious community. These studies show that discourse of faith and medicine intertwine in women’s sexual behaviors. They indicate that women that are religious are more likely to fear pregnancy and HIV and to have a fewer number of partners alluding to the ways in which women adhered and negotiate religious rules.

Thinking about the ways in which faith and culture intersect, the work of Hirsch (2008) is useful. She conducted an ethnographic study in Degollado, Jalisco, Mexico focusing on how religion influences fertility and contraceptive use for women. Hirsch (2008) reported that the younger women used different types of contraceptives such as the pill, the IUD, Depo Provera or condoms while the older women used sterilization as contraception. She also stated that Catholicism in Mexico was not just practiced in the heads and hearts of its followers but was practiced with their whole bodies. The study finds that women use Catholic teachings, such as

the biblical principles of self – help (‘help yourself so I can help you’) and the idea that smaller family size is favorable to God because God does not want his children to suffer, in order to justify their contraceptive use. Examining how women negotiate their faith with their reproductive health care choices is a theme of my research with Latinas in Lorain County.

Lastly, establishing the meaning of church and religion for Latinas’ is vital to understanding their lived experience. Brewster, Cooksey, Guilkey and Rindfuss (1998) state that the different historical experiences American Americans have had with churches in comparison to Whites in the United States produce different meanings of religion for these groups. Using this idea that different racial/ethnic communities interpret religion differently is valuable for my research. In many Latina/o communities, churches are the center of many resources for community members. Thinking about churches as centers of social networks reinforces the importance that faith has for Latinas. Contemporarily, churches have also been a place of refuge for immigrant families and extremely poor families. Understanding the meaning of the church and religion is important when assessing the ways in which Latinas negotiate, adhere or rebel against religious doctrine when it comes to making decision about their reproductive health care.

## **CHOICE**

Bird and Rieker (2008) study sex and gender-based differences and similarities in men’s and women’s physical and mental health. Through their work they present the idea of constrained choice. When thinking about gender differences in disease they argue, “what is missing is an understanding of constrained choice – that is, how decisions made and actions taken at the family, work, community and government levels differentially shape the health-related choice of individual men and women” (Bird and Rieker, 2008:224). The constrained choice model explains the process of making choices and indicates that when social policy

makers are constructing policy, they are not taking into account how social policies affect men and women differently and this becomes a constrain on their choice and negatively impacts people's health. Examples used in this work describe how community, work and family responsibilities add pressure to people's lives and at times these responsibilities make the individual's needs secondary in order to meet others' needs first. Additionally, the authors mention that most of the choices people made every day are influenced by the resources available. As an example the authors use the story of a couple that has many work and family responsibilities which at times are more of a priority than their desire to engage in healthy behaviors. Bird and Rieker (2008) explain, "They may behave rationally in choosing to grab a quick but not nutritious breakfast and to work through lunch, even if these choices are not consistent with their intention to make health a priority" (Bird and Rieker, 2008:68). This small example shows how everyday choices may become constrained by factors such as work and family responsibilities. Overall, they argue that if constrained choice were to become part of medical models as a new platform of prevention it could have good benefits for both individuals and among all levels of decision makers.

Thinking about constrained choices is very useful for addressing the cervical cancer disparity for Latinas. If women have different social contexts that shape their everyday life, then though their choices may not seem the most effective or rational, they are the choices that are the best when taking into account the social, community and work contexts for these women. Additionally, it indicates that not all people have the same options when making choices.

Another element that must be taken into consideration when analyzing factors that explain and shape women's choices are the degrees of freedom regarding choice. In Matters of Choice (Lopez, 2008), a study of Puerto Rican women's sterilization experience, begins by

critiquing the ideology of choice. She explains, that the assumption is “that we live in a free society, that as individuals we have an infinite number of options from which to choose, and that because all individuals are presumed to be created equally, regardless of race, class, or gender, we all therefore must have equal opportunity to choose” (Lopez, 2008:142). Like Bird she critiques the idea that as free agents, people will always decide on an option that is the most appropriate in fulfilling the desired goal, under the assumption that we all have the same options. Lopez’s definition of reproductive freedom is as follows, “reproduce freedom consists of individuals having the right to decide if, when, and how many children they will have without violence or coercion” (Lopez, 2008:xii). When thinking about freedom to choose she explains that there are different *degrees of freedom*. She argues that there is no one who can exercise optimal reproductive freedom but that middle-class women tend to exercise more degrees of freedom than poor or working-class women, especially women of color (Lopez, 2008:xx), meaning that marginalized women have more constraints on the choices that they can make.

Lopez (2008) also brings to scholarship the idea of breaking away from conceptualizing choice in a binary manner in order to be able to understand Latinas reproductive health care choices. Lopez explains, “sterilization has been discussed within a binary framework that opposes “choice” or agency to victimization or constraint” (Lopez, 2008:xviii). Working outside of the binary of agency (choice) vs. constraint (oppression) allows for a more complex understanding of women’s reproductive health care choices. Lopez presents an integral model of reproductive freedom that considers the four major realms affecting women’s fertility experiences: personal, cultural, social and historical realm in order to analyze women’s choices. She examines how each of these forces converge in the women’s everyday lives and to a more

full understanding of the process of women's choices. One example she uses is of a second generation Puerto Rican. Evelyn's story is as follows:

*“After Evelyn had two unplanned pregnancies, she felt that that she had achieved her desired family size. At the time, she was with a man who did not feel that birth control is a shared responsibility and who refused to use condoms. Evelyn was familiar with la operación [the operation], and so she decided to get sterilized” (Lopez, 2008:149)*

Using the integral model for analysis Lopez explains that Evelyn had a lot of social constraints in her life that included living in a neighborhood with high crime and that she had scarce financial resources. Evelyn also lacked access to other forms of birth control and had problematic pregnancies with caesarean deliveries. Culturally, Evelyn was more familiar with la operación and in her personal realm, her patriarchal relationship made it difficult for her to undertake other forms of contraception. Exercising her agency Evelyn decided that sterilization was the best option for her. In Lopez's example, multiple factors constrained Evelyn's choice however simultaneously she exercised her agency to make a decision for herself that did not make her feel like a victim. Lopez's integral model is important when thinking about patients at Family Planning Services who make many reproductive health care choices and are women that cannot exercise high degrees of reproductive freedom due to all four factors accounted for in her model.

Using this scholarship on choice will provide a more complex understanding of the experiences Latinas have in Lorain County when attaining reproductive health care. Binary ways of thinking about sexuality, faith and decision making cannot explain the negotiations that women undertake to make choices. The binaries also do not account for structural inequality that is partially responsible for the cervical cancer disparity, creating a need for different analysis.

## HEALTH CARE MODELS

To address some of the unique experiences that Latinas have when it comes to sexuality, faith, and gender negotiations in the United States, scholars are finding ways to work with different Latina communities to help them access health care. Allison, Duran and Pena-Purcella (2005) explain that cultural beliefs play an important role in cervical cancer screening behaviors in spite of “knowledge and access to health care” (Allison et al., 2005:65). Additionally they point to acculturation, misperceptions (lack of knowledge) embarrassment, and lack of access to screenings as factors that influence cervical cancer screenings. The authors present a theoretical framework (PEN-3) that includes three dimensions to increase the rates of cervical cancer screenings. The program that was developed with the PEN -3 model used the three forms of the acronym which include:

*“Person, Extended Family, and Neighborhood relating to social networks and health education; Perceptions, Enablers, and Nurtures as educational influences; and Positive [promoting health behaviors that lead to improved outcomes], Exotic [indigenous practices that may provide no health benefit but are not harmful] and Negative indigenous [behaviors detracting from optimal health outcomes], culturally accepted behaviors” (Airhihenbuwa, 1992 in Allison et al., 2005:64)*

From the PEN-3 forms the three dimensions pointed to were: health education, educational diagnosis, and cultural appropriateness. Though the last dimension of PEN-3 that address cultural appropriateness seems to be valuing indigenous beliefs through a biomedical lens, their understanding of its existence and importance brings medical communities one step closer to Latinas. Allison et al. (2005) argue that these three dimensions are essential to creating culturally appropriate education programs and to addressing communication barriers between the health care system and Latinas.

Cultural appropriateness is an important factor to health care because if patients have negative experiences, they are less likely to want preventative care. Allison, et al. (2005) cite, “A study conducted in west Texas indicated that satisfaction with health care many have a greater impact on preventative cancer screenings than merely increasing access to health care” (Borders. Warner, and Sutkin, 2003 in Allison et. al, 2005:63). Furthermore, PEN-3 did significantly increase screening rates for women under age 40. Overall, being able to assess what factors shape Latinas health care choices is important in order to create programs that can build greater communication between medical and Latina communities and one day construct different health care models.

The Promotoras de Salud model functions as a good source of education that could be used in different communities with proper organization in the future. The Promotoras de Salud (PS) are Latinas who work in their communities along the U.S. – Mexico border to educate families about the health care resources available, usually focusing on heart disease and diabetes. These women “serve as the interface between the community and health researchers who may or may not have these culturally specific competencies” (Anders, Belcazar, and Paez, 2006:72). Las Promotoras de Salud have been trained by medical professionals to spread educational information in the cities. This information is being delivered in a language that all community members can understand and by community members themselves. Anders, Belcazar and Paez’s (2006) work describes how the PS models can integrate research into community movements for addressing health disparities. Community based research models, in which investigators along with community members develop a research question concerning public health and the product of the research is what is disseminated in the community by Latinas, can work with the PS model to help achieve this goal. This model of research and education is one that is working well in

cities in the U.S – Mexico border because this model involves all of the family in health issues in the community. An example of this work is the initiative *Salud Para Su Corazon* (Health for Your Heart) in which the participants were community members and PS helped the National Heart, Lung, and Blood Institute to get the people involved in the research and later disseminated the health education to the community members. By using a community based research model, such as the PS model, scholars empower community members to answer their own questions and educate their community. Both models put forth by Allison et al. (2005) and Anders et al. (2006) are important to replicate in other communities to begin to address the disparity of cervical cancer. There is a need to have culturally and spirituality sensitive approaches by medical institutions to educate and make accessible reproductive and preventative health care for Latinas.

All of this work suggests that Latinas' experiences are unique and there is a need to have culturally and spirituality sensitive approaches by medical institutions to educate and make accessible reproductive and preventative health care for Latinas. When this is accomplished, we will begin to see the cervical cancer disparity rates go down. There is also a need to begin more discussions within the Latina community by Latinas regarding sex and sexuality without so much fear. Overall, in order to being to build models of health care that seem more inviting to Latinas there is need to understand how they make their reproductive choices and be able to address the constrains that they face such as socioeconomic status, language, lack of knowledge of faith by the medical institutions, and Latinas lack of knowledge about medical resources.



## **SOCIAL CONTEXT**

### **POVERTY AND REPRODUCTIVE HEALTH CARE OPTIONS**

Lorain, Ohio is the home of 14,824 Latina/os. Latina/os make up 21.0% of the population in the city (U.S. Census Bureau, 2000). Among these Latina/os, the largest majority are Puerto Ricans, with over 10,000 residents, while approximately 2,500 residents are identified as Mexicans (Mitchel and Pollack, 2010:149). One factor that is important in understanding Latina/os everyday lived experience is assessing poverty rates. In Lorain County, figures show that 14.4% of people live in poverty (Bureau of Census, 2009). The city of Lorain ranks among the top 50 impoverished cities nationally, as number 48 (Exner, 2009). Reports published in 2009 show that 33.7% of residents live with income below the poverty line in Lorain, indicating that the city of Lorain has a higher percent of poverty than that of the county.

When assessing poverty in Lorain by race/ethnicity, census data reported in City-Data (2010) shows that 41% of Hispanics residents have income below poverty level in comparison to 21% of whites. When examining poverty by poor family types, findings show that female, no husband present families account for 70.3% of poor families. These findings are necessary to take into account when thinking about the structural inequalities and constraints that Latina/os face. These numbers show that a large number of Latina/os live below or on the poverty line and that from these, many of the families experiencing this poverty are single mothers.

In Lorain and Elyria, there are only three clinics that provide reproductive health care for women that are of low-income and are uninsured. Those are the Family Planning Services clinics in Lorain and Elyria and the Planned Parenthood clinic in Lorain. There are three clinics (Elyria City Health Department, Lorain County Health and Dentistry and Women's Care) that provide prenatal care but those are not focused on pap smears and STD testing. Planned Parenthood and

Family Planning Services are Title X clinics, meaning that they are NGOs that provide services to patients on a sliding fee scale. This means that patients who are uninsured pay the amount that their income bracket signifies they are able to pay. This allows for low income people to be able to afford reproductive health care. However, due to the large number of people that are in need of services and the lack of funds that these clinics endure, clients are not able to attain the most complete reproductive health care.

## **FAMILY PLANNING SERVICES OF LORAIN COUNTY**

Family Planning Services (FPS) is a non-profit health care agency whose goal is to provide quality and affordable medical and educational services in the areas of reproductive health and family planning. It is a clinic that serves women of low-income who are uninsured. The purpose of the clinic is to provide care for women who are underserved. The agency was founded over 30 years ago from a recognized need that many women did not have access to quality and affordable reproductive health care.

The Northeast Ohio Family Health Program of 2009 report is used to assess the status of Title X health care programs in the area. In this report the agencies included are Planned Parenthood of Northeast Ohio, FPANEO, Family Planning Services of Lorain County, NHC/NFP and a category of “other agencies”. Family Planning Services reported seeing the most number of patients from all of the programs and almost all of their patients were from Lorain, while other clinics did not see many patients from Lorain. This suggests that FPS is the clinic that is providing much of the reproductive health care for residents of Lorain. When assessing the funding sources that patients used at these agencies, FPS sees the most Title X patients of any of the other agencies as a total and proportionally and FPS sees fewer Medicaid and privately insured clients. The National Latina Institute for Reproductive Health reports that

Title X of the Public Health Service Act is a thirty years old law that authorizes federal funding for family planning services which allows clinics to offer a number of services free of charge for women who live at or below the poverty line (National Latina Institute for Reproductive Health, 2005). The total percentage of Title X patients seen by all the agencies was 62.3 percent while the total of FPS is 84.6 percent. FPS is the agency that is servicing the largest number of people that are uninsured. In FPS's demographic information there is a racial breakdown for the agencies' patient population which shows that at FPS 12.8% of their clients are Hispanic.

One of the constraints that Family Planning Services faces is that like the Planned Parenthood office in Lorain, they do not offer Gardasil in their clinics because of the high prices of the vaccine. This becomes a factor in accessibility of Gardasil for women that are uninsured and are of low-income. If the places that they are able to visit do not have Gardasil available, how likely are they to actually get vaccinated? Lack of accessibility is constraining these women's choice to be able to get Gardasil.

## **GARDASIL AND ACCESS**

Today Gardasil is available for both girls and boys and men and women ages 9 to 26. Gardasil is given in three doses over a six month period and the cost is \$360.00 (Chesson, Ekwueme, Saraiyam, and Markowitz, 2008). One of the barriers that people in Lorain face is that for women who are uninsured and of low-income, there are few places where they can obtain the vaccine. The Lorain County General Health Dentistry office is the only place where patients without insurance can access the vaccine. This is an office that focuses on medical and dental services and is federally funded so is able to give services to people that are uninsured. Though there is a location where the vaccine is available at, there are barriers of access to the vaccine

because there is not enough information about this opportunity available due to the lack of advertisement.

A way that Merck, the pharmaceutical company that produces Gardasil, has attempted to make the vaccine available to uninsured patients and patients of low income is through the Merck Vaccine Patient Assistance Program. This is a private and confidential program that provides vaccines free of charge if patients are eligible. To qualify the person must reside in the United States, be of age 19 or older, have no health insurance coverage, and have an annual household income of less than \$43,320 for individuals, \$58,280 for couples, or \$88,200 for a family of four (Merck, 2010). After patients speak with providers that are part of the program, the provider will need to get a form signed that shows the patients eligibility. The program is available to “offices of licensed prescribers” and to clinics that are non-profit. Though this a great way to make the vaccine accessible to locations that serve uninsured people, Family Planning Services and Planned Parenthood do not have vaccine available and are not part of the program. There are still ways in which Merck is not reaching out to all of the NGO clinics that need this service for their patients. Patients do not know where to get the vaccine and the NGO clinics that people that are uninsured and are of low-income attend, for the most part, do not offer the vaccine in their offices. This signals that there is a disparity in access to the vaccine and that there is a disconnect between the pharmaceutical company, the NGO clinics, and patients regarding Gardasil.

Overall, it is important to examine what accessibility Latinas have to resources in Lorain. Though Merck has created a program to make the vaccine accessible to this population, the NGO clinics in the area are not part of the program and therefore cannot offer this to the women. Women who are able to gain all of the information necessary to be able to go to the one location

that does provide Gardasil must have the time and resources, such as transportation, insurance and money, to be able to accomplish this. However, attaining this information is the first step and this information is not very accessible. Information about the assistance program is very hidden in the information being released about the vaccine, which I will be discussing in the next section. These examples of lack accessibility to resources suggest that women's reproductive health care choices are constrained.

## **MEDICAL DISCOURSE**

What is interesting to analyze about discourse is what the rules and practices are of particular groups and what kinds of truths they produce. For this section I will examine how Merck and the CDC contribute to the medical discourse surrounding the vaccine Gardasil and it's consumers, along with how this suggests that there is a disconnect between the medical community and Latinas.

Merck, the manufacturing company of Gardasil, is one of the leaders within medicine. Merck produced the website [www.gardasil.com](http://www.gardasil.com) where one can get information that ranges from what the vaccine is to questions one can ask their own doctor about the vaccine. On Merck's website, an 'en Espanol' (Merck & Co., 2010) option did not exist until July 2010, four years after the vaccine had been released. This oversight is a reflection of the gap in information that is being provided to Spanish speakers in comparison to English speakers. If Latinas have the highest incidence rates, should they not be the first to have access to this information?

In the 'en Espanol' version of the website there is a pamphlet that you click through that is aimed to persuade mothers to vaccinate their children which excludes possible consumers ages 18-26, a PDF explaining the vaccine and a PDF which explains the prescription of the vaccine in very medical terms. The pamphlet is titled, "Protect your son or daughter from the diseases caused by HPV" (Merck & Co., 2010). The pamphlet contains a lot of information about what Gardasil is, what it protects against, why mothers should get their children vaccinated soon and side-effects. However, there is no information for adult women who might be interested in the vaccine. This information almost makes it seem that the only target population for the vaccine are actually the children. On the English website, one of the sections that was strong at guiding mothers to get their children vaccinated was the tab on "talking to your doctor." This section

provides a guide of questions to ask the doctor when asking about Gardasil. For the 'en Espanol' website, the section regarding speaking to your physician is on page 10 of the pamphlet and it states, "To attain more information, you can also visit the website [gardasil.com](http://gardasil.com)" (Merck & Co., 2010). The creators of [www.gardasil-espanol.com](http://www.gardasil-espanol.com) are asking Spanish speaking women to go get this information from a website they cannot understand. One of the consequences of not being provided information that informs women how to speak to doctors is that these women may not feel equipped to bring sex into the pediatrician's office. This example displays the gap in information and shows that Latinas are only given access to parts of the information and are not being provided the same tools that English speaking women are.

In order to create greater accessibility to Gardasil, Merck is supporting the Vaccines for Children Program (VFC). The information provided in Spanish and English on the website and on printed pamphlets show that the information provided regarding the VFC does not fully explain the program and how to utilize it. On page 12 of the pamphlet, in Spanish, at the very bottom in a small box it does have a section that mentions:

*"Gardasil is included in the U.S. vaccine program "Vaccines for Children" (VFC, the acronym in English). The VFC program provides help for families with children who otherwise would not have access to the vaccines (injections), providing dosages for free to the doctors that treat you. Ask your son(s)' or daughter(s)' doctor or health care provider if they are part of the VFC program. To obtain more information, visit the [Gardasil.com/freevaccines](http://Gardasil.com/freevaccines) page" (Merck & Co., 2010).*

In this translated version of the message published in the Spanish language Gardasil website, the consumer is expected to go find more information out about the program on their own and in language they cannot understand.

Additionally, due to the fact that this pamphlet/website is not geared to young adult women, Merck is not presenting the information about the Merck Vaccine Patient Assistance

Program for the women. This program is different than that of the VFC. The Vaccines for Children Program (VFC) also gives discounts unlike the assistance program. The VFC program has been in existence since 1994 and other pharmaceutical companies are also part of this program with the purpose of providing free vaccines to children who are Medicaid-eligible, uninsured, Native American and uninsured children who visit Federally Qualified or Rural Health Centers (Merck & Co., 2010). However, if women were aware that there was an option for adults then they may feel more encouraged to take the vaccine.

The English version of this information on Gardasil.com does mention the Merck Vaccine Patient Assistant Program, showing that there is a difference in terms of what information is being shared with particular populations. The English website has a tab for assistance programs and mentions both the assistance program and the VFC. However, there is no mention about what facilities are part of this program. As an upgrade for the Spanish information, in the information provided in English there is a link to the Merck company website that explains further detail on these programs. What is troubling is the contradictory information being published by the company about the programs. In the paper published version of the English pamphlet, it says that it is private clinics that offer the program and does not mention of the NGOs. This is a display of how English speakers are getting information that is also not complete and at times contradictory for people that need assistance services.

Overall, the problem with the information about the assistance program and the existence of the program itself is that uninsured and low-income women are not being reached by the program and they are the appropriate candidates for the program. Here again we see that there is some kind of disconnect between Merck's desire to make Gardasil accessible and women actually being able to access information in order to be vaccinated.



In an attempt to reach out to the Latina community, Merck produced a Gardasil commercial in Spanish in which Latinas, seemingly from different Latin American countries, were included. Even though the Gardasil commercial featured information about the vaccine and was delivered by in Spanish Latinas, the content of the commercial was identical to the one aired in English and only aired for a year. Having information in Spanish is not the only concern. It seems that Merck did not account well for the Latina discourse. There is a need for Merck to not only increase marketing to Latinas but additionally do so in a more culturally appropriate manner that would address the questions of Latinas. One potential fear some Latina mothers may have is that by vaccinating their children, they are pushing them to have sex. I hypothesize that including information that explicitly addresses this fear and shows that Gardasil is a preventative vaccine for certain types of HPV may make Gardasil more inviting to this community. Moreover, when marketing to the young adults, including a small part that explicitly says that you may contract HPV when you are young and not have it become cervical cancer until much later in life might frame the vaccine as a desirable preventative measure for this population. It would frame Gardasil as a necessary vaccine instead of luxury vaccine. Furthermore, including a part that showed young adult Latinas feeling empowered to ask their doctor about the vaccine would target that specific subgroup. These interventions may make Latinas more comfortable with the vaccine.

The disconnect between the medical community and the Latina community was evidenced by a statement made by the lead creator of the vaccine, Dr. Eliav Barr, as he received the 2009 Discoverers Award – the pharmaceutical industry’s highest scientific honor. When Dr. Barr was asked about his experiences and challenges creating the vaccine, he responded with another question, “How do you get **ornery** people—who either don’t go to the doctor very often,

believe in their own immortality, or try not to listen to their parents — vaccinated?”

(Pharmaceutical Research and Manufacturers of America, 2009). This quote suggests that Dr. Barr has a narrow understanding of potential consumers that are hesitant to take the vaccine. In the statement Dr. Barr suggests that any dissent can be labeled as deviant, irresponsible and disobedient. Being “judged” by health care professional is a sentiment that turns some Latinas away from health care providers. Potential consumers could be dissuaded from wanting the vaccine if they feel like their hesitancy is being viewed as deviance.

In an attempt to address patient hesitancy for the vaccine and the fears about the potential side of effects of Gardasil, the Vaccine Adverse Events Reporting System (VARES) report states that the most common side effects of the vaccine are classified as non-adverse and include swelling at the injection site (the arm), headache, nausea, fever, and fainting. Adverse side effects include events that involve hospitalization, permanent disability, life-threatening illness, and death. Out of the 14,072 reports only 7% were events considered to be serious. After analysis, “experts have not found a common medical pattern to the reports of serious adverse events reported for Gardasil that would suggest that they were caused by the vaccine.” (Centers for Disease Control and Prevention, 2009). Though this report is supposed serve as a way to make women trust the vaccine, one would have to have internet access and knowledge about the purpose of VARES reports to access this information.

Though the attempts that some of the members of the medical community have used to address the issues of cervical cancer have not been completely effective, there are initiatives taking place to address this problem. To overcome the disconnect between the medical community and the Latina community, a group of physicians and scientists have begun to organize to address prominent minority health disparities, including cervical cancer. The

American Association for Cancer Research (AACR) Conference on “The Science of Cancer Health Disparities in Racial/Ethnic Minorities,” was held for a third year on September 30, 2010. The actions taken by the medical community exhibit an effort to try to organize around the problems to find solutions. Taking an approach that focuses on minority communities helps to build frameworks of care that do not generalize all populations to be the same with the same needs. Though this is only one example of what the medical institutions are doing to address the cervical cancer issue, there is a need to not only study the disease and have new preventative measures created but also to find ways to disperse information to Latinas about the preventative measure that are already in existence to lower the Latinas’ high rates of incidence and mortality for cervical cancer.

The dilemma of cervical cancer can be addressed by many different groups or health care providers. Though some of the efforts are an advance in the fight against cervical cancer, there are ways in which Latinas are being underserved by these advances which is evidenced by the fact that information is not being dispersed in a manner that is accessible to them. The way that medical discourse is being produced is distant from Latinas.

## **LATINA DISCOURSE**

Discussions are beginning to emerge within the Latina community about reproductive health care. Resources available to Latinas regarding reproductive healthcare include publications like *Latina Style* as well as organizations like the National Latina Institute for Reproductive Health (NLIRH). *Latina Style* is a magazine that serves as a source of information for professional Latinas. Their website has a Women's Health section that contains a database of the most recent health care issues for Latinas, including reproductive health care. Although *Latina Style* has a large database for health care issues and opportunities for Latinas, their publications are only in English and they exclude some Latinas because the magazine "is dedicated to the needs and concerns of the contemporary Latina professional working woman and the Latina business owner in the United States" (Malaspina, *Latina Style*, 2009).

NLIRH is a reproductive justice organization that has a cervical cancer prevention campaign at work in several states to educate Latinas. Their mission is "to ensure the fundamental human right to reproductive health and justice for Latinas, their families and their communities through public education, community mobilization and policy advocacy" (NLIRH, 2009). NLIRH's three program areas are Abortion Access for Latinas, Addressing Reproductive Health Disparities in Underserved Communities, and Immigrant Women's Rights. Their website provides all of their information in both Spanish and English. All of their pamphlets and information sheets printed in both in English and Spanish as well. The efforts of this organization seem to be reaching some Latinas however, the organization is limited in ability to reach out to Latinas due to the nature of being an NGO. NGOs can serve Latinas well in specific communities but there is a need to have greater resources directed to existing organizations like NLIRH and for new organization formation. Overall, NLIRH is a very effective organization

because the activists are members of the communities that they serve, but there is still much to be done to reach more Latinas.

When assessing the Latina discourse, one of the most far reaching sources of information is, Univision, the largest national Spanish language media source. In 2009, in the first stages of this research, there was nothing on health care on their website. At that time on the *Mujer* webpage, their resource for Latina women, there were only tabs for baby care, beauty, weddings, the kitchen, diets and exercise, family, and fashion. There was no information for health care with the exception of the newest diets, sending the message that obesity was the only health concern in the Latina community. The lack of information on health care for Latinas through Univision could have had a many explanations but was important was that as biggest source of information, health information, specifically reproductive health care was absent.

Today, the website has undergone many changes and the layout is completely different. The *Mujer* webpage became *Vida y Familia* with a tab named *Relaciones de Pareja*, Relationships, under which one of the sub-tabs is *Sexo*. On this page there are articles on different sex topics such as, the most common sexual accidents, swingers, and famous people revealing their sexual secrets. Though having a sex page is a big step from having nothing for women on sexuality or health, there is no mention on this webpage about women's health. However, if Univision felt it necessary to include a page on this topic, this could suggest that there is a need to begin having conversation on sex, even if sex and health are not discussed together, and a dispersal of information on the topic in a language that Spanish speaking Latinas can understand.

Under the *Vida y Familia* they also have a tab for the webpage on Religion. On this webpage there is a forum for religious dialogue in general and then specifically separate tabs for

the Catholic, Evangelist, Mormon, Santeria, and Jehovah Witness religions. In each of these tabs people post the religious message of the day and calendar of religious events and holidays. The aim of the Religion webpage is to provide support in peoples' everyday life. The movement of Univision to include a webpage on religion that serves general and special religious groups suggests that there is a strong need for religious information in Latino communities.

Univision.com has 18 main webpages in which the *Vida y Familia* is one of them and another is *Salud*, Health. Under the Health webpage it has subpage titled *Salud Sexual*, sexual health. Inside of this webpage under key topics and related topics there is a sub-tab for *Salud de la Mujer*, Women's Health. Buried amongst all the tab options, there is information on this webpage regarding HPV. This is presented as a separate option inside of the Women's Health page titled: HPV: "Should my daughter get the vaccine?". On the page discussing HPV, there is a breakdown of what HPV is, how one contracts HPV, what the vaccine for HPV is, the benefits of the vaccine, and a bit on the assistance programs. The website also has a comparing your options portion. This webpage does walk mothers through the decision making process of whether they should or shouldn't get their daughters vaccinated. However, they did not include information about vaccinating their sons or young adult Latinas. All of the information was presented for the Latina mother to vaccinate her daughter.

The changes that the Univision website has undergone are very large. They came from a website that did not include any information on health or sexuality to a complete catalog of information on all the topics that Latinas could be interested in having access to in their everyday lives. The information about sex and religion speak to some Latinas need and desire for a place to get and participate in the production of knowledge of these areas. In the webpage on health, specifically the women's health page, having HPV come up as one of the top concerns for

women's health is an indicator that women do want to talk about this topic. Though this information on HPV is again only geared toward mothers needing to vaccinate their daughters, it is a first step. The information on this webpage is more detailed and presented in a decision making process model, very different than the presentation of information from Gardasil.com. Though information on Univision.com is made accessible only to women that know how to use a computer and have access to a computer, the fact that the information about these topics is documented in the website indicates that this information can be covered in other media sources owned by Univision. The changes made by Univision show a dramatic shift from no access to information on reproductive health care to detailed information about this topic and many others. This could be used as an empowerment tool for many Latinas.

When examining the Latina discourse, information regarding reproductive health care for Latinas is growing but that there are still limitations to how many people the information is reaching. It is exciting to see a change in what the Latina discourse looks like today from even a comparison of two years ago. However, there is also a need to assess the impact that information has had for Latinas. For this reason, in order to get a deeper understanding of the Latina discourse, I will have to speak to Latinas themselves. Speaking with Latinas will allow for a more complex understanding of what the Latina discourse looks like in everyday life.

## **METHODOLOGY**

My work during the summer of 2010 focused on exploring some of the barriers to accessing reproductive care in Lorain County that Latinas experience. I have identified Family Planning Services (FPS) of Lorain County as the site for my research. The Institutional Review Board for Research Involving Human Subjects (IRB) at Oberlin College approved this research project (IRB#S10SDJ-07). The Family Planning Services facilities are located in Elyria and Lorain. Family Planning Services serves people who are uninsured or are of low income. These factors make FPS a place accessible to women with socioeconomic barriers.

FPS has undergone some changes in the past year due to budget cuts. FPS used to have four offices and now it only has two that they operate. The Lorain clinic is only opened twice a week and staffed by only two people. The Elyria clinic is open five days a week and once a month it has a Saturday clinic day. They have also opened up a teen clinic day on Tuesday afternoons. Family Planning Services serves about 6,553 patients.

I began working with Family Planning Services as an intern about two years ago. At first I worked with the health educator at Family Planning and then later started spending time at the Elyria clinic. My experience there showed me that two important questions for FPS were ‘how do we find new ways to reach out to the community’ and ‘how do we get patients to continue their treatments and come back for follow up pap smears’. These questions along with my interest in reproductive health for Latinas were how this part of the project was constructed. In order to assess these questions in combination to the broader research question, I used a combination of qualitative and quantitative data collection. For the quantitative portion, a survey of about twenty questions was distributed in the clinic that would serve as a patient satisfaction survey and inquire about the research questions. Some of the questions included in the survey are



knowledge of Gardasil, desire to have Gardasil, dosages of Gardasil taken, patient's comfort at FPS, whether or not they would return for a repeat pap smear if necessary, whether they had medical insurance and how they found out about Family Planning Services. To inquire about patient satisfaction, the survey included questions asking 'how well did FPS serve you today', 'would you return' and space was provided for 'additional comments'. The survey asked open-ended questions on ethnicity/race, religion, parents' religion, country of origin, parents' country of origin, gender and age. Race/ethnicity was asked in this manner in order to give patients more freedom to self-identify.

The survey was distributed to all of the patients 18 years and older who were served at Family Planning Services each time they came to FPS. For this reason the survey asked if this was the first time they had taken the survey. Repeat respondents and respondents that were minors were discarded from analysis. Excluding these responses, 710 survey responses were valid for analysis. As a method of recruitment for participant interviews, attached to the survey was a slip of paper that asked women for their contact information only if they would like to provide this information in order for me to contact them for an interview later. This slip of paper would be detached from the survey and deposited in a locked box in the waiting room. I did not use the slips of contact information due to the large number of patients that volunteered while they were at the clinic. The front of the survey was completed in the waiting room. The patient then took the survey to the examining room and at the end of their visit they would fill out the patient satisfaction portion on the back of the survey and place it in an envelope in the examining room. These envelopes were in each of the examining rooms in the clinics. If a patient was only coming to pick up a medication and not to see the health care provider, there would be an envelope at the front window in which they could place their completed survey. The envelopes

served as a way to maintain anonymity of patients and no identifying information was asked such as names or dates of birth. In addition, surveys were collected at the end of day. I constructed the questions of the survey with the help of FPS staff and some preliminary research on Gardasil. The data provided information from patients of all racial/ethnic groups on the topics of FPS services, patients' knowledge of Gardasil, and feelings about pap smears, allowing for comparative analysis between different subgroups.

The qualitative part of my project involved in-depth interviews with patients. I spent June and July 2010 in the clinics collecting data and during my time there I asked self-identified Latina patients at FPS if they would like to be interviewed for my project. In some instances I would just start speaking with patients that I was checking in for the day or patients that were in the waiting room. During these conversations I would ask about their racial/ethnic identification and began discussing my project. In other instances the health care provider would introduce me as a researcher for the clinic and then the patient and I would have a conversation about my project and I would ask if they would like to participate. If the patient decided to participate in the project I would take them either to the back conference room in the Elyria Clinic or an empty room in the Lorain Clinic. These locations would keep the identity of the participants anonymous to the health care providers though they were still at the clinic. Interviewing the women at the clinic was the best option for the patients because a lot of women have trouble finding transportation to the clinic and others work so they cannot take any other time off.

All participants volunteered to be interviewed. All of the interviews were audio recorded. The ages of the 18 women interviewed ranged from 20 to 44, and the interview ranged anywhere from 30 minutes to 90 minutes in length. Interviews were conducted in Spanish and English. I provided consent forms to all of the interviewees. I explained the form by saying what the

interview was for, how I was going to use the interview, that they could stop the interview at any time, if they did not feel comfortable answering a question we could skip it, that FPS would not know it was them and that the interview would not affect the service they are provided at FPS. All except one interview were conducted at an FPS clinic. The questions in the in-depth interviews are geared towards understanding their experiences when attaining reproductive health care. The subject areas of the interview include personal history, sexual experiences, knowledge and beliefs about reproductive health, fears regarding reproductive health care, beliefs and knowledge of Gardasil, stories of all and any reproductive health care experiences and knowledge and opinions on pap smears and cervical cancer.

Answering the questions in both the surveys and in depth interviews would help Family Planning Services reach out to a wider group of potential patients and give insight on how to improve advertising and educational efforts to address Latinas specific questions and concerns. This would also allow me to bring light to the voices in the Latina discourse.

## **SURVEY DATA**

I had 710 responses to the survey. Because the question of race/ethnicity was an open ended question, participants responded with a variety of identifications. From these I selected seven categories because this would allow me to analyze the data in a more uniform manner similar to census racial/ethnic labeling. The race/ethnic breakdowns were Latina, 9.9%, White, 65.1%, African American, 13.0%, Asian American, 0.6%, Native American, 0.3%, Multiracial, 3.2%, and Self-Identified Other 0.1%, which are displayed in Table A. The Self-Identified Other category were participants that wrote in “other” as their race/ethnic identity.

The first question that I analyze from the survey data is, “Have you ever heard about Gardasil? The option was yes or no. Calculating crosstabs on this variable by race/ethnicity indicates that 58.6% of Latina, 57.8% of African American, 73.6% of White, and 56.5% of Multi-racial participants know about Gardasil (displayed in Table D). The Chi-square demonstrates that these differences are statistically significant at level of .001, meaning that the difference between the number of Latina/o and White patients is not due to chance and that there is a relationship between knowledge of Gardasil and race/ethnicity. I analyze this question because I hypothesize that more Latinas’ would not know about Gardasil compared to other women. These data support this hypothesis. Though the percentage of Latinas with knowledge of Gardasil is seemingly high, it is still significantly lower than White participants. Also, it is possible that the actual percentage of all Latinas who know about Gardasil is lower than the number above because this data is from a sample of women who actually do access reproductive health care. These numbers suggest there is lack of information being provided to Latinas regarding Gardasil because if these are the women that come to get reproductive health and they do not know, there is a need to provide more information.

The second part of the knowledge of Gardasil question asked, “if yes, how (check all that apply).” This question was designed to assess where women are getting information from on Gardasil and the results are displayed in Table B. The options included, Commercial on T.V., Pamphlet, Gardasil Website Friend, Insurance Company, Health Care Provider, Church, or Other. For the Other option, they could specify the communication source. Out of the respondents that said yes they had heard about Gardasil, 87.8% of respondents (409 people) said they found out through a T.V. commercial, 20.4% of respondents (95 people) said they found out through a health care provider, 20% of respondents (93 people) found out through a friend, 15.7% of respondents (73 people) said they found out through a pamphlet, 4.5% of respondents (21 people) said that they found out through Other methods of communication, 3.2% of respondents (15 people) said they found out through the Gardasil Website, 0.4% of respondents (2 people) said they found out through an insurance company, and no one found out about it through church. Seeing that the Gardasil commercials and other television publicity is the source that was the most effective in getting information out to people, it may be problematic that today the commercials are no longer being aired. It is also interesting to see that the next source with the highest number of people was the category of health care providers. This suggests the great importance that health care providers have for patients in not only providing health care but also education. These responses also point to what sources of knowledge do not provide information on Gardasil such as churches and insurance companies.

When examining each source of information on Gardasil by race/ethnicity, the only source that had a significant difference was the television commercials. The cross tabs show that 50% Latina/os, 64.9% White, 51.1% African American, 47.8% Multi-racial found out about Gardasil via a T.V. commercial. Looking at the data there is a significant association (chi-square

significant at  $p \leq .01$ ) between race/ethnicity on knowledge gained via television communication (view Table D). White women were more likely to report learning about Gardasil from commercial than Latina/os, African Americans and Multi-racial group. This suggests that the White group could have had more access to the commercial. Making a comparison with Latina/os, if some of them are Spanish speakers only and if the commercial was not aired as long in Spanish as it was in English, part of the variance in response may be explained. Overall, it is again interesting to see that the television commercial were signaled as the source of information for so many people.

The next question I analyze is, “Have you taken Gardasil?” The response options included, yes 1 dose, yes 2 doses, yes 3 doses, and none. The descriptive values show that 7.5% Latina/o, 9.9% White, and 7.0% Black patients had at least one dose of Gardasil. The Chi-Square test is not statistically significant ( $p > .05$ ) meaning there is no statistical variation between dosage of Gardasil by race/ethnicity (displayed in Table D). Though the mean differences are not significant these numbers do tell us of FPS patients that took this survey only 9.4% are vaccinated and that 90.6% of clients are not vaccinated. This raises the question why weren't FPS patients being vaccinated? Part of the response is that FPS does not have Gardasil in their offices but the other part is that these women are having trouble accessing Gardasil. Taking into account the previous survey question on knowledge of Gardasil and findings, the low number of women who have received at least a dose of Gardasil could also be because women do not have information about Gardasil.

The question on “How did you find out about Family Planning?” is a question that can give insight on what sources of information are responsible for encouraging women to go to FPS (view results on Table C). This question had eleven options. These are the percentages of people

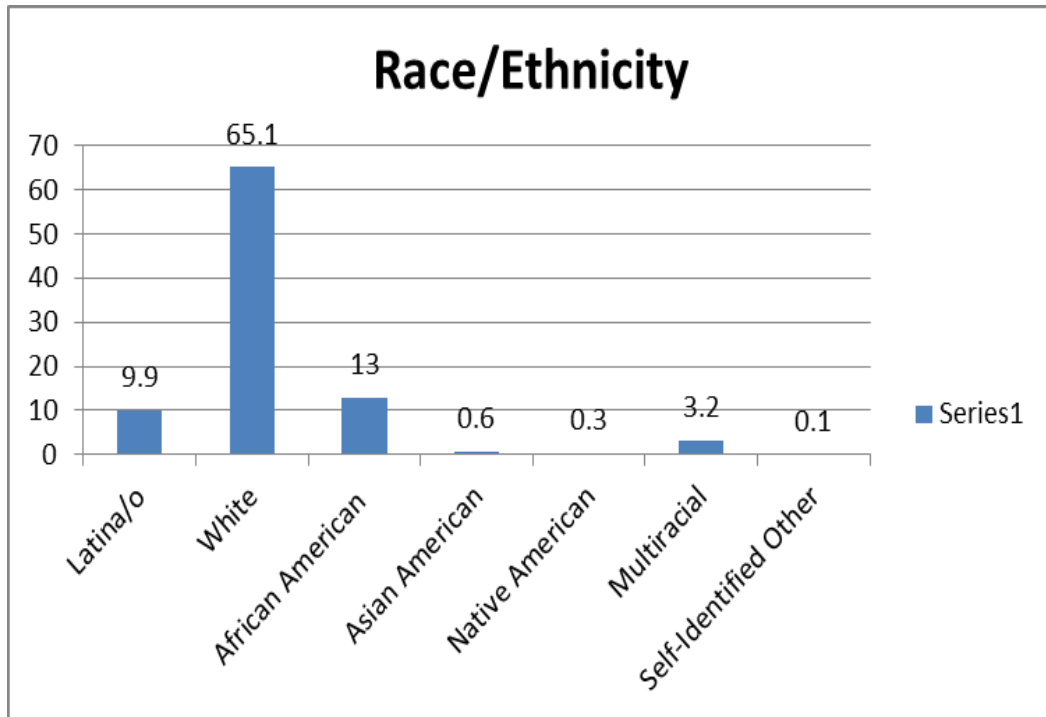
that selected each of the categories: 2.5% Poster/flyer advertisement, 0.9% Pamphlet, 3.0% Website, 75.9% Friend, 6.5% Physician, 4.3% School Counselor, 2.0% Teacher, 8.7% Parent, 0.2% Church/Religious Leader, and 13.4% Family Member. Examining these numbers, the two highest sources of information were friends and family members. For the variable of family member, the Latina/os, African Americans and Multi-racial group had higher percentages of people select this option than the White group. The chi-square demonstrates that there is a significant association (chi-square significant at  $p \leq .01$ ) between race/ethnicity and finding out about FPS from a family member (more details on Table D). This could suggest that there is strength in social networks for these groups. Assessing the data on friend as the source of information on FPS, 83.6% of Latina/os chose this option while percentage for other groups was 74.7% for White, 77.2% for African American and 73.8% for Multi-racial respondents. Though there is no significant association between race/ethnicity and the “friend” as the source for finding out about FPS, it is interesting to see the power of social networks through these variables. Specifically for Latinas, scholarship has shown that when people that they trust inform and advise them on health care choices, they are more likely to feel more comfortable making decisions regarding their health care. This is one topic that I will be discussing through the interview data.

Overall the survey data serves as a way to show a comparison between the race/ethnic subgroups in regards to how and what information they know about Gardasil and FPS. This data suggests that there are a lot of similarities between the groups when it comes to sources where patients gain knowledge from and that could be related to their similarity in class that we can deduct from the data that Family Planning gathered in 2009. Though there are similarities that exist there are some differences in percentages between Latina/os and White patients such as

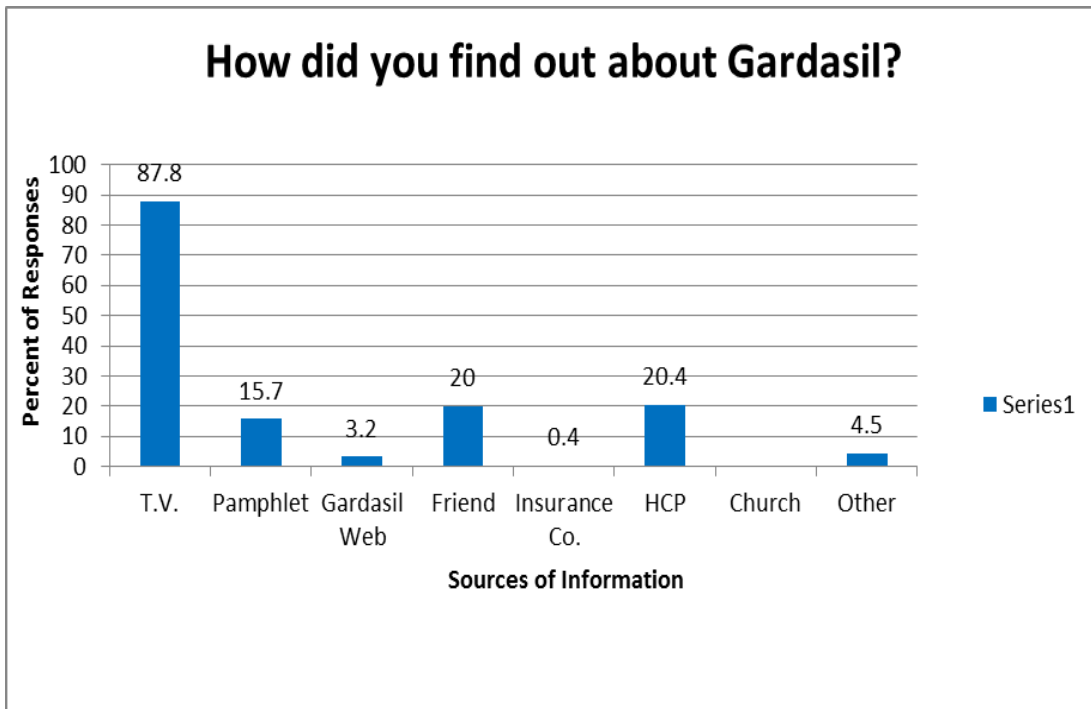
Gardasil vaccination rates and knowledge of Gardasil. In order to be able to understand the factors that influence these numbers interviews will be able to give a more detailed information on why it is that Latinas are not vaccinated and if they know about Gardasil or not.



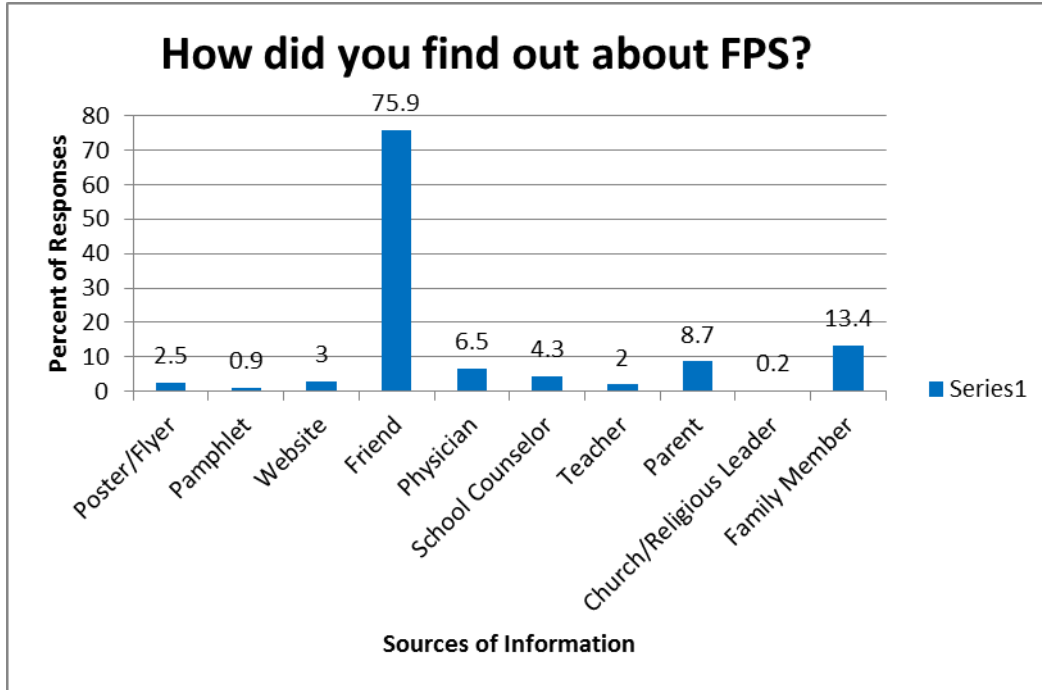
**Table A**



**Table B**



**Table C**



	Percentages that Responded Yes			
	Latinas	White	African American	Multi-racial
Have you heard about Gardasil? **	58.6%	73.6%	57.8%	56.5%
Finding out about Gardasil via T.V. **	50.0 %	64.9%	51.1%	47.8%
Have you taken Gardasil? (NS)	7.5%	9.9%	7.0%	13.0%
Finding out about FPS via Family Member **	17.9%	10.8%	17.4%	34.8%
Finding out about FPS via a Friend (NS)	83.6%	74.7%	77.2%	73.9%

\*\*Significance at  $p \leq .01$

NS = not significant

## **INTERVIEW DATA**

My goal with the interview data is to address the research question: Why is it that rates of cervical cancer screenings and Gardasil vaccination are lower than other women? I chose to speak with women about their experience accessing reproductive health care to answer this question. I will be examining four themes that arose in the semi-structured interviews and allow the women stories to explain the disparity. The four themes include lack of knowledge of medical discourse, Latina discourse on sexuality, faith, and trust and social networks. For the discussion of the women's stories I have chosen to give them numbers in order to keep their identity anonymous and due to the fact that I have eighteen interviews, using numbers will make it easier to keep track of the stories throughout this section instead of using pseudo names.

### **TRUST AND SOCIAL NETWORKS**

#### **Distrust and Violations**

The experiences that Latinas have at reproductive health care clinics become fundamental to future decision making. During my interviews with the patients at Family Planning Services I inquired about their experiences in the health care system. Two interviewees shared with me stories of negative experiences when attaining reproductive health care that became barriers for them to continue pursuing medical care for some time. I chose to speak on these two stories because I believe that each brings interesting questions to the Latina discourse.

Interviewee #13 is 22 years old and a Mexican immigrant. This interview was conducted in Spanish and this is the translated version. This experience she speaks of happened two or three years ago in Lorain when she found out she was pregnant during a visit to her cardiologist. She had been diagnosed with a heart murmur that if pregnant, the labor and delivery would put her life at risk. Here is how she found out she was pregnant:

*#13: "He grabbed me by the face and said to me, 'You are going to die! I told you that you could not get pregnant!!!..... But he made me cry."  
"I responded to the doctor, 'I know that I am going to die but I assure you it won't be because of this! Because for that, there is God.' The doctor is no one to tell me, you are going to die."*

She goes on to tell me that she was very scared and that her social worker that was helping her interpret started to cry as well instead of being of help to her. She continued to say that after she told him this that only God knows, she told me that it was all about the faith that people had because her baby girl was born without any problems after nine months of pregnancy.

What I find very interesting about this story is that this woman had trust in the doctor and that this was broken after his disrespect to her. The action of the doctor makes me think that this was a display of medical authority in which the doctor knew the right answer and that she was being deviant by not following his instructions. I also see that when this authority no longer seemed legitimate, she turned to a higher authority than him, God and that this seemed as the greatest authority to her. Thus faith became part of her decision making regarding reproductive health when she opted not to see this doctor again and rely upon faith. In her case, the faith discourse was more influential than the medical discourse.

The second story is of a Puerto Rican woman that is 38 years old. I began to ask her about the first time she ever went to receive reproductive health care and she told me that it was when she was 12 years old because her mother took her because she had very bad cramps. She and her mother were being very proactive and responsible about her reproductive care by visiting the gynecologist at an early age. However when I asked her, "were you ever scared to go to a place like this?" she answered,

*#7: "Umm... I didn't like going to the first doctor I had because he thought it was ok behind closed doors to kiss me."*

She continued to tell me that she was alone in the room with him and just in a gown. She said that she never told her mother about this experience because she was a kid and who were they going to believe, her or the doctor. She tried urging her mother to change doctors and after a while, she just stopped going for a number of years. She said that it wasn't until 7 years later when her cousin told her about a trustworthy doctor that she decided to go to a reproductive health care clinic. What I find interesting about this story that unlike some of the dominant rhetoric that states that Latina women aren't always proactive about their reproductive health care, this Latina was and for that it seemed that she was penalized instead of rewarded. This violation to her body was one that she remembered and that became a barrier to her and her ability to want to attain reproductive health care.

Reflecting on the two stories one can see that displays of medical authority that violate patients bodies and emotions create barriers of distrust that can have long lasting effects. In the first story, faith becomes an important factor in her health care choices. Faith does not always act as a tool of disempowerment and oppression of the sexual body but can be one of protection against medical authority and a tool of empowerment to make difficult decisions. I think that a lot of the time studies that show that Latinas are disproportionately not getting preventative health care compared to other ethnicities can at times be interpreted as, these women choose to not take advantage of the resources available to them and that they are the ones that decide not to take the opportunity. These stories suggest that these women's choices become constraint by their negative health care experiences. The questions that arise from these stories are: how can trust be built again when these violations have occurred? What can motivate patients to want to further medical care? I have assessed these questions by inquiring about what has brought women to FPS.

## **How did you find out about Family Planning Services?**

One characteristic that all of the interviewees have in common is that they are Latinas that are actively getting reproductive health care. Some have been coming to Family Planning Services for a very long time, for others, this visit was their first. When interviewing these women, one thing that I was very interested in learning was, what brought them to FPS? The responses to this question can be an insight to what factors work in drawing Latinas to Family Planning Services. One of the questions that I asked the interviewees was, “where did you first hear about Family Planning Services?”. The sources that they identified were a sister, a friend, from school, a social worker, a partner, and a lady from church. These multiple responses show what the sources of publicity regarding FPS actually get the women to come to FPS. More importantly, the people they identified as the ones who told them about FPS shows that trust and personal communication had to do a lot with their decision. Having someone they trust tell them that they recommend the place is very important for these Latinas.

Interviewee’s #1, #6, #11, #16, and #17 share that they found out through a friend about FPS. Interviewee’s #1, #6, #11, and #17 shared that their sister’s had come to FPS before and recommend the clinic to them. All of the women were in need of birth control and because their sisters’ were sexually active too and had previously gone to FPS, they felt that this was a place that they could go. Some of them discussed with their sister what the experience was like and how FPS functioned before they came. Interviewee #1 shares a little bit about her conversation with her sister:

*C: Do you remember what your sister might have told you about her experience here?  
#1: My sister had, you know she got pregnant early as well and she would come to do her birth control and stuff like that. And then when she knew that I was sexually active with my husband that is exactly what she ummm.. she said you come you have nothing to worry about it, it is private and that’s why I came.*

A need for privacy was important for her, meaning that others couldn't find out she was coming to FPS. In her story and that of the other women, the actual birth control and other reproductive health care resources were important in their decision to come to FPS but additionally, the kind of place that this was really mattered to them. Making sure that their sister had had a good experience was important along with privacy issues.

Another way that the interviewees found out about FPS was through a friend.

Interviewee's #3, #5, #7, #8, #14, and #15 shared that they had conversation with friends about their need for birth control, a pap smear or reproductive care in general. They also explained to their friend that they did not have insurance or a lot of money to pay for their care. From there came their friend's recommendation of FPS. Interviewee #5 shares her interaction with her friend:

*#5: My friend, my best friend. She says, well she told me well there's a Family Planning. I was like a what? Is that like a counseling for family? And she's like no, they do like pap smears and stuff. I go there, they give me like—cause I guess she had an incident and she came and got the Plan B. They gave her that. And then she started coming here and then she said she liked it. And then she's the one that told me about it. And I was alright, I'll try it. If I don't like it, then I'll go back to Women's Care. Cause this is closer, Women's Care is in Amherst. So I was like alright, we'll try.*

Her statement suggests that she had some doubt of whether or not the clinic was going to work for her but because her friend recommended the clinic she was going to try it. She shared with me that her friend had found out about FPS through El Centro, an NGO in Lorain County that predominately serves Latina/os. What is important to understand from the stories in which Latinas found out about FPS through friends and sisters is that they rely heavily on social networks to make reproductive health care choices.

The last six interviewees stated that a counselor (#2 and #9), a social worker (#4 and #13), a partner (#10), and a lady from church (#12) were the people that informed them of FPS.

They all shared that because this person that they trusted told them about FPS they decided to come. Interviewee #12 shares that at her church they had someone come to the church to talk about FPS because one of the members was a member of the church. She further explains,

*#12: ...we had—the church that I go to, one of the ladies, I want to say it was this one that she worked at. And that was just enough to say, “Okay well I’ll just go into this one.” That was kind of more of a reality of why to go in.*

Her story suggests that there are ways in which faith and reproductive health care can intersect. It also suggest that when outreach efforts are made for the community, they actually can work and recruit people. She says knowing that that the church member encouraged women to go was enough for her to want to go. What her story has in common with that of interviewee’s #2, #9, #4, and #13 are that these people are also authority figures that they listen too.

The last story that I want to share conveys the need to have someone of trust that is part of their social network to provide information on FPS. Interviewee #4’s story. Though she was a bit unsure of her title, this is the person that was very connected to health care and helped her find other resources in the community. She shares:

*#4: Because I didn’t know. I didn’t know what was going to happen. I didn’t know what was going to go on, I didn’t know how they were going to make me feel. But the lady that I worked with that let me stay with her when I was 18, the one that was a nurse, she gave me the ends and out of everything. She was completely open and honest about everything. Disease, pregnancy, the whole thing. So knowing is part of conquering the fear. And a lot of girls don’t know because nobody is talking about it especially to girls.*

She identifies “fear” as a barrier to girls going to FPS. She also points to lack of knowledge as another barrier that can be overcome through dialogue on this topic. These are some of the strategies that she believes will work because they worked for her.

The responses to how these women found out about FPS show the strength of their social networks. These women’s stories support the survey data that indicate that 83.6% of Latina/os



found out about Family Planning Services through a friend. Additionally, data shows that “a strong social network, that is, the number of close friends, was found to be positively associated with increased cancer screening behaviors for Hispanic women in a study of older Mexican women” (Suarez 1994 in Allison et al. 2005, pg. 64), meaning that social networks could be a way to disseminate information on preventive care and increase rates of cervical cancer screening for Latinas. The closeness of the informants to the future patients may be a way to overcome other barriers of fear and lack of knowledge on FPS that may be preventing Latinas from coming to FPS. Their responses suggest thinking about social networks as methods of outreach initiatives would be effective for Latinas. This move could help trust begin to be (re)built between Latina communities and medical communities.

## **LACK OF KNOWLEDGE OF MEDICAL DISCOURSE**

The next theme of analysis is interviewees’ knowledge about Gardasil, cervical cancer and pap smears. I am examining this part of the interview data because I believe that women’s choices are constrained when they lack access to information about these kinds of reproductive services. Additionally, in this section of the interview, the women point to different resources as the providers of knowledge which can be very helpful when thinking about changes in health education and reproductive health care.

### **Knowledge of Gardasil**

When examining knowledge of Gardasil I found the responses of the interviewees to fit into three categories, those that did not know about Gardasil, those that knew something vague about Gardasil, and those that felt that they were secure in what they knew about Gardasil. To all the interviewees with the exception of #7 I asked, “Have you ever heard about Gardasil?” From this question I received a variety of answers. In the first group are those that said they

didn't know what Gardasil was. I placed seven women (#2, #4, #5, #6, #8, #13, #16) in this group. There were five interviewees (#2, #4, #5, #6, #13) who said that they had never heard about Gardasil. The remaining two interviewees provided responses that were guesses about Gardasil. The reason that it is important to look at this group is in order to understand how these women understand this information and to document the lack of knowledge of Gardasil.

Interviewee #16's response highlights how women's lack of information on Gardasil can create confusion when dealing with medical terms. The following is the dialogue between interviewee #16 and I:

*C: Have you heard about the vaccine Gardasil?*

*#16: No I don't think so.*

*C: Have you heard about HPV?*

*#16: Yes.*

*C: What have you heard about that?*

*#16: It is AIDS?*

*C: No that is HIV.*

*#16: cancer?*

This exchange displays how these medical terms do not have a clear meaning to interviewee #16. Though this Latina is a patient at FPS, she is still not being provided the information that she needs in order to be able to understand the differences in diseases. When I asked her this question, though this happened toward the end of the interview and we had established trust, she became embarrassed because she felt that she did not know what these terms meant.

The danger with inaccurate information about certain preventative measures is that when people do not have access to medical knowledge, it keeps people from being able to make health choices. When I asked interviewee #8 if she had heard about Gardasil she responded,

*"#8: Yeah. I think so. What is that, a pill or something?"*

In the interview, my impression was that she was guessing for an answer in order to not admit that she did not know what this was. Seeing that she was not too sure of her answer and that her information wasn't accurate signals a need to provide more information to people regarding Gardasil.

Overall it is important to understand these seven patients do not have access to information on Gardasil and for them, the question of whether to get it or not does not exist because they have never really heard about it.

The next group of women (#1 and #3) are those that had vaguely heard about Gardasil. Both interviewee #1 and #3 shared that they had vaguely heard about the vaccine. Both interviewees at first told me that they had not heard about it but after I explained to them what Gardasil was, they both recalled hearing something about the vaccine on a commercial. Interviewee #3's response shows how hearing about it is not enough to know about a vaccine or make a decision about it,

*#3: I did see something on TV about it but I really didn't know what it was. Like what that was.*

She continues to share that she wants to know more about it because she doesn't know if she would be interested in taking the vaccine. Though both women say that she did hear about it, I wonder how pressured they felt to say that they had heard something about it. Even though they did hear about Gardasil, it is evident that they do not have detailed information about the vaccine.

The last group is the group that said they heard about Gardasil. Out of the eight interviewees who said that they heard about Gardasil, seven of them said they heard about it on t.v. from a commercial (#9, #10, # 11, #12, #15, #17, #18). The other interviewee did not say

where she heard it from (#14). Most of the interviewees stated details such as, it is the HPV vaccine, or you take it in 3 doses when I asked them what they heard about Gardasil. Most interesting, some women discussed their views and decisions on the vaccine.

Out of these responses, interviewee #10's was the most confusing and disturbing. When I first asked her about Gardasil she said that she didn't know about. However, later she said that she remember Gardasil vaguely from a commercial. After continuing the conversation on this topic she stated that she had indeed received the vaccine and that she just didn't remember a lot of information about it. From this conversation I understood that she had gotten the vaccine without knowing what it was for. Though interviewee #10 has heard about Gardasil and has gotten it, she is still missing detailed information about the vaccine.

On the other hand, interviewee #11 rejected the vaccine. She said that she was offered the vaccine and rejected it because she just didn't feel comfortable with it. It was new and she had heard it had some type of problem. She shares her hesitations to vaccinate her daughter because she "*wasn't raised like with stuff like that*" suggesting that this is too sexual for her young daughter. She was very uncomfortable with the vaccine overall.

In the middle of this decision spectrum stood the rest of the women. After getting over the barrier of not having access to information about the vaccine some women stated other factors that kept them from getting the vaccine. Interviewee #14 shares:

*C: What questions do you have about this vaccine?*

*#14: I don't have a question specifically, but I have heard it being said that a while ago, that it is good for teenagers but I also heard that so many have also died so that had me doubting. I asked the pediatrician if she recommended this for my daughter and she said yes. Then she gave me the prescription but it was too expensive and I couldn't buy it.*

Interviewee #14 points to distrust and money as her barriers to getting her daughter vaccinated.

The stories that she heard of people dying were meaningful and powerful to her because they

“had her doubting”. This fear is one that may not be her burden alone and become a factor in the decision making process for many Latinas. Additionally, in her case it is evident that she is interested in getting the vaccine for her daughter. Later on she shared that she was told that she had to pay \$400.00 for the vaccine and she could not afford it. She didn’t mention anything about other ways to be able to pay for the vaccine, which I assume is because either the place that she went to was not part of any vaccine assistance program or she was not given information about this option. She said that if it were not for the money she would have given the vaccine to her daughter. In her case, one can see how she is facing multiple barriers to being able to get her daughter vaccinated.

Interviewee #9 also points to cost and insurance as barriers to getting the vaccine. She shares,

*#9: I’ve heard it so many times on TV, all the commercials and stuff... it’s a vaccine, right? It’s cervical cancer? Ok. I’ve thought about getting it, but I didn’t know... I thought I’d go to my family doctor for that but I do not have health insurance right now, so... I don’t know, I would probably get it if I wouldn’t have to pay for it, or if it could be cheaper for me.*

This woman also attempted to get the vaccine but economic factors are constraining her choice. Looking at both this interviewee and #14, they counter the assumption that Latinas do not get the vaccine because they do not desire to get it and instead highlight the constrains some Latinas face.

Looking at these interviews, what I find interesting is that because these women do know about Gardasil, they can provide explanations as to why they do or do not take the vaccine. These interviews serve to show that Latinas are interested in getting the vaccine but there are factors that prevent them from being able to do so. The interviewees point to cost, insurance, trust, and lack of knowledge on Gardasil as constrains. Pamphlets aren’t reaching these women

and the commercials were effective but needed to be aired for longer and needed to be followed up with more information distribution. These responses also points to a need for more education by health care providers.

Through the question “Have you heard of Gardasil?” in the interviews, I am able to get an insight to the need for more education on the vaccine. These comments reflect the survey data that indicates that about 58.6% of Latinas have heard about Gardasil. However, the interview data shows what kind of information women know and what is lacking, which is important in being able to design information that can help Latinas with their decision making process. When looking at this data, it is also important to remember that these are the Latinas that are accessing reproductive health care and are experiencing barriers to attaining the most optimal care.

### **Knowledge of Pap Smears**

Thinking about the great importance of information and the power that it has to shape women’s decisions I find interviewee #18 useful in this discussion. Part of the discussion I had with her on pap smears arose from her sharing her mother’s story of uterine cancer. She said that her mother never went to the doctor and never had any check-ups. She said that her mother had a miscarriage and that she didn’t go to the doctor to get examined after the miscarriage. From there she got uterine cancer and decided to have a hysterectomy at 35 years old. I then asked her if her mother ever got any reproductive health care and the discussion on pap smears began.

Interviewee #18 shares,

*C: When did you get your first pap smear?*

*#18: Well like at 23 years old.*

*C: Why after that time did you decide not have them done?*

*#18: I didn’t think that I need it.*

*C: Nobody told you anything?*

*#18: No one told me anything. I didn’t know what a pap was for.*

She continued to tell me that she did not really understand that people were supposed to have these every year or what they tested for, even today. She explained to me that she didn't get pap smears even after she had her first child because she didn't know that they were necessary. This example suggests that knowing about the procedure is not enough, she needed to know what it was, why it was necessary to have it and how often. I asked her when it was that she found out about pap smears and she explained her story.

*#18: When I got sick with hemorrhages because once I was going up some stairs and I began to bleed too much. I went to the doctor and the doctor told me that I had a cyst the size of an orange and that we had to remove it or give me medicine so that it went away. But then they ran some test on me and told me the cyst was from birth. I have had it all of my life. I had never known this. Throughout the time it kept growing and it had taken 23 years for it to get to that size. So they were going to give me medicine to make it become small again. Then it would take another 23 years to become that big.*

What this story tells is that when there is a lack of knowledge on pap smears, the consequences are that women are less likely to get the screening and do so regularly. Her story conveys that her mother's experience and her experience with her cyst brought her closer to reproductive health care. However, what her story also shows is that knowing about a pap smear is not enough. Her mother's experience, having a child, and then experiencing the cyst were all experiences that introduced her to a pap smear but were not enough to establish a meaning of its importance. This was a common trend that I found with the other interviewees.

Like interviewee #18, there were a number of women (#2, #3, #5, #9, #11, #12, #14, #15) that had limited information regarding pap smears. Most of the interviewees gave me a response similar to interviewee #11 who states:

*#11: I know they check you for if anything that you have. And if anything is normal. They take a little swabs or whatever they call it to test if everything is okay or normal.*

She explains that she understands what the pap smear is with some vague terms and that this test is important to her. Having access to reproductive has helped her gain an understanding for pap smears but like the other interviewees, she needs to have more information about the procedure.

There were other interviewees (#1, #6, #10, #4, #6) that simply understood that pap smears are a routine procedure but also were not able to share with me the reason they get it or what results mean. For example interviewee #10 responds to the question of what she knows about a pap smear with the following:

*#10: The only thing that I really know is that if you are sexually active you're supposed to get a yearly pap smear.*

She conveys that the pap smear is a routine to her that she must follow. Knowing that it is something that she had to do is good because it encourages her to actually come to FPS and have the exam. However, not knowing what the exam is for keeps her from having the fullest amount of information regarding her health care.

Though there were two interviewee's that did not know about pap smears (#13 and #17), the interview data show that most people know something about pap tests but that there is still information lacking on what the exam tests for and the meaning of results. A study conducted by Allison et al. (2005) states that "knowledge of an exam existing was lower among Hispanic women in the study (92.1% compared to 100% of non-Hispanic women)" (Allison et al., 2005:65), which supports the findings in my research. In the structure of the interview, this was one of the last questions I asked and I asked it at the end because I wanted them to feel comfortable with me. The data point to a missing parts of information. If Latinas learn what a pap smear test is, then maybe women who do have conversations about pap smears with their family/friends could actually explain to others what they are. Additionally, studies show that



there is a strong connection between lack of pap testing and the disparity of cervical cancer incidence and mortality rates among Latinas (Thompson, Coronado, Solomon, McClerran, Neuhouser, & Feng, 2002 and Allison et al. 2005). This association makes the need for information on pap smears a priority for health education for Latinas.

### **Knowledge of Cervical Cancer**

In order to get an insight into the disparity of cervical cancer for Latinas, I inquired about their knowledge on cervical cancer. To all of the interviewees with the exception of interviewees #5, #7, and #16 I asked, “what have you heard about cervical cancer?” in order to gain a better understanding of what kind of access they had to knowledge of this disease. From this question there were three trends present. The first trend was that of the five patients (#1, #8, #11, #13, #18) who felt that they really didn’t know anything about cervical cancer. The answers range from, “I don’t know much about that” to more complex answers such as that of interview #1. She states,

*C: What have you heard about cervical cancer?*

*#1: Nothing because I never knew anyone in my family to ever have anything like that. I think that if I knew someone, I would probably know more.*

For interviewee #1, she points to the lack of the lived experience with cervical cancer as the factor responsible for why she does not know about this disease. There is however a need to understand that medical communities are responsible for providing health education to patients and they are responsible to do so for all patients. This lack of knowledge of cervical cancer is an indicator that there is a gap in the education being provided by health care providers in the community. Family Planning does give education sheets on cervical cancer but there must be more done to get information to everyone in ways that are assessable to multiple groups of

people. Additionally, interviewee #1's story brings to light the importance of having to experience a disease in the family in order to actually be able to understand it.

Looking at these women's stories, four interviewees ( #4, #6, #17, #18) stated that they had history of cervical cancer in their families and interview #15 said she has HPV and it became cancerous a couple of years ago. Interviewee's #4, #6, and #17 expressed that they felt like they knew some information about it because of their experience. Interviewee# 18 felt that she didn't really know about this disease because she wasn't too sure what happened with her mother and her case. For her there are still a high level of confusion and lack of information about the disease and her mother's case. In her case, having a family member experience a gynecological cancer was not enough to make her feel informed and that points to a barrier to access of reproductive health care education.

The second trend in these interviews regarding knowledge of cervical cancer was interviewees that had heard about cervical cancer and felt they knew something about it. These five interviewees (#3, #6, #9, #12) responded by saying that they had heard about it but didn't know what caused it but they knew it was bad. I was not able to inquire where it is that they heard this from.

The last trend was that of patients that felt like they know about cervical cancer. The way that I grouped these interviewees was according to the detail of the explanations that they gave regarding cervical cancer. These interviewees' (#2, #4, #10, #14, #15, #17) responses ranged from describing cervical cancer as connected to pap smears and HPV to others that said they just read about it online without providing too much explanation. Though these are the interviewees that told me they did know about cervical cancer, some of them felt like they did not know enough and couldn't provide me with too many details. For example, interviewee #4 is a college

graduate who has family history of cervical cancer and she shared that she did not really know much information about it. She did tell me that cervical cancer was what they check for with pap smears but also told me that she didn't know too much. This makes me question where the sources of this kind of information are and what empowers women to search some of the information on their own. Her education provides her resources that women who have less education may not have, yet she does not feel like she knows a lot of information about cervical cancer. Her experience with her family brought her closer to the issue but that was not enough information for her to be able to feel like knows about cervical cancer. The optimistic part of the responses to this question is that this last group of interviewees is the biggest group of them all. A possible explanation is because they are patients at FPS meaning that FPS is reaching patients.

The interviewees' stories signaled family members experiences, the internet, FPS and other health care institutions as sources of knowledge on cervical cancer, Gardasil and pap smears, with the most common being family members and their experiences. If family members were addressed more often during the explanation of diagnosis and the diagnosis provided was comprehensible to the family, this could become of method of health education for women who experience cervical cancer in their families. What I find important when examining the responses to the questions regarding knowledge of pap smears, cervical cancer and Gardasil is if these women do not know what the connection between these different medical terms are, how is this lack of knowledge constraining their choices and what does this show about the disconnect between the Latina and medical discourse? Why would these Latinas feel they should make the choice to take Gardasil or have cervical cancer screenings when they do not know what they are for or the importance of them. These are the women that do access reproductive health care and their stories show that there are gaps in the amount of information that they know about these

topics. These interviewees' responses point to a need to have more education regarding these topics for Latinas. These women's stories point to a need to improve methods of education for Latinas and thinking about more holistic ways of serving them.

## **LATINA DISCOURSE ON SEXUALITY**

My main objective for this research is to find ways to decrease the number of Latinas whose lives are affected by cervical cancer. A way to accomplish this is by making preventative, reproductive health care available to Latinas. There is a need to understand what culturally appropriate health education would look like for Latinas. One way of gaining insight on this is by examining how Latinas learn about sex. The way that they learn about sex can point to strategies that are in place that work and those that occur that do not. The stories may also point to parents concerns when having these conversations. Addressing these factors can allow for more accurate information to be disseminated to these Latino communities.

Research in the area of communication between Latina mother-daughter dyads opens by reporting that Latinas have disproportionately higher rates of pregnancy and higher rates of STD/STIs (Baumeister, L.M., Flores E., Marin B.V., 1995; Gilliam, 2007; Guilamo-Ramos, V., Jaccard, J., Dittus, P., Collins, S., 2008; Hutchinson, K.M., 2002; Rafaelli, M., Green, S., 2003) and this could be partially explained by the way that Latina mothers and daughters are communicating about sex. When exploring information about the conversations that Latina mothers and daughters are having regarding sex much of the information states that Latina mothers do not talk to their daughters enough and this is correlated with higher pregnancy rates and higher rates of STDs. Additionally, studies by Menses, Orrell-Valente, Guendelman, Oman and Irwin (2006) and Guilamo-Ramos et al. (2008) state that Latina mothers have very high

levels of discomfort and at times do not have the resources they need to be able to engage their daughters in these conversations.

In my interviews with patients at Family Planning Services, one of the questions that I asked the women was, when did you first hear about sex? In some interviews I followed up with the question, did you talk with your parents about sex? From these two questions I saw four trends displayed by the interviewees. The first trend was those that did not have conversations about sex before they had their first sexual intercourse. The second trend is of the women that first learned about sex through a conversation with a family member. The third is of women that learned about sex from another source first but then also had communication about sex with a family member. Last is the group of women that learned about sex from other sources that were not their family and did not have communication with family members about sex. In these interviews what I am searching for is how Latinas are communicating about sex and who/what they are signaling as the sources of information.

### **Group 1: Latinas that do not have conversations about sex**

The first trend of interviewees' stories (#7, #11, #15, #18) provide us with information about the silences regarding sexuality that occur during their adolescence. Interviewee #11 begins by sharing that she believes that sex is a private thing. She also shares that she waited until she was 19 to have sexual relations. She explains that when growing up, she wasn't too curious about sex so doesn't remember having conversations about it. In her story, she says that *"it wasn't anything that would come up,"* displaying the lack of conversations that she had about sex. Additionally, she shares this idea of lack of interest in wanting to know information about sex.

The theme of lack of interest in knowing about sex is one that is shared by interviewee's #15 and #7. Interviewee #15 stated that she did not speak with anyone about sex either because she wasn't too interested in boys back then. Interviewee #7 shared that she read a book titled *Period* with her mother and that was close enough for both of them to sex as they could get. The lack of interest in wanting to engage in these conversations can indicate that there are high levels of discomfort regarding the topic for both the mother and the daughter. The interviewees explained that if they are not having sex, they have no need to talk about it. McKee and Karasz (2006) in a study on direction of communication of sexuality between mothers and daughters state the mothers had a high level of embarrassment when it came to this topic and that both the mothers and daughters indicated that daughters were not always receptive to conversations on sexual health. McKee and Karasz (2006) explain that this happens because both the mothers and the daughters do not want to engage in conversations are of high-conflict risk.

As a contradiction to these interviewees' lack of interest, all of these interviewees later shared that they wished that they had been more prepared for their first sexual relation and that more information about sex itself and contraception would have been the way to do so. Though these women do understand what sex is now that they are older, they were missing this knowledge when they were growing up.

To tie all of these group's interviews together, interviewee #18 shares with me that she heard the word sex when she was almost 15 years old. She said that it really did not mean anything to her and that she really did not know anything about sex until the day she was married. I continued to ask her about her experience regarding sex and she responds:

*C: What did you want to know?*

*#18: I wanted to know everything (she giggles). I wanted to know but my mom never communicated with me and she never told me anything.*

*C: You would have liked her to talk to you?*

*#18: Yes. She never... she didn't even tell me I was going to begin menstruating or what it was. She never told me anything. She never talked to me about that topic.*

*C: Why do you think that was?*

*#18: Because of ignorance. I do not classify my mom as ignorant, no. It is lack of information. Because of ignorance because they don't talk to their kids about that. Because of lack of information because in Mexico there are a lot of myths and taboos, things like that. So then they, "I can't talk about that because that is my daughter. How could I ever talk to my daughter about that?" Maybe they could talk about it with someone else but not their daughter. Or somebody else can tell her [meaning the mother's daughter] but not me because I am her mom. That's what I think it is.*

What is powerful about her story is that it reveals her desire to actually want to know information about it. She explicitly blames the lack of information regarding sex to the silences of women like her mother. She also signals to sex being seen by her mother and other as taboo and conversations as a fulfillment of bad myths. These understandings of sex are what reinforce silence between mothers and daughters.

This group of women shows that there is lack of communication regarding sex and that they wished that their mothers had talked to them about it. These women experienced high levels of worry and unpreparedness when it came time to experience their first sexual intercourse. All of them shared that they wished things would have been different along with a high level of discomfort when thinking of their mothers as the source of information. Their stories can suggest that some Latinas have difficulty engaging in these kinds of conversation and that there is a lack of conversation happening among some Latinas. Scholars McKee and Karasz (2006) state that there is a need for *confianza* (trust) to be built in order to overcome the mother's embarrassment and daughters' resistance to these conversations. This lack of conversations about sex can function as a factor that keeps women away from reproductive health care because they do not know about it.

## **Group 2: Latinas that first learned about sex through conversations with family**

Opposite to group one, the second group of women (#3, #4, #6, #17) are those who first received information about sex through a family member. The distinction between this group and the others I will be discussing is that when these women find out through their families, fear tactics are used when delivering the message. The advantage is that these women feel more comfortable actually conversing about sex because of these conversations. For interviewee #17, she said that she found out about sex at age 10. She said that she had older siblings that were already sexually active. Below is our conversation about how she first found out about sex:

*C: Did you ever talk to your mom about sex?*

*#17: Mmm I'm sure it came up. I didn't have to go to her though and say let's talk about sex. It was just always something that everyone kind of knew in the household. Like I said, older siblings that were like 4 and 5 years older than you, you know. They were already...it was just something understood. Everybody could openly talk about it 'cause there were so many females in the house.*

She explained that learning about the meaning of sex through the mistakes of her siblings functioned for her as a type of birth control. She said her sister got pregnant at 14 and that it was very hard for her family and that all of her household knew about this and experienced the hardship. Thinking about knowledge of sex as a form of birth control in some ways reveal that there is fear involved when learning about sex. Fear could make a person feel unprepared for sexual intercourse or afraid of sexual contact. Though fear may be involved in the process of learning about sex, interviewee #17 feels comfortable discussing sex with family which can be a positive tool when attaining health care. However, it is interesting to see that in this dialogue she never used the word "sex".

Similar to interviewee #17, interviewee #6 stated that she first found out about sex because of her sibling. She shared that she used to go through her brother's stuff and that she



found magazines that made her aware about sex. I inquired about her gaining knowledge about sex:

*C: So did your mom talk to you about this?*

*#6: Mm-hmm.*

*C: What did she tell you?*

*#6: She just, you know told me if I was sleeping around and using protection.*

*C: What did she tell you? To not sleep around? Or that it happens? What did she tell you?*

*#6: No she just told me that when it does happens, to protect myself. Always protect myself.*

Although the conversations with her mother seems like it was not very detailed in information, she later explained that her mother did bring condoms up in the conversation. This works as a preventative strategy for her and other Latinas. It is important to note that other interviewees in this group encountered a lack of clarity and detail in these conversations.

Sometimes parents aren't the source of knowledge that Latinas prefer when it comes to attaining information about sex. Interviewee #4 shares that her first time she found out about sex was from her cousin Rosalinda. She said that her cousin had already had her quinceañera and then had her child at 16. From speaking with her she found out about sex. Similarly, I asked interviewee # 3 about her first conversation about sex and if it was with her parents, she responded:

*#3: No, no! My dad, he was a pastor so he was really—you really couldn't talk to him about anything. He's just, I guess he was on his own thing. And my mom, I really didn't talk to her about it either. So it was basically my friends that I knew about it. Or my sister cause she was doing it.*

She felt that because her parents were very religious that she could not talk with either of them about sex. She was both embarrassed and shared she would be in trouble because she was asking questions about sex. Her feeling of embarrassment and feeling like she would be in trouble when

asking questions frame sex as a thing to be afraid of. Being afraid of sex makes people not be as prepared when their first experience happens. For her the alternative, her sister, was the better option and source of information.

These stories reveal the impact that family members can have when providing communication regarding sex. They are crucial because they may be the sources that provide deep connections in order to have a continued dialogue. What one can see in these conversations is that sex can be framed through fear tactics as something to be scared of. Additionally, some of the conversations had may not provide the most complete or accurate information. However, these conversations do provide dialogue and information which is empowering to Latinas.

### **Group 3: Learning about sex at school facilitates conversations about sex with family**

Examining how one first learns about sex shows what kind of resources are available to the person and what factors construct the dynamics of the conversation. For the women that first learned about sex from a source other than their family, this source was school (#9, #10, #14, #12). This group of women used the knowledge gained at school to have discussions with family about sex. Interviewee's #9, #10, and #14 first found out about sex in middle school. All of them shared that they were introduced to sex through a health education class. What was common was that the conversation began with puberty changes and then moved to sex from there. For interviewee #9, she said that the class helped facilitate a conversation with her mother.

Interviewee #9 shares,

*#9: It wasn't really uncomfortable for me because I knew I could talk to her about it because she had me and my sister very young. She had my sister at 18 and me at 20. So she just didn't want me to go through that without being prepared for it.*

She also shared that conversation with her mother became a lot easier once her mother knew that she was sexually active. What is key in this mother-daughter dyad is the level of comfort that is had in order to have the conversation.

Interviewee #10 went to a Catholic school. She said that she was shown a video of the reproductive health care system. Later she continues to explain that her parents talked to her when she was 14 because they were alarmed by the number of girls her age getting pregnant in Cleveland. She explains:

*#10: They told me [pause] you know, it wouldn't be the smartest thing you've ever done, but if it happens, you know [pause] um... you know, if it happens, we'll take care of it. But they actually said that if I were to get pregnant at a young age, they would rather me have an abortion because it's kind of a disgrace to the family for a 14 year old being pregnant. My family was very strict when I was younger, so it was kind of like, I wasn't even allowed to talk to boys until I was about 14, 15 years old. They didn't really believe in boyfriends and all that. Very strict; if I were to hang out with any of my friends the parents had to be there or some older adult.*

Her discussion displays that family status is connected to sex, which may be shared by other Latino/a families. This family status does not come from money or material assets but the values and the image that family members display that bring respect to the family. For her, her choices on sex are not only about her and her body but also about her family. The strictness that she speaks of is an outcome of the cultural rules that her family follows and she had to abide to. In her story one can see that her description of the “strictness,” “disgrace,” and “pregnancy as a mistake” are ways in which values and warnings are being transmitted to her. Thinking about young pregnancy as a mistake brings the factor of fear into play, making sex a dangerous thing with bad consequences. When fear tactics are used, it can distance the person from being comfortable when dealing with sex. One can see that even when conversations are being had about sex which are informative, some conversations could make some Latinas feel that they are

unprepared for their first experience or afraid. But again we see the power of these conversations and how they form an understanding on what sex means. A question that arises here is how to address the meaning of pregnancy and family status in a health education class.

Interviewee #14 shares with me her first experience learning about sex. In her story she points to the factors of tradition and cultural norms through generations as factors that shape her understanding of sex:

*C: Can you talk to me about the first time that you heard about sex?*

*#14: About sex? I think that was when I was in 7<sup>th</sup> grade in a class on education because before it was taboo for parents to talk to children about sex. You didn't hear that too much in the homes, sex being talked about or anything like that. But at school there was a class that was about health and they talk to us. They talked to us a lot about [sexual] relations and how to prevent pregnancies and all of those things. It was a very interesting class.*

*C: Did you ever talk to your mother or father about sex?*

*#14: Oh yes, I would ask my mom (laughter).*

*C: What did you ask her?*

*#14: When they talked in school and the teacher would say something, I would go ask my mom. She would openly answer me. One time I remember that she got mad at me about, I asked at what time could one have sex. And she scolded me because of the taboo that they had, why was I asking that question? But she answered me, she said that, I still remember, I was too young to have sex but she did tell me that when I was prepared, you will see. I didn't have a boyfriend at that time, she told me, when you have a boyfriend you let me know so that I can prepare you.*

She illustrates complexity of conversations with mother. Conversations can occur but that doesn't mean that discomfort and boundaries will be excluded from the conversation. I think that it shows that there are different degrees of openness that can be had with conversations about sex. The daughter acknowledging that there is a taboo regarding sex makes this conversation very interesting. This conversation shows that there are ways in which some information can be shared while still having to negotiate with taboos on sex.

The last interviewee in this group is interviewee #12. Like interviewee #14, she shared that her friend from school really was the one who taught her about sex in the 4<sup>th</sup> or 5<sup>th</sup> grade at

school. Though she had conversations with her parents about sex, she said that they were not very informative and that there were boundaries. So instead, she signaled her friends at school as her greatest resources of information regarding sex. She said that her father used a lot of code-switching to talk about sexual things. Additionally she shared that,

*#12: Sex is great. God created sex, there's nothing wrong with it. It's just knowing when it's right, who it's right with and just putting your faith in God.*

For her, sexuality and faith are discourses that are very intertwined. Similarly to the rest of the women in this group of interviewees, school and friends at school helped facilitate the conversations about sex.

Group 3 shows how health education at school can help facilitate or launch conversations with family about sex. In these stories cultural values and faith became part of the discussion or the shared knowledge regarding sex. Factors that was crucial to making these conversations happen were trust and comfort. Finding a high level of comfort is one of the challenges for these conversations on sex. When analyzing the mothers' comfort with conversations of sexuality across ethnic groups, a study conducted by Meneses et al. (2006) looking at White, Black, Latina and Asian women found that Latinas and Asians had the greatest levels of discomfort about having conversations of sexuality. A point of reflection is that these women did experience the conversations with their parents and these are the women that are receiving reproductive health care.

#### **Group 4: learning about sex outside of the home and not conversing about sex at home**

The last trend was that of Latinas (#1, #5, #8, #13, #16) who first heard about sex through places that were not their family and had no communication with their family on the topic of sex. Interviewee's #1, #5, #8, and #16 all stated that the source of their first knowledge of sex was at

school but this did not function as a way to facilitate conversations about sex. Interviewee #1 learned about sex during her Home Ec class in high school. She spoke very strongly about how her mother is very uncomfortable talking about sex even now with her though she is an adult and has children. Interviewee #5 stated that she learned about sex in her family class in middle school when she was beginning to become sexually active. She said that she became sexually active when she was 12 and that she had a terrible relationship with her mother. Interviewee #8 said that she heard about it in school when she was 15 years old from her friends that were having sex. She also said that she never spoke to her parents about sex. Interviewee #16 stated that she learned about sex through a class called Sexual Orientation in Mexico. She says that she learned about menstruation, reproductive systems and what happens when people have sexual relations -- meaning pregnancy. She explained to me her communication with her mother with the following,

*"#16: Back in that time, sometimes the mothers were afraid to talk with us about things that for one reason or another they didn't tell us."*

This statement was the opening of her discussion regarding her mother's silences regarding sex and sexuality and her value of virginity. The common thread for this group of Latinas is that their parents were silent when it came to these conversations and though they were able to gain information in other places, they lacked the communication within family.

Similarly, interviewee #13 explained to me what sex meant to her. For her, sex could only be enjoyed with her husband. She was a virgin until marriage and was very happy with her decision. She whispered to me in the interview that she really didn't know about sex until she had her first intercourse with her husband and that it took her a while to get comfortable about

sex. While we were having this conversation she was very nervous. I proceeded to ask about conversations with her family, she responded:

*C: Can you talk to me a little bit about your family. You said that everything starts at home. Did they talk to you about sex in your home?*

*#13: Actually because they didn't talk to me is the reason why I didn't go from here to there (referring to being loose). Because my mom is a woman that was born in a ranch. She is very conservative and is very embarrassed about that and because she is embarrassed about that, I am also embarrassed and I never..... my father is a bit special. You can't really talk to him because he is a man and I say that the men understand themselves with the men. Women not so much. And because my father is a really special person, I don't really talk to him.*

She says that not talking about sex is a good thing and has kept her a good woman. She defended her virginity and stated that sex was only enjoyable with her husband. I think that it is necessary to understand this point of view and the logic. Some women like interviewee #13 feel that having conversations about sex is not a good thing. When health care providers approach this topic of conversations about sex framing Latinas believes on the topic as wrong, many feel excluded. Finding ways in which health education can be respectful of this and find ways to provide education would be the way to address her desire. This is an example of a question in which cultural norms intersect with sexual health and that through more dialogue can be better understood.

What is very specific to this group of women is that they only heard about sex outside of the home. I think that in some ways this adds a mysticism and mystery to sex that some of them find it a problem and that others find normal and beneficial. Though some women like interviewee #13 state that it was fine that she didn't know about sex until she was with her husband, it is important to remember that other women said that they wished they had been more prepared for their first experience.

Overall, conversations about sex are not only about whether to have it or not. These are the times where education on preventative health measures such as contraception are good to be shared. Using fear tactics can make women feel more unprepared for their first intercourse. These conversations on sex signal to three main sources of information, family, school, and people in their social networks that they trust. It is important to understand who and what the sources of information are for Latinas so that health care institutions can use these sources to disseminate greater amounts of accurate information. Additionally, factors that were discussed that were linked to sex were family status, virginity, pregnancy, honor, disgrace, promiscuity and faith. Health care providers must work with Latina communities to address some of these factors in health education. Though these factors may be important to other women, Latinas have unique ways in which their cultural norms and faith shape their sexual choices. Thinking about how sex is not just about the woman and her partner for these Latinas but about their social context is very important. An innovation to health education would be to find ways to educate the parents and their concerns using this kind of language. Taking these factors into account along with the high levels of discomfort, lack of knowledge regarding sex and sexual health, and embarrassment, training for mothers could be holistic and daughters could gain more information at young ages that could grant them access to information about contraception and other preventative health measures. Knowledge on sex and contraception is so vital to preventing cervical cancer. Contracting HPV can be from the very first partner a woman has and may not become dangerous until much later on in the woman's life. For this reason, conversation about sex that spread knowledge regarding reproductive health care options is vital.



## **FAITH**

When thinking about improving health care for Latinas and seeing where discourses can connect, faith was signaled by the Latina interviewees as an important factor in their reproductive health care choices. Faith functions differently for all of the patients. There were two overarching trends in the experiences that these Latinas had with faith and reproductive health care. I have decided to only discuss these two trends and exclude from my analysis those that did not find faith as an important factor and those whom I did not have an opportunity to ask this question to. I have done so because dominantly, the medical discourse does not intersect with the faith discourse. The two trends include experiencing faith as a barrier and faith as a space of negotiation for their health care choices. In these stories, it is interesting to note what discourses are in conflict or triumphant. Overall, it is important to acknowledge what role faith plays in these Latinas reproductive health care choices and sexual choices.

### **Faith vs. Medical Discourse: Faith as a Barrier**

Faith was experienced as a barrier by a Latina who was being denied reproductive health care services because the services did not coalesce with religious doctrine. Interviewee #18 is a woman of faith but doesn't go to church regularly. She considers herself culturally Catholic. For her when thinking about the question of faith and reproductive health, she experienced a situation where it wasn't exactly her abiding to her rules of faith that kept her from getting the health care she wanted but instead the faith of the institution providing the care restricted the choices she could make. She explains:

*#18: .....I also told her that I wanted to go to a place where they could give me pills or injections, I wanted a method. I wanted to get operated. I wanted to get operated after my second daughter was born. But I didn't get operated because the hospital was Catholic and they don't operate. For me to get operated I would have needed to go all the way to Michigan and for the baby to have been born there so that I could have gotten operated there. That is why I didn't get operated.*

Her story displays that though she is a woman of faith, she feels that her reproductive needs are in conflict with some of the Catholic religious doctrine which constrains her reproductive health care choices. By not providing her a tubal ligation, religious belief was imposed on her body though she did not agree. She shared with me that she was nervous about it because she did not want any more children. Though this operation is a permanent method of contraception (sterilization), because she was not able to attain any other method of contraception, this was the method she wanted and was also denied. Hearing from Interviewee #18 that sterilization was the only method she felt she could get displays her lack of access to reproductive health care and lack of options. When she does gain care, it is not one that provides many choices. In her story, faith conflicted with her reproductive health care choices but she still lives her life as culturally Catholic.

Faith functions as a barrier when it creates silences in conversations about sexuality because these silences produce a lack of knowledge of information regarding reproductive health care options. The next example is of interviewee #15, a 44 year old Puerto Rican with HPV who spoke to me about how her family was very strict and how they were not open to talking about sex because they were very Catholic. When speaking about her sexual experiences she said,

*"#15: ... Like I said you know I wish I would have known more back then because really all of this wasn't out with, all of this that I have you know. And I said I wish I would have been more careful or known how to just carry my own rubbers in my purse."*

She blames her lack of knowledge about contraception and reproductive health care to her mother's silence influenced by Catholic cultural norms. She explains,

*“#15: Yeah I think it has a lot to do with that [religion]. Not talking about uh being open, because you know their parents [meaning her grandparents] were very strict in the way they [her parents] were raised, way stricter than me and I was raised strict.”*

Interviewee #15 explains that her mother’s strictness comes from the way that her mother was raised by her grandparents. So this problem becomes one that crosses generations. Her comment, “wishing she would have known more” is in reference to her contraction of HPV because as she says, she didn’t know about condoms. She believes that she contracted HPV from a partner at a very young age when she did not really know about contraception. She is resentful in many ways because of her lack of knowledge and how her parents didn’t talk to her about this. In her situation, faith helped shape her parents silence regarding contraceptives which produced her lack of knowledge on contraceptives that constrained her choice in being able to have safer sex.

Lastly, interviewee #2 experienced faith as a barrier due to her fear of becoming a “bad girl.” She spoke about how Catholic culture sets rules about how girls should act especially the rule that people shouldn’t have sex before marriage. She was raised Baptist by her adoptive parents and her biological parents were Catholic. Both faiths have influenced her religious beliefs. In the interview we discussed her first sexual experience and her reproductive health care choices. She said that she became sexually active at 14 or 15 and wanted to get on birth control but was nervous to come to a place like Family Planning. Below is her response to why that was:

*#2: [Be]cause I was young. I didn’t want people to say, ‘what is she doing there?’  
(nervous laughter)*

*C: Do you feel that you would have been judged because you were here?*

*#2: Yea*

*C: What do you think they would have said about you and who is they?*

*#2: Just adults you know in general. Anyone that knows what Family Planning is. I would have thought that they probably said, ‘she’s a bad girl. Anybody that goes there is bad.’*

*C: So did you feel like you were being a bad girl when coming here?*

*#2: Um... a little bit. When I was that young yeah.*

For her, these Catholic cultural rules brought her feelings of guilt and shame that constructed her as a “bad girl.” The fear of being judged kept her from going to Family Planning right after becoming sexually active. She said that she came when she was like 16 or 17 after she had more information from people like her friends and a counselor from school. For her faith produced a desire to abide to Catholic-cultural rules which in effect has made her feel guilty about her actions and kept her from going out publicly to a place like Family Planning Services which would incriminate her a rule-breaker. Being able to understand how faith produces feelings of guilt and how this becomes a factor in making reproductive health care choices is important for the medical communities to understand in order to be able to welcome more patients of faith.

When examining the way that guilt is closely tied to faith and influences reproductive health care choices, many of the interviewees experienced feelings of guilt after having premarital sex. Interviewees #1, #2, #3, #9, # 10, #14, and #16 shared some kind of guilt for their choices however, many of them showed me that faith for them works in more complex ways than just the binary of faith being good or bad for making reproductive health care choices.

### **Faith vs. Sexual Discourse: Faith as a Negotiation**

Examining faith as a barrier functions within a binary in which faith or religion is either good or bad. Some of the women’s stories and their descriptions of the process that they undertake to make reproductive health care choices and choices regarding sex show that they undergo a negotiation in which they set new strategies to make these decision. Eight women’s stories portray this trend (interviewees #1, #3, #7, #9, #10, #11, #14, #16). These stories also highlight what discourses are part of their experiences. Analyzing the factor of faith in reproductive health care choice functioning as a negotiation process challenges the dichotomous way of thinking about the function of faith for Latinas.

The first example is of my first interviewee sharing her ideology on premarital sex and how that intersects with faith. She states,

*“#1: I felt [guilty] because of the sex and being [that] my parents always talked to us about the Bible and stuff like that ....., well I’m doing fine if I knew that this is the guy that I want to be with, then I’m not going to be doomed or go to hell.”*

She shared with me that she became sexually active at 15 years old with the man that she married. She said that it would have been a disgrace to have not married him but because he was the man that she married and stayed with for 17 years, this choice was acceptable. The rule she negotiated with was premarital sex being amoral which came from her Catholic upbringing. The criteria she created during her negotiation was that if she were to have premarital sex, it would be acceptable because her sexual partner would become her husband. She was not considered a ‘bad girl’ because she had thought about her decision and fit the criteria that she created as appropriate. Her negotiation between what it means to be a ‘good girl’ vs. a ‘bad girl’ challenges the virgin/puta (virgin/whore) binary.

Ayala (2006) helps explain both the binary of sexuality that Latinas grapple with and the ways that Latinas disrupt the binary. She explains that, “These heterosexuality scripts are not located just within the women but are situated in a broader context of culture and structure.” Her findings in her interviews with 11 mothers and daughters were that by these girls becoming “players,” dating men and going outside of the home, they were implying that they can respond to their own needs and desires which contradict and challenge the idealized image of the self-sacrificing Latina (Ayala, 2006). She goes on to explain that, “the power component of sexuality is implicit in these sexuality narratives, where virgin/puta binaries are being disrupted” (Ayala, 2006:39).

The virgin vs. puta dichotomy describes women's sexual behavior being either pure, a virgin or a whore and sexually active or suggestive. What the interviewees have revealed to me is that they do not only exist in these two categories but instead through internal negotiations, they have created a third space in which they can be women of faith who have pre-marital sex when deemed appropriate, and still feel like good girls, like interviewee #1.

Interviewee #1 was not the only Latina that identified criteria that she created that would give her the liberty to have pre-marital sex and keep her from hell as a good woman of faith. In the case of interview #3, her father was a pastor of a Christian non-denominational church. When I asked her if her faith had to do with her decision on sex she said yes. I asked why and she answered, "*#3: Because our religion was you don't have sex before marriage. That's what it was.*" Then after discussing rules set by her faith for a bit, I asked her if she ever experienced conflicts with her faith she responded yes. I asked her to speak about her experience when becoming sexually active, she responded:

*#3: Maybe like 16-17. Yeah, around 16 or 17. I tried. And like I said it was an on and off type of thing. I tried not to have it. Then I'll start and then try not have it. So you know it would be like that little battle. You know you're not supposed to have it but you fall, you do that, you do that.*

She says that she works very hard at abiding to the bible and asks forgiveness when she doesn't. Her strategy in the "little battle" is to ask for forgiveness. In her "little battle" the faith and sexual discourses are in conflict and are resolved by her strategy. She shared that she did feel guilty for her decision to have pre-marital sex but that she wasn't going to beat herself up about it. She said that she understood that she made a mistake and that she just had to ask for forgiveness, had to get back up and and continue her walk.

Another example of a woman that challenges the virgin/puta binary and has conflict with the faith and sexual discourse is of interviewee #10. We were discussing what sex meant to her and her views on pre-marital sex. When I ask her how she sees pre-marital sex for herself she explains to me her rationale for her decisions,

*“#10: Um... [pause] I don't think I've made a bad choice, because I've been with this person for 4 years. I've known him for 6. So, it's not a bad choice. I mean... [pause] I probably shouldn't have, but it was just something that I felt that I was ready for and accepted it.”*

She shared with me that she felt that sex should only be had with someone that is special. She stated,

*“#10: I do believe, you know, that you're supposed to be married beforehand. But if you find that special somebody that you know you're going to be with and... [pause] just as long as it's somebody special, not just to do it just to do it.”*

In these statements she is distinguishing between a promiscuous action in which people just have sex to have sex versus how she sees herself and her decision, having sex with someone special. This criterion makes her different, in her mind, than a 'whore.' Through her life experience she feels that she has been smart about her sexual activity and is content with her decision.

Some of the other interviewees presented similar information as part of their strategy in the negotiation of the discourse of faith and sexual discourse. Interviewee #9 stated that her strategy to negotiate her faith and her choice to have premarital sex was to be engaged. She felt guilty at times and at first was concerned about the level of respect her partner would give her but she says that because she is engaged it is fine. Interviewee's #11, #7, #14 also shared with me their strategies to deal with the guilt, have premarital sex and still be good women of faith. Interviewee #14 shared that her strategy was to go confess. After her first relation, she first confessed to her mother the truth and then her mother told her what she already knew, that she

had to confess to a priest. So she did. Interviewee #7 shared that her strategy was that she didn't actually follow the rules and that she let the sexual discourse win for a long time. Now that she is older, she is letting her faith take over more and be more influential in her choices. She hasn't gotten pregnant in 11 years. Interviewee #11 states that you have to know your partner for a couple of years before you can really have sex with him and love him. She says that men change their mind and lie so you have to give it a couple of years. All of these women's strategies show how they have had to negotiate how they want to live their faith and use it to make sexual choices.

Examining how faith can function as a barrier and a factor of negotiation brings forward stories that are not dominantly heard. Though there were a couple of interviewees who did not share that faith was an important factor in their reproductive health care, I believe that that is the dominant assumption. This is seen through the lack of discussion of faith by medical communities. These women's strategies or even stories in which faith became a barrier call out for a need for medical communities to acknowledge how these women understand their sexual choices and faith. Additionally, for medical institutions that do currently acknowledge faith, they need to make sure that they are still providing women the highest quality of care in which patients are allowed to have the highest possible degree of freedom in order to get the care that they desire.



## CONCLUSION

The story that helped me understand the struggle that some Latinas experience when encountering multiple, competing, discourses was the story of Interviewee # 16. She is a Mexican immigrant patient that is 29 years old. She shares with me the story of her fourth child. Over a year ago she suspected that she was pregnant and went to FPS to get a pregnancy test. After her positive result she was given information about her options. She felt empowered to take control of her body and make a difficult decision. She decided that she would visit an abortion clinic. She went to her first visit and scheduled her abortion for the coming Saturday. Here is the rest of her story.

*“Like I told you, I am Catholic. Days before I had told La Virgin, [the Virgin Mary] you know what, if you want me to do this, if this is what you want I will wait for a signal but if you don't give me no signal, I am going to go and I am going to do it.”*

*“#16: Someone had given my husband this keychain as a gift of La Virgin de Guadalupe and he hung it on top of the review mirror. When were about to get to the clinic I told him, ‘You know what I am going to do, I am going to close my eyes so that I don't have to see the people that are out there outside screaming at you [pro-life protestors] and I am going to bend down so that I don't have to see anything. He says, ‘ok.’ But when we were arriving the keychain began to start turning and turning and turning and it caught my attention. I began to look at it intensely. When I looked straight forward I see a huge [cloak or veil] of La Virgin that was my stature. It was big..... I could not close my eyes and I couldn't bend down.... At that moment I tell him, ‘No. I don't want to. I no longer want to go in there because the signal I was waiting for has arrived.’ I started to cry and cry and cry. My husband says, ‘you know what, I also didn't want to do it.’”*

The complexity of the story raises a lot of question. The fact that she went to a reproductive health care provider to gain information was something that was empowering to her. By saying that she was going to take control of her body and make a decision was difficult for her. She shared with me that she had to be very strong throughout the process especially when asking for partner to respect her and her decisions, because he didn't want her to have an abortion. He

supported her throughout the whole process because she asked him to treat her as her partner and support her decision.

Another part that was very interesting was the fact that though religious discourse is seen at times as oppressive of women's rights, choices, and bodies for this woman it was her religion that she used as a bargaining tool to make her decision. This was a conversation that she had with La Virgen and it was not one of fear or guilt or mediated by any other person. It was not the protesters, it was not a priest, it was her own relationship with La Virgen that influenced this decision because she had asked for this. For her it was a very empowering to see La Virgen and know that this was the right decision for her. She ended up naming her son Jesus and is very happy with her decision.

This story made me not only question whether faith could function as more than a barrier and instead as a negotiation space of conflicting discourses. Through analyzing her decision making process and her use of the dialogue with La Virgen, I began to see that there was something important about the way that faith functioned in this decision making process, along with other factors that she had to overcome to make a decision, such as language barriers. Through this story there is evidence that the religious discourse and medical discourse were conflicting and that the religious discourse was the one that interviewee #16 followed for this decision.

In this story I see all of the components previously discussed in my research. Faith, medical, and Latina sexual discourses were competing in her decision making process. Structural factors simultaneously constrained and shaped her choices. As a working class Latina, her concern was that if she had another child, she could no longer work and provide the necessary monetary support for her family. She also described that though FPS had provided so much

support to her in her reproductive health, she was still having problems with her birth control. Her individual agency was vital to her decision making process. The choice that she was able to make was because she had acquired knowledge from medical institutions, beginning with FPS, a place where she feels safe and comfortable at. She said that she felt empowered to even contemplate an abortion because one of the Latina medical assistants at FPS was being very supportive of her throughout this process and reminded her that this was her decision to make. This statement also influenced the gender role negotiation that she had to experience with her husband. Additionally, she had to deal with the cultural taboos against abortions by both hiding that she was going to have an abortion and explaining to her sister why she had made that decision. She used her social network to be able to attain reproductive health. In the interview she shared with me that her friend made the appointment at the abortion clinic for her and that this friend's son used his computer skills to find a map to get them to the clinic. Acknowledging how all of these factors intersect in the choices that Latinas, like interviewee #16, have to make is vital to being able to address some of the barriers that keep Latinas away from reproductive health care. The question that arises from this story and the previous interviewee's stories is: what are the ways that all of these elements could be incorporated into the medical discourse?

### **WAYS FOR CHANGE: WHAT THE LATINAS SUGGESTED**

Being able to construct a vision for change is something that I needed to speak with the interviewees themselves about. For this reason I asked the interviewees what their thoughts were on health care in general and their specific needs. I asked two questions to get responses regarding ways for change: "What does being treated well mean to you?" and "What do you think could be changed?" Because my interviews were semi-structured, some women got one question or both.

Among the top explanations of what it meant to be treated well was being made to feel comfortable, having health care providers that are easy to talk to and being respected. Other explanations given by these patients were to not have health care providers judge them, being treated as an equal, not being talked down to, not being looked down on for not being able to pay right away, not being made feel like there were a burden to a health care provider, being given more accurate information, being given options regarding their health care, having their questions answered by health care providers, wanting health care providers to provide care not just service to their patients, wanting more Hispanic people working as clinics and lastly, no discrimination. All of these responses were a reflection of negative experiences they have had previously. Many of these requests may be some that women of other ethnicities desire or experience a lack of. Overall, these are issues that must be addressed for not only Latinas but for all people.

The responses to the second question provided answers that could aid outreach efforts for Latinas. The most popular response was to make pamphlets that could be distributed in schools, other medical facilities that Latinas visit and in the neighborhood answering questions that Latinas had while also providing resources. What was interesting was the two interviewees requested that the information not only be in Spanish but friendly to the old Hispanic women. I was not able to inquire more about what that would look like but generally what is important is that this conveys a need for culturally sensitive materials and an acknowledgment of generational differences within the Latina/o community.

Another interesting response to the second question was a need for medical institutions to provide information about why preventative health care is necessary. Two interviewees shared that preventative care or even seeing a doctor when they were ill was not something that they

thought as a normal response but one that they would make if it was absolutely necessary. Both shared that they thought that the idea of preventative health care does not exist in Mexico so it was hard for them to understand how to participate in this kind of care in the United States. They explained that if nothing was wrong with a person, then why should they go to see a doctor. This could become a barrier when it comes to medical exams such as pap smears. Not knowing what the need for preventative care could be an explanatory factor for the high rates of cervical cancer.

Methods that these women identified as ways to disperse information were very helpful. They suggested community workshops and group talks in the community (*platicas*). The idea of *platicas* comes from the church framework in which someone can informal lecture about a topic and then people create dialogue with each other about it. Because some Latinas are familiar with this model of communication, it may be very beneficial to pursue something like this for health education outreach. Other methods of information dissemination included trucks that could go out to the community and give information, having health care providers attend local festivals, creating centers for information, and making phone calls providing resources to Latinas. They stated that this information also needs to be provided in Spanish.

All of the suggestions that these Latinas provided are vital to creating new models of health care education and creating new ways for health care providers to give care to Latinas. These suggestions come from their lived experiences that are shaped by the intersection of class, gender and race. Taking these suggestions and the experiences that the interviewees shared may be the key to creating a change in reproductive health care.

## **WAYS FOR CHANGE: HEALTH CARE MODELS**

The responses given by the interviewees calls for improvements in the health care system. One way that this could be achieved is through the implementations of health care models such as Promotoras de Salud. The Promotoras de Salud model is effective because the community members themselves become the disseminator of health education. They become a link between the governmental and non-governmental systems and the communities they serve (The Way of the Hearth: The Promotora Model, 2009). This model was created based on research on pilot interventions of community health worker models in the 1950s and 1960s such as the Navajo Community Health Representatives and the migrant farm worker programs (The Way of the Hearth: The Promotora Model, 2009). The objective of the Promotoras is to target medically underserved communities and provide education on health issues to these communities which brings them closer to health care. The Promotoras Model looks different in each state they exist in. Usually their duties are to create a bridge between the community and the health care system, provide culturally appropriate health education, connect people to medical resources, provide a social support, and advocate for individuals in order to help them meet their basic health care needs (Northwest Georgia Healthcare Partnership, 2011). If this model were to become widespread in the United States, then some of the barriers that Latinas face could be addressed and Latina/os would become closer to the health care system.

Latinas would be trained with more knowledge about health and health care and this would work as a domino effect where many more women could be the resources of accurate information. They also do not need to be afraid of disrespect and being looked down on because these educators would be women they already knew and had relationships with. Trust would already be established and strengthened through these new interactions. Additionally, language

barriers and cultural differences would be diminished. Overall, this model of education outreach could be very beneficial for Latinas and address a lot of their concerns.

Another avenue for change is thinking about health care provider and patient interactions. Lujan and Campbell (2006) present a religious status assessment. Their work reviewed the origin and role that religion plays in the health practices of Mexican Americans and what the implications would be if there was a change in which patients religious needs were met. Their research found that religion was associated with health promotion and disease prevention and that Mexican Americans viewed illness as punishment from God or as purposeful. For this reason patients believed in divine intervention (Lujan and Campbell, 2006). The religious assessment is as follows:

1. *Do you identify with any organized religion? If so, what religion?*
2. *If you do not identify with a particular religion, do you have a belief system that provides comfort and strength?*
3. *How do your religious or spiritual beliefs influence how you care for yourself?*
4. *Who are your support people?*
5. *What provides you with strength and hope?*
6. *What gives your life meaning and purpose?*
7. *How has your life changed since you became ill?*
8. *How might we (your health care providers) best address any needs in this area? (Lujan and Campbell, 2006:189)*

They argue that this assessment could be beneficial in creating a health care plan for Mexican American adults. The research found it was important to Hispanic elders that they considered doctors as one of the family, who was focused on their inner importance as a person and that the provider had respect for their spirituality (Lujan and Campbell, 2006). They concluded that, “holistic health care demands that the religious beliefs and activities of Mexican American client be assessed by clinicians that acknowledge and respect this important dimension of the individual” (Lujan and Campbell, 2006: 188)

Using the religious status assessment would allow for more culturally sensitive care to be provided. Additionally, it would create space for family to be involved in the patient's health care. Thinking about how some of the interviewees also identified faith as a very important factor in their decision making process suggests the need and success that this assessment would have for these Latinas. It would be able to reduce the fear of being judged and would create trust with the health care provider. It could be the catalyst for the "openness" that the patients want to see and create a space where Latinas feel comfortable asking a lot of questions. Overall, it would be a way to bring the discourses together instead of having them be in conflict with each other when it comes to reproductive health care choices.

These two options of change only offer ways for Latinas to get provided better care. I understand that economic barriers along with other barriers that create inequality would still exist in these women's lives and will not be solved with these models. In order for that to occur there would need to be a change in the health care system that made full health care an option for all people. However, I think that a benefit that could come from change through these models is that Latinas would feel more empowered by these models to feel closer to the health care system.

## **WHAT DOES THIS MEAN?**

The stories shared by these Latina patients show how women make choices under constraints. The stories shared by these patients at FPS show that they do not know or have limited knowledge of pap smears, Gardasil, and cervical cancer. The interviewees shared that some of them didn't have conversations about sex when growing up and that those that did had a lot of fear tactics at play in their conversations. They also shared that faith functions as a space of negotiation that is most visible when competing discourses are at play. An important factor for these Latinas reproductive health care is being able to trust medical institutions. In their stories



there were a couple of examples in which distrust was formed after bad experiences with health care providers. Lastly, regarding knowledge of sex Latinas signaled to three main sources of information, family, school, and people in their social networks that they trust. All of these factors shape these Latinas reproductive choices and provide insight on what changes could occur to make reproductive health care more accessible to Latinas.

Additionally, there is evidence that low-income women have less access to Gardasil because of their lack of insurance and the high prices of Gardasil. In Lorain County, their ability to attain reproductive health care is also limited because there are few clinics that provide services for uninsured, low income women. The disconnect between the medical and Latina communities is not only through lack of accessibility but also through examples like Merck, who does not disperse information about their resources in Spanish and targeted for Latinas. Latina and medical discourses need to become more connected in order to provide Latinas with greater access to reproductive health care.

Through this research I argue that there is disconnect between the Latina and medical discourse and the lack of integration of the discourses potentially contributes to the disparity of cervical cancer for Latinas. To reduce the racial disparity in usage of reproductive care, it is necessary to bring these communities into communication with integrative and culturally sensitive models of health care and dispersal of culturally appropriate health education. Doing so will pave the way to reducing the number of Latinas whose lives are affected by cervical cancer.

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