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April, 15, 2015

“Those who love, vaccinate”: An Anthropological Perspective on HPV Vaccination in Brazil

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Abstract

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Brazil launched an HPV immunization campaign in March of 2014. In less than 6 months, national uptake of the first dose surpassed 80%. Understanding the apparent acceptance of the HPV vaccine in Brazil gives insight into what sorts of factors drive vaccine uptake. Various theoretical frameworks have been developed to help explain, predict, and modify vaccination behavior. Some of these theories propose that biomedical knowledge has a primary influence on decisions to vaccinate. From this perspective, increased knowledge would correlate with increased vaccination. However, a growing body of literature strongly suggests that the provision of scientific knowledge about HPV and its vaccine is not sufficient to motivate parents to vaccinate their daughters. Instead, vaccination is context specific and parent perceptions are shaped by various social, political, and cultural factors that affect how biomedical information is interpreted, the meaning of HPV vaccination, and vaccine access. This study aimed to identify these distal influences and assess the role of HPV knowledge in determining the acceptability of HPV vaccination within a subset of 30 parents from São Paulo, Brazil. The results suggest that the widespread acceptance of the vaccine in São Paulo can be understood by examining the culture of vaccination from which the vaccine gains more than just a biomedical identity. HPV vaccination was portrayed as an act of parental love that provides both health and social insurance against the many unknowns that affect a child’s health. This prevailing vaccination culture is mediated by trust in the Ministry of Health and healthcare workers. Thus HPV vaccination isn’t just a matter of biomedicine; it intersects the realms of parenting, sexuality, gender roles, power structures, stigma, and social inequality. As hypothesized, these distal factors held more explanatory power for vaccine acceptability than parental knowledge levels. The findings indicate that attempts to understand or modify vaccination rates require the consideration of distal factors.

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I. INTRODUCTION

Vaccination has become a hallmark of public health and is revered as an effective and low-cost medical intervention for combating the burden of infectious diseases in a population through prevention. Vaccines build up an individual's immunity to the targeted disease by triggering specific immune responses in the body, which increase the body's ability to fight off future infections. Herd immunity refers to when the individual protection created by immunization extends to the community level, increasing in strength as the proportion of vaccinated individuals increases. Thus health professionals strive to reach high levels of vaccine uptake within a population. Coverage rates for the Human Papilloma Virus (HPV) vaccine have varied both within and between different countries, even in countries with funding sufficient for widespread vaccination (Hopkins & Wood, 2013). In the United States, for example, reaching optimal uptake levels of the HPV vaccine has been a public health challenge. As of 2013, only 57% of girls ages 13-17 had received at least 1 of the 3 HPV vaccine doses, which falls well below the 80% coverage required for herd immunity (CDC, 2014). In stark contrast, the national coverage rate for the first HPV vaccine dose among girls ages 11-13 in Brazil exceeded 90% in less than a year of its introduction into the National Immunization Program (PNI) (SI-PNI, 2014). What accounts for this huge difference in vaccination rates between two countries with histories of high uptake of other vaccines? Aside from vaccine access, what determines why some individuals choose to be vaccinated, while others do not?

Public health models that are used to explain and predict the use of health services often emphasize the role of biomedical knowledge in determining behavior. From this perspective, lower vaccination rates reflect inadequate levels of knowledge and call for educational interventions to correct misconceptions and subsequently increase vaccine uptake. The

controversies that emerged from the introduction of the HPV vaccine in the United States show that vaccination is entrenched in social, political, and cultural meanings and conditions, which influence the interpretation of the biomedical information of a disease and its vaccine. The resulting perspective shapes vaccine acceptance and uptake. This implies that increased biomedical knowledge may not correlate with increased vaccination because this knowledge does not exist in a vacuum and will continue to be affected by the same social forces. Differences in access to healthcare services also affect immunization rates not only from a logistical standpoint, but also because the organizing bodies of vaccination belong to the social, political, and cultural milieu from which vaccination gains its meaning.

As Conis covers in her book, the American opposition unique to the HPV vaccine emerged from its dissonance with the longstanding framework of vaccination in the U.S. Vaccinating adolescents against a primarily sexually transmitted infection to decrease the individual risk for a chronic disease, cancer, clashes with the tradition of vaccinating children against a disease of higher communicability with more proximate health consequences for a wider proportion of the population. The initial exclusive targeting of adolescent girls that are not sexually active raised concerns about female sexuality and sexism not previously related to vaccination. The emphasis of the individual benefits of HPV vaccination was a shift from the usual portrayal of vaccination as a civic duty. Lastly, the vaccine does not serve one, clear purpose and does not have one, clear target since HPV vaccination recommendations have expanded to include adolescent boys to protect against genital warts and other HPV related cancers that affect both women and men. The downstream effects of this dissonance resulted in HPV vaccination opposition that reflected concerns regarding female sexuality, intentions of pharmaceutical companies, and body sovereignty (Conis, 2015).

In light of the dialogue surrounding HPV vaccination in the U.S., the purpose of this study is to examine the overwhelmingly positive acceptance of HPV vaccination in Brazil through an anthropological perspective that considers the distal influences on vaccination, which encompass the social, political, and cultural contexts of health care. The project intends to identify the meaning given to HPV vaccination among a subset of parents from São Paulo, Brazil. Although the HPV vaccine is now recommended for both girls and boys in the U.S., this analysis focuses on the vaccination of adolescent girls, the target group of Brazil's national HPV immunization campaign. The project also examines whether parental knowledge levels of HPV vaccination were predictive of decisions to vaccinate. While public health infrastructure impacts vaccine access and uptake, a thorough presentation of these factors in Brazil falls outside the scope of this thesis. These systemic issues will be briefly mentioned in terms of their position in shaping vaccination culture.

Thus this project specifically aimed to answer the following three questions: (1) What is the meaning of HPV vaccination for these parents? (2) What are the distal factors that shape this meaning? (3) Is HPV knowledge level predictive of HPV vaccination within these parents? Based on the introduction of the HPV vaccine in the U.S., I hypothesized that the meanings of HPV vaccination would reflect issues of sexuality and parenting and would be more influential than knowledge levels in predicting vaccination.

This chapter provides the introductory information necessary for delving into this examination. First, there is a brief background on HPV and its related health consequences. Next, the introduction of the HPV vaccine in the U.S. is further explored and the literature on the role of knowledge and educational interventions in promoting parent decisions to vaccinate are discussed. Then an anthropological perspective of vaccination is presented before exploring the

case of HPV vaccination in Brazil. The last portion of the introduction presents the prevalence of HPV related health burdens in Brazil, the launch of the HPV immunization campaign in March of 2014, and the studies that have examined HPV knowledge levels in Brazilian adolescents and parents prior to the campaign. The meanings surrounding cervical cancer and childhood vaccinations in Brazil are also presented in this section.

HPV Background

HPV Types, Transmission, & Associated Health Consequences

Human Papillomavirus (HPV) is a categorical term for more than 190 genotypically distinct, but related viruses that infect human epithelial cells (WHO, 2014). About 40 of these HPV types are transmitted primarily via sexual contact with infected mucosal membranes of anogenital areas and are therefore classified as genital HPV infections (Koutsky, 1997). In most cases, the body's immune system clears the infection, however, persistent and unresolved HPV infection can lead to the formation of genital warts or precancerous lesions (Stanley, 2012). The overexpression of two HPV proteins, E6 and E7, leads to the inhibition of apoptosis and cell cycle arrest, which can result in tumor formation (Schiffman, Castle, Jeronimo, Rodriguez, & Wacholder, 2007). Genital HPV strains that are highly associated with carcinoma are classified as high-risk. HPV types 16, 18, 45, 31, 33, 52 and 58 are the most common high-risk HPV strains worldwide (Munoz et al., 2004). Low risk HPV strains are less associated with causing cancer and can result in genital warts (Doorbar et al., 2012). Two low risk strains, HPV 6 and HPV 11, account for 90% of anogenital warts (Patel, Wagner, Singhal, & Konthari, 2013).

HPV research has concentrated on the high risk HPV types associated with cervical cancer because epidemiological studies have identified HPV infection as a necessary cause for cervical cancer (Bosch, Lorincz, Munoz, Meijer, & Shah, 2002). Unresolved HPV infection is

also associated with cancers of the mouth, oropharynx, vagina, anus, and penis; however, lower ratios of these cases are attributable to HPV infection (Parkin & Bray, 2006). HPV DNA has been found in 95-100% of studied cervical cancer cases (Bosch & de SanJose, 2007). The two most common HPV types found in women, types 16 and 18, are also found in about 70% of cervical cancer cases and are classified as human carcinogens by the International Agency for Research on Cancer (Munoz et al., 2003). One study found a 99.7% prevalence of HPV infection in their sample of women with cervical cancer concluding that HPV infection was the most significant risk factor for developing cervical cancer (Walboomers et al., 1999). Oral contraceptives, smoking, high parity, and prior exposure to other STIs increase the risk of cervical cancer in women infected with HPV (Bosch & de Sanjosé, 2007). Cervical cancer is the second most common cancer for women ages 14-55 with an estimated 527,624 new cases and 265,653 deaths per year (Bruni et al., 2014). Thus detection and prevention of HPV infection has implications for reducing the prevalence of cervical cancer cases, 80% of which occur in developing countries (Munoz et al., 2003).

Detection & Prevention of HPV Infection

HPV infection usually does not result in the development of immediately noticeable symptoms. In the case of cervical infection, there is about a 10-year gap from HPV infection to detectable precancerous cervical cancer lesions. The Papanicolaou (Pap) test screens for these lesions by testing a sample of cells from the cervix for abnormal growth. This sample of cervical cells can also be screened for the presence of HPV infection through DNA testing (WHO, 2014). The implementation of these screening methods has effectively reduced the cervical cancer rates, because early detection and treatment of abnormal cells has made cervical cancer highly preventable.

Prevention of some HPV infections has been made possible through the development of prophylactic HPV vaccines. The first prophylactic HPV vaccine, Gardasil[®] was available to the American public in 2006. Gardasil[®], manufactured by Merck & Co., is a quadrivalent vaccine that offers protection against HPV types 6, 11, 16 and 18. Cervarix[®] is a bivalent HPV vaccine that was introduced in 2009 and offers protection against HPV strains 16 and 18. A nine valent vaccine is currently being developed by Merck & Co. and will include HPV types: 6, 11, 16, 18, 31, 33, 45, 52 and 58. The new vaccine will provide wider protection with the potential to prevent 90% of invasive cervical cancer cases (Serrano et al., 2012). The prophylactic HPV vaccines contain virus like particles (VLPs) that model the L1 proteins that comprise the viral capsids of the included HPV strains. VLPs do not contain the viral genetic material necessary for infection, but they instead function to trigger an immune response from the host. The VLPs will cause the body to produce antibodies specific to the L1 proteins of the HPV strains included in the vaccine (Schiller & Lowy, 2000). In the case of an actual infection, the host immune response will be stronger and more efficient at fighting off the infection. Both the quadrivalent and bivalent vaccines have been shown to be safe and effective against HPV infections and the occurrence of cell abnormalities and lesions (Cutts et al., 2007; Harper et al., 2004; Villa et al., 2005).

The vaccines were manufactured to be administered in 3 doses at 0, 1-2, and 6 month intervals yet they are also effective when given in two doses or on extended schedules, where the interval between the second and third doses is longer (LaMontagne, Thiem, Huong, Tang, & Neuzil, 2013). Both vaccines are recommended for females, but only Gardasil[®] is recommended for males. The HPV vaccines are available for 9 years olds, but in the United States the target age range is 11-13 year olds. The upper age limit of HPV vaccination is 26 years because studies

have shown marginal benefit from receiving vaccination above this age. Ideally, HPV vaccination should be administered before the individual becomes sexually active and therefore at increased chance of being exposed to HPV (CDC, 2012).

HPV Vaccine Introduction: Social, Political, & Cultural Influences

“The contemporary U.S. health care context is one in which biomedical innovations are not only material entities; they are culturally symbolic, increasingly shaping people’s conceptions of their health, identities, and bodies (Mamo, Nelson, and Clark, 2010).”

Social, political, and cultural circumstances shape public opinion and receptiveness of healthcare services. A look at the reactions to the HPV vaccine in the United States illustrates how the dialogue surrounding a new vaccine reflects the prominent cultural ideologies of that time. Recognizing that vaccination behavior is context driven results in a more accurate understanding of vaccination uptake both within and between different populations.

Reframing HPV from an Unknown STI into a Carcinogen

Prior to the introduction of Gardasil[®] in 2006, HPV infection was neither well known nor a major health concern for the majority of the population. The availability of the vaccine led to a restructuring of the American perspective of HPV, which was heavily influenced by Merck's marketing approach. Merck launched commercials prior to FDA approval of the vaccine to increase public awareness of the link between HPV and cervical cancer, thus defining and priming their vaccine market: young girls (Conis, 2015). Prescott argues that the gendered message of HPV infection as a health risk for women echoed the previously prevalent view that women are “reservoirs” of sexually transmitted diseases. The message also fell in line with the principles of “scientific motherhood” that began in the 20th century. Poor health outcomes among children were attributed to mothers lacking the scientific knowledge needed to prevent and properly handle childhood diseases. This ideology placed the burden of the nation’s health on the shoulders of women by heavily directing health messages towards mothers and adolescent

girls (Prescott, 2010). Thus Merck's decision to define women as the HPV vaccine market both reflected and perpetuated the social and cultural beliefs that regarded health maintenance, especially sexual health, as a woman's responsibility in the United States.

Although focusing on women instead of men aligned with social norms, Merck now had to confront the culturally constructed need to control female sexuality prevalent in American healthcare, which could shape the HPV vaccine paradigm given the sexually transmissible nature of HPV. This kind of vaccine opposition was rooted in the fear that HPV vaccination would encourage risky sexual behavior in young girls. The Gardasil® "One Less" commercials, advertised after FDA approval, attempted to dissociate the vaccine from these concerns of sexuality by framing the vaccine as cancer prevention. Thus the role of HPV vaccination was portrayed as mitigating cancer risk rather than the risk of acquiring a sexually transmitted disease. The resulting message inaccurately presented cervical cancer risk as equal for all females due to their anatomy and glossed over the other HPV associated diseases that affect males and females (Mamo, Nelson, & Clark, 2010). Some opponents argued that investment in the costly 3 dose vaccination series, about \$390 total, to reduce cervical cancer was an inefficient use of resources due to the existing use of pap tests for cervical cancer screening (Conis, 2015). Once again, the reframing of HPV infection helped counter this concern. Distancing cervical cancer from sex and framing it as a preventable risk for all women presented Gardasil as a superior technology for cancer prevention while diminishing the importance of pap smears (Mamo, Nelson, & Clark, 2010).

Those that were aware of the other HPV related health risks questioned the effectiveness and benefits of Gardasil® because the vaccine does not include all of the cancer linked HPV strains. Although some saw the vaccine as a product of increased investment and improvement in

women's health care service, the vaccine was introduced during a time of growing distrust in the intentions of pharmaceutical companies, which translated into skepticism of the vaccine's safety and efficacy. Later on, the change in vaccine recommendations to include boys added to this growing distrust. Due to the time lapse between HPV infection and cervical cancer development, clinical studies evaluating vaccine efficacy used persistent HPV infection, neoplasia, lesions, and genital warts as endpoints rather than cervical cancer, which some critics found provided unconvincing evidence (Conis, 2015). This uncertainty was amplified when it was discovered that Governor Rick Perry, who was advocating for an HPV vaccination mandate, was receiving financial support from Merck (Epstein & Huff, 2010). Opposition to these mandates also came from HPV vaccine supporters whose arguments reflected libertarian ideals of body sovereignty and limited governmental role in healthcare that are prominent American ideologies. Parents, not the government, should be in charge of the health of America's daughters (Conis, 2015). This opposition appears out of place when considering pre-existing compulsory childhood immunizations and reflects the dissonance between the HPV vaccine and the framework of vaccination in the U.S. as previously explained.

The history of the HPV vaccine in the U.S. is not the focal point of this project, but is raised in order to illustrate the roles of social, political, and cultural conditions on shaping HPV vaccine perceptions and uptake. The recognition that decisions to vaccinate are subject to these context specific influences provided the motivation to examine how these factors manifest themselves in HPV vaccination decisions in Brazil.

How is HPV Vaccine Uptake Explained & Predicted?

The social, political, and cultural meanings attached to HPV vaccination as described above influence parent decisions to vaccinate their daughters and therefore ultimately influence

HPV immunization coverage. A closer examination of parent decisions to vaccinate is therefore crucial for understanding HPV vaccination rates. Various theoretical frameworks have been developed to help explain, predict, and modify health behavior and uptake of healthcare services. These individual level theories are founded on the concept that knowledge influences health behavior and therefore plays a fundamental role in producing changes in health behavior (Rimer, & Glanz, 2005). One of the most widely used interpersonal level theories is the health belief model (HBM), which was developed in the 1950s for predicting uptake of preventative health services. The HBM proposes that health behavior is determined by the value a person places on maintaining health and the estimated probability that a certain action will help maintain health. The four characteristic dimensions of the HBM are: perceived susceptibility, perceived severity, perceived benefits, and perceived barriers (Janz & Becker, 1984). Two additional constructs, cue to action and self-efficacy, were later added to improve the model's strength (Rosenstock, Strecher, & Becker, 1988). A cue to action in this scenario is something that helps prompt vaccination such as physician recommendation or a vaccination reminder card (Brewer & Fazekas, 2007). Self-efficacy refers to an individual's belief in his or her ability to overcome barriers and implement a health behavior or access a health service. In the case of vaccination, a person who believes that receiving a particular vaccination would be an easy task is classified as having high self-efficacy (Gerend & Shepherd, 2012).

The first four HBM tenants are largely shaped by knowledge of both the disease and the health behavior or service and have therefore also been used to target health education interventions. In terms of vaccination, increased perceived disease susceptibility is expected to correlate with greater vaccine uptake. If a person has a low perceived susceptibility, an educational intervention would emphasize the disease risks and prevalence in attempts to

encourage vaccination. This education-based strategy is based on the idea that perceptions that hinder vaccination result from a lack of accurate biomedical information. Thus predictions of and changes to health behavior are believed to be directly mediated by education (Conner & Norman, 2005).

The HBM has been shown to be predictive of HPV vaccination and acceptability among parents in some studies, but the strengths of the different HBM components vary in explanatory power. One study quantitatively surveyed 190 women from a rural area in North Carolina and found that perceived severity and susceptibility of HPV infection and cervical cancer for their daughters was associated with higher intention to vaccinate their daughters (Fazekas, Brewer, & Smith, 2008). Contrastingly, a systematic review of HPV vaccine acceptability studies from the U.S. showed that perceived severity of HPV infection was unrelated to acceptability, which may be due to low knowledge levels of HPV. Perceived vaccine effectiveness, perceived susceptibility to HPV infection, and physician recommendation were predictive of HPV vaccine acceptability (Brewer & Fazekas, 2007). Reiter and colleagues used the HBM to assess initiation of HPV vaccination through phone interviews with 889 caregivers of girls ages 10-18 from North Carolina. HPV vaccine initiation, uptake of one or more doses, was negatively associated with perceived barriers to vaccination and perceived severity of vaccine side effects, but positively associated with a physician recommendation of the HPV vaccine. Perceived severity of cervical cancer was not associated with HPV vaccine initiation (Reiter, Brewer, Gottlieb, McRee, & Smith, 2009).

Cross-cultural differences also influence the explanatory power of the HBM as demonstrated by a study done in Singapore. The researchers interviewed 1,231 residents of Singapore that fell into one of the following ethnic categories: Chinese, Malay, or Indian. The

HBM did not significantly explain any of the preventative health behaviors included in the analysis within the 3 different groups. The HBM also demonstrated varying explanatory power between the subgroups. Social dimensions that fell outside of the HBM, such as religion and gender roles, were important motivational factors that influenced and were predictive of health behavior. The argument against the universal application of the HBM presented by this study is weakened since self-efficacy was not evaluated (Quah, 1985). However, the HBM's varied predictive ability both overall and in terms of its individual components indicates that its applicability is limited, which may imply that its emphasis on knowledge provides a weak theoretical foundation.

Does Knowledge Predict Vaccination?

Several studies have examined the association between parental knowledge of HPV and uptake of the HPV vaccine among adolescents. A systematic review of 55 studies that examined the barriers to HPV immunization among adolescents in the US found that the need for more information about HPV was cited as a major barrier to vaccination among parents (Holman et al., 2014). This finding is consistent with other studies in which parents wanted more information in order to make a decision about HPV vaccination for their children (Dorell, Yankey, & Strasser, 2011; Trim, Nagji, Elit, & Roy, 2011). Additionally, several studies have found a positive correlation between levels of parental knowledge of HPV and the HPV vaccine with HPV vaccine acceptance (Gerend, Weibley, & Bland, 2009; Kepka, Ulrich, & Coronado, 2012; Woodhall et al., 2007).

On the contrary, a growing body of literature indicates that increased knowledge does not determine HPV vaccine acceptability (Davis, Dickman, Ferris, & Dias, 2004; Dursun, Altuntas, Kuscu, & Ayhan, 2009; Krawczyk et al., 2015; Lenselink et al., 2008; Perkins et al, 2010; Walsh

et al., 2008). A systematic review of 28 studies about the predictors of HPV vaccine acceptability in the U.S. found high acceptability overall despite low levels of HPV knowledge (Brewer & Fazekas, 2007). In support of this, a qualitative study done in Québec found that both groups of parents, vaccinators and non-vaccinators, exhibited a lack of information, inaccurate information, or doubts regarding HPV and the vaccine (Krawczyk et al., 2015). Similarly, in an American study 61% of 129 parents had already vaccinated or planned on vaccinating their daughter even though the average HPV knowledge score, assessed through a quantitative survey, was 36% (Grabiel et al., 2013). Likewise, within a subgroup of low income, minority parents in the U.S., knowledge of HPV was not correlated with HPV vaccine acceptance (Perkins, Pierre-Joseph, Marquez, Iloka, & Clark, 2010). Among 746 Indonesian parents, 96.1% favored HPV vaccination for their daughters even though only 16.6% had ever heard of HPV and the average knowledge score of HPV, the HPV vaccine, and cervical cancer was 1.8 out of an 8 point scale (Jaspers, Budiningsih, Wolterbeek, Henderson, & Peters, 2011). In another study, out of 356 Dutch parents, 88% expressed support for the HPV vaccine even though only 29.5% had heard of HPV and only 14.3% knew of the relationship between HPV and cervical cancer. Vaccination acceptance was not predictable by HPV knowledge scores and was most associated to adherence to all recommended childhood vaccinations (Lenselink et al., 2008). Therefore, beliefs about vaccines in general may be more strongly associated with HPV vaccine acceptability than knowledge of HPV or the HPV vaccine specifically. Parents who associate vaccination with disease protection are more likely to accept vaccinating their children (Mays, Sturm, & Zimet, 2004). Perceiving vaccination as beneficial was associated with acceptability of the HPV vaccine in various studies (Davis, Dickman, Ferris, & Dias, 2004; Dempsey, Zimet, Davis, & Koutsky, 2006; Gottvall et al., 2013; Lazcano-Ponce et al., 2001; Lenselink et al., 2008). Trust in vaccine

recommenders might also outweigh parents' vaccine safety concerns (Gottvall et al., 2013). A positive view on vaccines in general could be tied to a trust in biomedicine and the organizations that recommend vaccination, i.e. physicians, national health systems, and government agencies. For example, most of the 133 interviewed Vietnamese parents perceived vaccination as effective for disease prevention and accepted HPV vaccination for their daughters due its endorsement by the Vietnamese National Expanded Program of Immunization (NEPI) and trust in the government (Cover et al, 2012). Decreased trust in medical opinion can also alter vaccination behavior and has been observed among parents from higher socioeconomic classes (Poltorak, Leach, Fairhead, & Cassell, 2005).

In agreement with these studies, a qualitative analysis of the childhood vaccination decisions of 33 postpartum mothers in the United States found that decisions were primarily determined by who the parents trusted to provide accurate and relevant healthcare information. Vaccinators trusted biomedicine and the conventional medical professionals, whereas non-vaccinators did not and had trusting relationships with someone that opposes vaccination, such as a homeopath or naturopath. A trusting relationship was dependent on the amount of time the person spent addressing the parent's concerns, individualization of the case, having a passionate demeanor, perceived competence, and refraining from patronizing the parent. All mothers in this study had low knowledge of vaccines and of the vaccines their children had received. Vaccine acceptors had the lowest knowledge levels, which the researchers suggest results from the trust in the medical profession to act on valid information. Parents with intermediate levels of trust: selective or delayed vaccinators, had the most doubts about the right course of action, which likely caused them to seek out more information thus explaining why they had the highest knowledge scores. Benin and colleagues assert that the perceived validity of information is

assessed within a framework of trust therefore the provision of information is not enough to motivate vaccination (Benin, Wisler-Scher, Colson, Shapiro, & Holmboe, 2006). Similarly, Gottvall and colleagues found that support for in school HPV vaccination among 27 Swedish parents was influenced by trust in the school nurses to act on accurate information. The parents themselves had limited knowledge of HPV and the vaccine, but their trust in the recommendations of health professionals contributed to their support of HPV vaccination. Parents did voice the need for more publically available HPV information to supplement the written information they received from the school. It is important to note that while they wanted more information, they themselves supported HPV vaccination in the absence of this information (Gottvall et al, 2013). These studies suggest that trust in the recommending body mediates how parents assess the validity of healthcare recommendations and biomedical information.

Does Increasing Knowledge Increase Vaccination?

Some researchers propose that the health belief model can help target educational interventions that aim to correct misconceptions of vaccination and increase vaccination coverage (Dardis, Koharchik, & Dukes, 2014). Yet evidence for the effectiveness of educational interventions on HPV vaccine uptake is weak. Davis and colleagues found that written information about HPV can increase parent acceptance of the HPV vaccine (Davis, Dickman, Ferris, & Dias, 2004). Contradicting these findings, another study found no significant difference in HPV vaccine acceptability between a group of parents that was provided with written information about HPV and a group of parents without any such information. The group given the information had higher HPV knowledge scores but did not have statistically higher acceptability of the vaccine (Dempsey, Zimet, Davis, & Koutsky, 2006). In another study, the provision of flu vaccine information to study participants decreased the belief that the flu vaccine

gives you the flu, but also reduced the intentions to vaccinate among those that were concerned about the vaccine side effects (Nyhan & Reifler, 2015). A web based survey that included 1,759 participants found that four educational interventions, both textual and visual, did not increase parent intentions vaccinate their child against measles, mumps, and rubella (Nyhan, Reifler, Richey, & Freed, 2014). The results from these studies indicate that increasing knowledge does not have a significant effect on parents' decisions to vaccinate. Adoption of a health promoting behavior requires more than just the provisioning of knowledge so a risk benefit approach to understanding vaccination decision making is not sufficient (Ritchie, 1991; Meszaros et al., 1996).

Beyond Knowledge: An Anthropological Perspective on Vaccination

The focus on proximate causes of HPV vaccination such as an individual's lack of HPV knowledge ignores the larger social conditions in which vaccination occurs. These social influences fall into two broad categories: (1) the sociocultural values that contextualize the meaning of vaccination and (2) the social conditions that influence health and access to healthcare. Understanding vaccination behavior and implementing any intervention aimed at increasing immunization requires the consideration of these distal influences (Link & Phelan, 2005).

Streefland and colleagues use the term "local vaccination cultures" to encapsulate how the biomedical framework only partially contributes to the meaning making of vaccination. Local vaccination cultures encompass things like personal and familial histories of disease, previous healthcare experiences, beliefs about parenting, beliefs about the body and health, gender roles, and trust in government and biomedicine, which all shape the perspective of a vaccine and its targeted disease. The cross-cultural variation in these factors explains why

different patterns in vaccine uptake occur even though the biomedical or scientific presentation of the vaccine is consistent (Poltorak, Leach, Fairhead, & Cassell, 2005; Streefland, Chowdhury, & Ramos-Jimenez, 1999). The role of social, political, and cultural forces in determining how a vaccine is framed is exemplified through the earlier look at the introduction of Gardasil in the United States. Thus health behavior models that do not take distal factors into consideration not only fail to acknowledge the larger social context, but also are limited in cross-cultural application. For example, the tenant of self-efficacy in the health belief model reflects Western ideals of autonomy that are not universally relevant (Straughan & Seow, 2000).

A qualitative study conducted in the United States among low income, minority parents identified several distal influences on intentions to vaccinate against HPV. Perkins and colleagues interviewed 76 mothers of 11-18 year old daughters that were waiting at either at a medical center or community health center. Mothers were an average age of 43 and daughters were an average age of 15 years old. HPV knowledge scores didn't differ between parents who did or did not intend to vaccinate their children and was not predictive of vaccination. The majority of mothers had positive views of vaccination in general and only 8% had ever refused a recommended vaccination. The majority of mothers believed that vaccines protect and prevent and expressed trust in the efficacy of biomedicine for preserving health. For these mothers, HPV vaccination was in the best interest of the child and provided them with "peace of mind" that their daughter's cervical cancer risk was minimized. Comparably, Gottvall and colleagues found that parental desires to protect daughters against cervical cancer was part of the motivation that led Swedish parents to support HPV vaccination (Gottvall et al, 2013). In Perkins' study, vaccination also alleviated some worries that came from the recognition that parent guidance has limited influence on the decisions of their children. Many mothers did not see a downside to

HPV vaccination and focused on its role to protect health. Some mothers did voice concerns with possible vaccine side effects and the way these concerns were weighed affected intentions to vaccinate. The parents that intended to vaccinate viewed the consequences of not vaccinating as more severe than the possible vaccination side effects. Overall, mothers mentioned that the current generation has begun having sex at an earlier age and criticized their apparent carelessness towards sex. For the majority of mothers, HPV vaccination would function to protect against some of the possible consequences of this careless behavior and possible stigma that comes from having a sexually transmitted disease (Perkins, Pierre-Joseph, Marquez, Iloka, & Clark, 2010).

Just as there is a need to contextualize the significance of vaccination, there is also a need to contextualize the proximate barriers to vaccination that most research emphasizes. Drawing back on the knowledge example, an anthropological perspective would look beyond an individual's need for more information and consider the environmental conditions that led up to this knowledge gap. The fundamental cause theory takes these social conditions into consideration and argues that health disparities are created by unequal access to resources, which reduce disease risk and impact (Link & Phelan, 1995). These resources encompass not only financial, but also social capital in terms of social networks, power, and representation. From this perspective, unless the unequal access to resources is addressed, health disparities will continue despite advancements healthcare technology. Polonijo and Carpiano examine this argument in terms of the HPV vaccine. While the HPV vaccine has been presented as an intervention that could reduce the disparity in the cervical cancer burden in the US, the researchers concluded that the vaccine only perpetuated these inequalities because the larger social conditions that determine cervical cancer disparity continue to be left unaddressed (Polonijo & Carpiano, 2013).

After the consideration of distal influences on vaccination behavior, it is clear why a purely risk-benefit portrayal of HPV vaccination has little impact on the decisions to vaccinate (Larson, Cooper, Eskola, Katz, & Ratzan, 2011). HPV vaccination isn't just a matter of biomedicine; it intersects the realms of parenting, sexuality, gender roles, power structures, stigma, and social inequality. **With these considerations in mind, my project set out to identify some of the distal determinants of HPV vaccination within a subset of parents from São Paulo, Brazil.** The research focused on the distal influences that define the “local vaccination culture” and shape the meaning of HPV vaccination. A comprehensive evaluation of the distal influences that arise from systematic barriers to vaccine access covered by the social cause theory fall outside the scope of this thesis. However, some of these factors are considered by taking a look at the unequal distribution of cervical cancer morbidity and Brazil's National Immunization Program (PNI) in the following chapter sections.

HPV Vaccination in Brazil

HPV Infection & Cervical Cancer Prevalence

HPV infection is a health concern in Latin America and the Caribbean, where cervical cancer is second most common cancer and the second leading cause of cancer deaths in women. The rates of cervical cancer mortality are 3 times greater in Latin America and the Caribbean than in North America and account for 10% of cancer deaths (PAHO, 2014). Cervical cancer continues to be a significant health burden in Brazil with an estimated 18,503 diagnoses, and of these cervical cancer cases, 71.2% are attributable to HPVs 16 or 18 (Bruni et al., 2014). There were an estimated 8,414 deaths in 2010 from cervical cancer, however cervical cancer mortality in Brazil has declined in the past two decades, which may be due to increases in the proportion of women that received a Pap smear, 84.5% in 2008 (Bruni et al., 2014). Despite these

impressive trends, there continues to be considerable regional and income disparities in screening and cervical cancer mortality rates. Inadequate funding and infrastructure for cancer treatment poses barriers to the continuation of decreased cervical cancer mortality (Schmidt et al., 2011).

The Meaning of Cervical Cancer in Brazil

The link between cervical cancer and sex has led to risk theories that explain differences in cervical cancer risk between groups of people based on differences in promiscuity (Lowy, 2011). These explanatory frameworks lead to the stigmatization of the women diagnosed with cervical cancer. From her ethnographic experience, Jessica Gregg found that this sexual stigma was present in a *favela* in Recife, Brazil and resulted from the web of meanings used by the women to define cervical cancer in terms of the larger social constructs of female sexuality. As Gregg explains, sexuality simultaneously defines and restricts Brazilian women: “*Because all Brazilian women are expected, to lesser or greater extents, to be more sensual than women of other cultures, every woman’s sexuality needs to be controlled (Gregg, 2011).*” The result is the paradoxical expectation for women to be both hypersexual and sexually controlled, which influences the dialogue surrounding disease and health care, especially in terms of diseases that directly or indirectly result from sexually transmitted infection, such as cervical cancer.

Accordingly, cervical cancer risk was defined in terms of promiscuous female sexual activity. The Brazilian women in the *favela* had their own interpretations of cervical cancer risk because deviation from the cultural expectations of controlled sexual activity was common and often admired as a form of liberty. Pap smears allowed women to redefine cervical cancer risk in a way that aligned with their daily realities of sexual activity. Although surrounded by misconceptions in terms of its purpose, the Pap smear was generally recognized as important in

mitigating the health consequences of sexual activity. This interpretation realigned risk so that not getting a Pap smear became the primary risk factor for cervical cancer, whereas sexual activity became a secondary risk factor: *“Women in the favela interpreted lack of the Pap smear as their primary risk, and sexual behaviors- both their own and their partners- as a given, not a risk for which anyone could actually assume responsibility (Gregg, 2011).”* While this meaning was beneficial to the women whose sexual behavior diverged from what was expected, it also added another layer of blame towards the women diagnosed with cervical cancer. A woman with cervical cancer could now be blamed for both being sexually promiscuous as well as being lazy by failing to take care of herself and prevent disease through Pap screening. While in the day to day, sexual liberty was revered, the meanings given to cervical cancer echoed and perpetuated the traditional female centered blame for disease and constraints on female sexuality (Gregg, 2011). Gregg’s fieldwork was conducted in 1995 prior to the introduction of the HPV vaccine, but based on her conclusions regarding the interpretation of Pap smears, the vaccine might also play a role in defining cervical cancer risk and directing blame for disease. The blame for cervical cancer might now shift partially to parents, who determine whether or not their daughters are vaccinated. This research project is unique in that it will be the first to qualitatively search for these themes among Brazilian parents that have already vaccinated or are considering vaccinating their daughters.

Social Inequalities Drive the Unequal Burden of Cervical Cancer

The perceived association between sexual promiscuity and cervical cancer is not consistent with epidemiological work: in a sample of 1,616 female adolescents from Rio de Janeiro, Brazil, there was no significant difference in the number of sexual partners between the females with precancerous cervical cancer lesions and those without these lesions. The groups

also did not significantly differ in the average age that they began having sex (Monteiro, Trajano, Silva, & Russomano, 2006). Additionally, HPV vaccination in a cohort of 1,938 girls from the U.S. was not associated with increased rates of pregnancy, sexually transmitted infection testing or diagnosis, or contraceptive counseling (Bednarczyk, Davis, Ault, Orenstein, & Omer, 2012). Poverty more so than promiscuity likely accounts for differences in cervical cancer risk. The influence of socioeconomic status on HPV infection and cervical cancer progression was assessed among a group of women in Rio de Janeiro. The Pap smears of a group of 454 women that utilized a private health clinic were compared to those of a group of 220 women that frequent a public clinic. HPV infection was found in 58% of the women from the private sector and in 77% of the public clinic group. Notably, abnormal cytology tests were concentrated among the public clinic group, where 26% of the women exhibited high-risk cervical cancer lesions and 16% were diagnosed with cervical cancer. In the private clinic group these percentages were 8% and 0% respectively. Oliveira and colleagues argue that this difference in cervical cancer progression is determined by differential access to the early detection and treatment of HPV infection, precancerous lesions, and cervical cancer. Income, education, distance from health clinic, transportation issues, and lack of health insurance coverage were proposed as the important factors in determining this unequal access (Oliveira, 2008). In line with these findings, an analysis of a cancer incidence from 1998 to 2003 in the United States revealed that higher poverty was associated with higher incidences of HPV related cervical, penile, and vaginal cancers (Benard et al., 2008). Predictive health behavior models mainly focus on proximate causes of vaccination and are not well equipped to factor in the influence of distal factors, which encompass these social barriers. Thus socioeconomic status has direct

implications for health care access and health status (Wilkinson, & Pickett, 2006; Mamo & Epstein 2013).

National HPV Immunization Campaign

The potential for the HPV vaccine to reduce these disparities in the cervical cancer burden has incentivized several countries to fund the introduction of the vaccine. As of August 2014, 58 countries have added either the quadrivalent or bivalent HPV vaccines to their national immunization programs (WHO, 2014). Brazil joined this list in March of 2014 with the launch of their national HPV vaccination campaign (Ernstes, 2014). The goal of the campaign is to “...prevent cervical cancer in Brazil, reflecting on the reduction of the incidence and mortality by this infirmity. Outcomes such as the prevention of other types of cancers induced by HPV and genital warts are considered secondary outcomes” (Ministerio de Saúde, 2014). Gardasil[®] is now included in Brazil’s National Immunization Program (PNI), which offers certain vaccines free of charge to all Brazilian citizens and residents. PNI was established in 1973 and merged into Brazil’s Unified Health System (SUS), which was created after the 1988 constitution declared health a human right. The SUS publically provides healthcare free of charge to all Brazilian residents and foreign visitors (Domingues, Teixeira, & Carvalho, 2012). PNI has worked to mitigate the health inequalities created by the social inequality in Brazil, where the wealth disparity is among the highest in the world with a GINI index of 52.7 in 2012 (World Bank, 2012). A study by Barata and colleagues found that households in São Paulo from the lowest census tract had vaccination rates greater than or equal to those from better socioeconomic statuses demonstrating that vaccination is accessible to low income populations in Brazil, whose socioeconomic standing places more barriers to healthcare access (Barata, de Almeida Ribeiro, de Moraes, & Flannery, 2012). Furthermore Brazil has one of the highest

immunization coverage rates worldwide and the PNI has been pivotal in reducing socioeconomic disparities in disease burden (Barreto et al., 2011). Reducing of the disparities in the social distribution of cervical cancer through the HPV vaccine is therefore likely to be an effective approach.

Brazil's Ministry of Health has partnered with Merck & Co. to reach self-sufficiency in HPV vaccine production by 2019. Instituto Butantan and Fundação Oswaldo Cruz, the two most prominent biomedical research centers in the country, are leading this partnership. Due to limited economic constraints, the vaccine could not feasibly be offered to both girls and boys, therefore HPV vaccination is only available for girls based on the results of cost analysis of implementing the vaccine for reducing cervical cancer cases (Agosti & Goldie, 2007; Goldie et al., 2007; Koulova et al., 2008). During the campaign's first year, the quadrivalent vaccine was offered to girls ages 11-13. In 2015, the vaccine will be offered to girls ages 9-11 and as of 2016, only 9 year old girls will be eligible to receive the HPV vaccine. These vaccines are available at the Basic Health Units (UBS), which are the primary care centers of the SUS and are located in almost every neighborhood. UBSs in several municipalities have partnered with schools to organize in-school HPV vaccination days. The local UBS staff are stationed at a school for the entire day and the eligible students are vaccinated unless their parents signed an opt out vaccination form (Ministerio de Saúde, 2014). This strategy has been very effective in reaching high vaccination rates for the first HPV dose. As of December 2014, coverage for the first dose reached 99%. This vaccination rate surpasses the target goal of 80% vaccination and exceeds the 57% of females in the United States that have received at least one HPV dose as of 2013 (CDC, 2014; SI-PNI, 2014). Administration of the second dose began in September 2104. Brazil has adopted an extended vaccination scheme so the third dose will be available 5 years after the first

dose. The gap between the second and third doses may pose a challenge for maintaining high coverage rates because of the extra recruitment efforts required to ensure that these girls come back for the last dose especially since those that were first vaccinated at age 13 will be 18 or older by the time of the third dose.

Knowledge of HPV in Brazil & HPV Vaccine Acceptability

Few studies have assessed the levels of HPV knowledge in Brazil before the HPV immunization campaign of 2014. The conducted studies indicate that the majority of adolescents in Brazil recognize HPV as a STI. In a group of students from São Paulo with the average age of 20, 69% of males and 76% of females knew that HPV is sexually transmitted. These percentages were lower relative to those for HIV, Syphilis, genital herpes, and gonorrhoea (Caetano et al., 2010). Similarly, Costa and Goldberg interviewed 283 Brazilian students in São Paulo that ranged from 18-23 years in age and found that the majority had heard of HPV, but that there was a limited understanding of HPV transmission and HPV related diseases. HPV was not as well known relative to other STIs and ranked around third or fourth in terms of STIs this population was concerned with. Males were seen as the primary transmitters of HPV and female consequences of HPV infection were perceived to be more severe, which added to the notion that HPV prevention in males was not as necessary. After the researchers talked about the HPV vaccine with the female participants, 90% of them expressed interest in receiving the vaccination if it was available (Costa & Goldenberg, 2013). In Salvador, 66.7% of interviewed women ages 16-23 identified HPV as an STI, but only 10% mentioned the connection between HPV and cervical cancer. Although 81% of the participants had undergone a Pap test, 78% had limited knowledge of the purpose of the test (Moreira et al., 2006). Rama and colleagues found lower recognition of HPV among low income, primiparous women of the average age of 19.9 in São

Paulo. Of 301 surveyed women, only 37% had ever heard of HPV, only 19% knew that HPV is an STI, 7% knew HPV could lead to cervical cancer, and only .3% knew that HPV could cause genital warts. Having a STI was significantly associated with increased HPV awareness. Despite these low HPV knowledge levels, all of the participants said they would accept the HPV vaccine if it were offered (Rama et al., 2010). Similarly, a study conducted in Natal, Rio Grande do Norte found that only 20% of women knew that HPV is an STI and only 9.1% had high knowledge levels of HPV (Lima et al, 2013). Only one study has looked at intentions of both mothers and fathers to vaccinate their children against HPV in Brazil. This study took place in health posts in Campinas, São Paulo, where 538 parents were interviewed prior to the launch of the HPV immunization program. Forty percent of these parents had heard of HPV and of these parents, less than 30% had adequate knowledge levels of HPV. Adequate knowledge required knowing at least one of the following affirmations: (1) HPV is an STI; (2) HPV infection can lead to cervical/penile cancer; (3) HPV can result in genital warts. Additionally, only 8.6% of parents had heard of the HPV vaccines. Of those that knew about the HPV vaccine, 95% said they would vaccinate their children if it were available publically (Osis, Duarte, & Sousa, 2014). In some cases, initial exposure to HPV information coincides with diagnosis of an HPV infection, which was the case for some of the women receiving HPV treatment in Fortaleza (de Sousa, Pinheiro, & Barroso, 2008). The existing studies in Brazil indicate that prior to the vaccine campaign, younger populations were more aware that HPV is an STI, but a deeper understanding of HPV and its health consequences was lacking. Based on the literature previously presented, these low knowledge levels likely will not dictate HPV vaccination behavior in Brazil.

A Culture of Vaccination

In Brazil, vaccination is normalized, as demonstrated by the population's strong adherence to vaccine schedules and demand for the inclusion of more vaccines in the PNI. The strength and success of PNI's forty years of existence in Brazil has perpetuated this culture of vaccination. The fight to eradicate smallpox in 1966 in Brazil set the stage for the establishment of PNI. Eradication of smallpox in Brazil was achieved in 1971, five years after the initial roll out of the campaign (Fenner, 1988). During this period, an outbreak of 51 smallpox cases in an area that was reported to have reached target vaccination rates led to a major investment in immunization program evaluation and monitoring that was previously lacking. The outbreak resulted in the development of a reporting system that reported weekly cases of smallpox outbreaks and served as the foundation for the passive surveillance system for adverse events that is used to monitor vaccine safety today. The success of smallpox eradication effort led to the normalization of vaccination and general consensus regarding the necessity of compulsory vaccination in Brazil. The structures implemented during the smallpox campaign enabled the eradication of poliomyelitis in the 1990s, a success that further cemented the vaccination culture. Public demand for more immunizations increased with the integration of PNI with SUS, which resulted in vaccines being offered free of charge (Hochman, 2009).

Despite a history of generally high levels of support for vaccines in Brazil, the most well known anti vaccination movement from the past took place in 1904 and resulted from distrust in government intentions (Meade, 1986). A mandatory smallpox vaccination law, which permitted forceful vaccination through home entry and police force, was passed in Rio de Janeiro. A week long, violent revolt resulted in deaths, injuries, and imprisonment, but successfully halted the implementation of the law (Sevcenko, 1993). Contemporary vaccine opposition in Brazil, as in

the U.S., exists on a small scale and is concentrated in the higher socioeconomic classes. The overall vaccination rate within the higher socioeconomic classes was estimated to be 76%, which is lower than the national average of 81%. Opposition to vaccination is mainly expressed on online forums and is largely absent from mainstream media (Barba, 2014). A recent outbreak in 2011 of 26 measles cases in São Paulo increased concerns about this antivaccination trend (Mello & Collucci, 2014).

Vaccines: A Symbol of Parental Care

An anthropological analysis based on interviews with parents from the highest socioeconomic strata in São Paulo revealed that childhood vaccine decisions in Brazil fall within the domain of parental responsibilities (Couto & Barbieri, 2015). The biomedical and public health meanings of vaccination are overshadowed by its significance in childcare, in which the prevailing cultural consensus asserts that a vaccinated child is indicative of a good parent. Couto and Barbieri found that the couples that either selectively vaccinated or did not vaccinate at all acknowledged that their decisions not to vaccinate threatened their reputations as parents. All three groups of parents: vaccinators, selective vaccinators, and nonvaccinators, based their decisions on the intention to protect their children. The different outcomes between these three groups result from differing interpretations of vaccination. Choosing not to vaccinate was portrayed as protecting children from the harms of vaccination, which appear to be more severe than the harms of not vaccinating. This attitude would fit into the perceived susceptibility component of the HBM, but would not be modifiable by a simple educational intervention since the parent dialogues reflect that changing this perception hinges on much more than biomedical knowledge. The low visibility of the vaccine preventable diseases made the potential vaccine side effects appear more harmful to some parents. Some parents mentioned that their

socioeconomic status allowed them to implement other disease preventative measures, such as a healthy diet, that protected them and made vaccination less necessary. Other parents also perceived that generalized vaccination recommendations minimized parental autonomy from health care decisions and needed to be tailored to individual circumstances. Even though the public sector implements vaccination in Brazil, fears of the influence of corrupt pharmaceutical companies was also mentioned by some parents (Couto & Barbieri, 2015). These results demonstrate that decisions to vaccinate children in Brazil are shaped by the culture of vaccination and the different meanings attributed to vaccination. My research sample consisted of low income families, who are generally more reliant on the public health system in Brazil, whereas high income families often supplement public coverage with additional private insurance. This research will give insight into whether or not the themes Couto and Barbieri identified are also relevant to HPV vaccination decisions among low income Brazilian parents.

Importance of my Research

The literature presented in this chapter suggests that the provision of scientific knowledge about HPV and its vaccine is not sufficient to motivate parents to vaccinate their daughters against HPV. Instead, vaccination is context specific and parent perceptions are shaped by various political, social, and cultural factors that give meaning to the act of vaccinating and can intervene in vaccine access. To my knowledge, no studies have specifically examined parent perceptions of the HPV vaccine after the launch of the national HPV immunization campaign in Brazil and only one study has explored parent perceptions of the HPV vaccine prior to the campaign. In light of the greater than 90% national HPV immunization coverage for the first dose, it is important to identify the motivators of HPV vaccination to help understand how and why such large coverage levels were reached so quickly. Examining parental perspectives is

important in Brazil, where parental consent is currently required in all states for HPV immunization. While my study population is not generalizable to all of Brazil, the data give insight into the framework involved in the parental decision to vaccinate against HPV because participants included both parents of vaccinated and unvaccinated daughters. Furthermore, a qualitative approach allows for more nuanced responses that could be lost through a quantitative survey.

II. METHODS

Research Project Development, Collaboration & Approval

This study is part of a larger research project, Human Papillomavirus Vaccination in São Paulo, Brazil: Perceptions and Implementation, which also includes a quantitative component for parents and a quantitative assessment of provider knowledge, attitudes, and practices surrounding HPV vaccination in São Paulo. Daniella Figueroa-Downing, Misha Baker, and Jasmine Camps-Claiborne are the additional team researchers. The in-country collaborators are Dr. Jose Eluf Neto, Dr. Luisa Villa, and Maria Luiza Baggio, who hold positions at the University of São Paulo Medical School (FMUSP) and the São Paulo Institute of Cancer respectively. Funding for international travel and research expenses was obtained through a Global Health Institute (GHI) Field Scholars Grant, supervised by Dr. Dabney Evans and Dr. Robert Bednarczyk, and a Scholarly Inquiry and Research at Emory (SIRE) Grant.

All necessary Institutional Review Board approvals were obtained for this study. Emory IRB classified the study as exempt from review. After receiving approval from the FMUSP IRB Board, the study proposal was then sent to and approved by the São Paulo municipal IRB board. The study was approved to take place in the seven health posts that make up Projeto Região Oeste (PRO), a network of UBSs managed by USP. The study proposal and IRB approvals were sent to the directors of each UBS, five of which agreed to have the study take place in their respective UBS. Meetings were arranged with the five directors to introduce the researchers and address the logistical aspects surrounding the study.

Data Collection

Semi-structured interviews were conducted in the five UBSs from late July 2014 to early August 2014. These five UBSs are: Vila Sonia, Boa Vista, Malta Cardoso, Jardim D'Abril, and

Vila Dalva. Two days were spent at each UBS for a total of ten days over the course of a two and a half week period. Each field day began at 8AM and ended at 5PM. Upon arrival, patients in the waiting areas were screened for eligibility using the following inclusion criteria: (1) must be Brazilian and a resident of São Paulo; (2) must have at least one female child between ages 9-13; (3) must be 18 or older. If no eligible parents were identified and successfully recruited, I stationed myself at the entrance of the UBS, where I screened each person that entered for eligibility. Because the interviews ranged from 20- 64 minutes in length, after each interview, I surveyed the waiting areas again to screen any patients that may have entered the UBS while I was conducting the previous interview. A tally of the number of people that were approached, eligible, and/or interviewed was kept at each UBS and is listed below in Table 1.

Table 1. Participant Recruitment

#	UBS	Number Approached	Eligible	Interviewed
1	Vila Sonia			
	Day 1	104	3	3
	Day 2	35	4	3
2	Boa Vista			
	Day 1	137	10	3
	Day 2	133	5	4
3	Malta Cardoso			
	Day 1	182	11	3
	Day 2	75	8	3
4	Jardim D'Abril			
	Day 1	45	6	3
	Day 2	64	6	2
5	Vila Dalva			
	Day 1	100	8	3
	Day 2	54	6	3
	Total	929	67	30

At every UBS, the interview location was determined by room availability. There was a specific room designated for my interviews in two of the UBS. One room was a small, narrow examination room not being used that week. At the other UBS, I conducted interviews in a large room that was being remodeled into a new dental treatment area. There was old equipment and debris in most of the room so interviews were conducted at the door at which two chairs were placed. At another UBS, interviews were either conducted in an examination room or outside, in a secluded corner. At the remaining two locations, there were no specifically designated interview rooms. Once a participant was recruited, I would check with a designated nurse to see if there were any available rooms at that time. If there were not, then interviews were conducted in the far end of hallways or in the outside areas of the health posts. Interviews were only conducted in these areas if they were isolated enough to maintain participant confidentiality and if the participant was comfortable.

Once each participant was recruited and taken to the interview location, both verbal and written consent were obtained. The written consent document was formatted according to both USP and São Paulo municipal IRB standards. There were two copies of the written consent, one copy for the participant and one copy to be stored with the other research materials. After the consent process, a voice recorder was turned on and the participant was asked a second time, for the record, if they consented to having their voice recorded. The semi-structured interview was conducted in Portuguese and began with demographic questions before moving onto the open ended questions. An interview guide was created for note taking and to help direct the interviews. The interview guide is included as Appendix A. The semi-structured interview approach allowed for a deeper and more subjective understanding of the research questions.

Parent opinions of disease prevention methods, the HPV vaccine, and vaccines in general were explored through these interview questions.

Each participant was assigned an ID that took the form of “A#” with the number ranging from 1 to 30 in order to ensure confidentiality. Any names that appear in the results section are pseudonyms. All interview guides and audio recordings were labeled with the corresponding participant IDs. All research materials were stored together at the end of each workday in a secure cabinet. At the end of the data collection period, the documents were scanned and uploaded onto a secure drive. The paper copies remain locked in a secure cabinet at the Institute of Cancer in São Paulo. The voice recordings were uploaded to a secure computer and a password protected external drive.

Data Analysis

Each recording was transcribed directly in Portuguese beginning with the open-ended questions section. All 30 transcripts were uploaded into MAXQDA in Rich Text Format for coding. Interview text was analyzed inductively following the principles of Grounded Theory (Bernard & Ryan, 2010). Open coding involved line by line examination of the text and helped conceptualize the interviews. During this phase, all new identified concepts were coded. Focused coding then collapsed these specific codes into broader, overarching thematic codes. The creation and organization of the thematic categories was facilitated by memoing.

III. RESULTS

This chapter begins with an overview of the demographic characteristics of the interviewed parents. Next the HPV information sources that were mentioned by the parents and their HPV knowledge levels are outlined. The following section then presents the proportion of vaccinated and unvaccinated daughters before describing the parental perceptions of both the HPV vaccine and vaccination in general. These viewpoints provide the basis for the subsequent reporting on the themes of vaccine use in parenting, the conditions of “nowadays”, and support for HPV vaccination in boys. Then the perceived non-medical consequences of HPV are presented. Lastly, the chapter ends by outlining the themes of trust in vaccine supporters and the perceived knowledge deficit of non-vaccinators.

Participant Demographics

Of the 67 parents that were eligible to participate in the study, a total of 30 parents were interviewed and no responses were excluded from data analysis. Table 2 lists the demographic characteristics of the sample. The participants were mainly female (87%) and lived with a significant other (50%). The average age of the parents was 38 and most had 1-2 children (46.7%). All of the interviewed parents had daughters that would be eligible for HPV vaccination within the first 3 years of the national campaign. The average monthly household salary for this sample was about 630 U.S. dollars (\$R 2,033.57) and at the time of the interview the minimum monthly wage per person in Brazil was \$R724. Based on the categorization of the Brazilian Institute of Geography and Statistics, households with this income belong to the socioeconomic Class D based on a ranking of A-E, A being the highest. In one household, all members were unemployed at the time of the interview and two participants chose to skip this question.

Table 2. Participant Demographics

Sex	N (%) or Average (Range)
Female	26 (87%)
Male	4 (13%)
Age	38 (26-65)
Number of Children	2.7 (1-7)
1-2	14 (46.7%)
3-4	12 (40%)
5 or more	4 (13.3%)
Relationship Status	
Single	6 (20%)
Married	6 (20%)
Divorced	1 (3.3%)
Living Together	15 (50%)
Widowed	2 (6.7%)
Household Monthly Salary	\$R 2,033.57 (0-6,500)

Sources of HPV Information

Initial Encounters with HPV information

During the interview, parents were asked to describe the first time they had heard about HPV and where they had encountered HPV information since that first time. Five parents first became aware of HPV after having either personal or proximal experiences with HPV related diseases (16%). For two of these parents, the first time they heard about HPV was after a personal diagnosis with HPV infection, one had genital warts and the other had cervical cancer

and had to remove her uterus. A third parent had two sisters who underwent treatment for both HPV associated genital warts and cervical cancer. When another parent was 12 years old, a close family friend passed away from HPV and HIV coinfection. The fifth parent first heard about HPV when her sister's friend started treatment for HPV associated genital warts.

The campaign accounted for 5 of the parents' first encounters with HPV related information (16%). Most of these parents saw a brief advertisement on TV about the campaign or watched a more in depth health special on HPV infection. As one parent put it: *"I heard about it [HPV] on TV, but I didn't pay much attention (P13)."* For another parent, the interview was the first time the parent had heard of HPV, despite the fact that the daughter had already received the HPV vaccine. Another 5 parents recalled being exposed to HPV information in passing during their visits to health posts prior to the campaign (16%). One such parent said: *"I've seen things about it [HPV] only in health posts, but I've never had the interest to look, to find out what it is (P2)."* Another parent recalls having seen the word "HPV" in a pamphlet after a gynecological check up. Similarly, at an STI testing clinic, one parent also came across the term for the first time listed among other STIs in an educational brochure.

Previous school based sex education first provided information about HPV for three of the remaining parents. During nurse technician training, a different parent first learned about HPV, but mentioned that the information was very vague: *"When I heard about HPV, I was in a nurse assistant course and we were studying the female body. The professors talked very vaguely about it...it wasn't anything very detailed (P16)."* One parent mentioned that the subject of HPV had come up a long time ago during a conversation about health among friends. For an additional parent, television coverage of HPV about five years ago was the first time the parent became aware of HPV. Lastly, several of the parents could not pinpoint the first time they heard about

HPV (23.3%). The following quote encapsulates a general reaction from the parents that had previously encountered HPV information: *“I’ve heard about it [HPV], but I’ve never paid close attention to it (P20).”*

Encounters with HPV Information Today

Excluding the televised campaign announcements, most parents mentioned that they currently come across HPV information in passing at health posts, on TV, or through their daughter’s school. Some parents felt that HPV information wasn’t commonly found within their communities. As a consequence, this parent believes that HPV isn’t well known among the general population: *“Rarely do people talk about this [HPV]. More people talk about it in college or during a campaign like this one, but in principle the disease isn’t well known (P12).”*

One parent expressed frustration with the lack of HPV education, especially in poorer regions:

“No, I never heard anyone talk about it [HPV] or lecture about it or anything. It’s worth it. I think a lot of money is wasted on unnecessary things, especially in poorer areas where HPV is most prevalent...there are a lot of young homosexuals in my neighborhood. Do they know? I wonder if they know that HPV stays latent in the man’s body for several years...if you inform the person, they learn that in the man’s body the virus stays latent for several years and then emerges if the immune system weakens...[HPV] needs to be explained because if not you end up with one hell of a mess. I think it’s a lack of information not only about HPV but about all venereal diseases. But the focus is on HPV because HPV kills (P28).”

Several of the parents reiterated that they did not retain much of the information they were exposed to. A parent that watched an extended TV special about HPV said the following: *“I found what they were teaching on TV to be very important. I didn’t retain anything, but I did learn that we need to prevent disease (P9).”*

Low Knowledge of HPV

All participants were asked to describe and say everything they knew about HPV during the interview. Afterwards a short paragraph about HPV and HPV related diseases was read aloud to the participants. This blurb can be found in the interview guide included as Appendix A.

These responses were then scored on a scale of 1 to 4 based on the criteria listed in Table 3 below. Only one parent exhibited the highest knowledge score of 4 and eight of the parents had knowledge levels of 0. According to these results, over a fifth of parents (26.7%) had no knowledge of HPV. Four of these parents had vaccinated daughters. Table 4 below displays the average knowledge scores overall and within different parent subgroups. The total average knowledge score was 1.23, almost equal to the average score of 1.20 among the parent of girls that were vaccinated. Parents with unvaccinated daughters scored only slightly higher with a 1.27 average. The two parents in the unvaccinated and eligible category had the highest average knowledge score of 1.38.

The parent with the highest knowledge score of 4 had personal experience with HPV infection, genital warts, and cervical cancer. She also knew about the latency period and that there are cancers that men can develop from HPV infection. In contrast, another parent who had personal experience with genital warts attributed to HPV infection, was not aware of the link between HPV and various cancers. Two of the parents mixed up HPV with HIV and could not distinguish the two diseases. Several parents knew that HPV is primarily sexually transmitted, but also proposed incorrect, alternative modes of HPV transmission. These included transmission through blood transfusion, drinking after another person, and sitting on a toilet seat that has been in contact with a carrier of HPV infection. The personal lack of knowledge did not determine support for vaccination as portrayed by one parent's comment about the HPV vaccine: *"HPV, I still don't know what that means, but I think if something can prevent a disease, then of course that's a good thing and not a bad thing (P26)."*

Table 3. Knowledge Score Criteria

Knowledge Level	Criteria
0	nothing OR confused with HIV
1	sexually transmitted OR cervical cancer OR genital warts
2	sexually transmitted AND cervical cancer OR genital warts
3	sexually transmitted, cervical cancer, AND genital warts
4	sexually transmitted, cervical cancer, genital warts, AND other cancers

Table 4. Vaccination Status & Average Knowledge Score

	Average Knowledge Score (N)
Total Vaccinated	1.20 (15)
Vaccinated & Eligible	1.21 (14)
Total Unvaccinated	1.27 (15)
Unvaccinated & Eligible	1.38 (2)
All Parents	1.23 (30)

HPV Vaccination Status

The majority of the daughters that met the age criteria for HPV vaccination during the first year of the campaign had been vaccinated at the time of the interview (87.5%). Table 5 displays both the percentage and number of HPV vaccinated girls overall and by eligibility. The two parents with eligible daughters that had not yet been vaccinated were not aware of the immunization campaign. Both parents expressed interest in vaccinating their daughters after learning that the vaccine was publicly available. Two of the parents with eligible and vaccinated daughters realized their daughters had received the HPV vaccine through the interview

conversation. One daughter had been taken to the health post to receive the vaccine even though her parent did not know specifically what vaccine it was:

“She got vaccinated here, downstairs. I think it was for the HPV virus. I don’t know. They were vaccinating adolescents through a campaign that was held here. Oh, I don’t know if it was for HPV. I don’t know. I know it was in the vaccination room, here in this health post, that she was vaccinated. A lot of adolescents came here that day so I brought her (P2).”

The second parent was uncertain of her daughter’s vaccination status because her husband had taken their daughter to be vaccinated:

“Well I think it was this vaccine, it was right in the beginning [of the campaign] that she was vaccinated and the next one [dose], will be given next year, I think, but I don’t know. I don’t know which one they said she should receive. My husband was the one that brought her to be vaccinated (P3).”

After discussing the timing and specifics of the vaccination with both parents, it was concluded that the vaccine that both girls had indeed been vaccinated against HPV.

Of the daughters that did not fall into the eligible age range, only one had been vaccinated. All but one of the parents of unvaccinated and ineligible daughters expressed interest in vaccinating their daughters through the public sector once the age criteria was met as was indicated by their comments and stories. One parent took her daughter to the health post to be vaccinated, but was unaware of the age specifications and was turned away: *“I told my daughter: I will take you there to see if you can be vaccinated. But the lady said, no, only 11 and older (P30).”* One parent expressed disappointment when she realized that her daughter was not eligible for vaccination through the public sector: *“I was reading the announcement and then I thought: darn, Sandra won’t be vaccinated (P23).”* Another parent worried during the campaign when her daughter was not among the vaccinated girls: *“I got worried because my daughter wasn’t vaccinated (P24).”* One daughter told her parent she wanted to be vaccinated once it was her turn after seeing her older peers receive the vaccination in school: *“She is already teaching us about the subject because at her school they talked about it [HPV] a lot. She already said that*

she will be vaccinated just as the older girls were... (P4).” A parent that had personal experience with adverse health consequences of HPV infection expressed interest in purchasing the vaccine for her nine year old daughter even if the vaccine became no longer publicly available:

“Let’s suppose that when Maria Ester reaches the vaccination age, the vaccine is not longer [publicly] available. If I have the financial means, I will pay for her to be vaccinated because I am aware of its importance and of the importance of my daughter in my life. Understand? And of the life she has ahead of her. For her to have a good adolescence...for her to climb the steps in her life with health because without health, you go nowhere. I would have preferred it a thousand times more to have paid, to have had the condition to pay to have myself vaccinated, than to have gone through the entire process I went through (P28).”

Although supportive of HPV vaccination for both girls and boys in general, the one parent in this group that was hesitant about vaccinating her own daughter worried about her daughter’s ability to handle the vaccine:

“I am afraid that she will have a reaction because she is very delicate, you know, with vaccines. She has bronchitis so I am afraid. I am afraid that she will get tired, that the asthmatic bronchitis will be triggered...that a reaction will stop her heart (P10).”

These concerns existed even though the daughter had never experienced adverse reactions to other vaccines outside of developing a cold after flu vaccination. The parent believed that vaccination is an effective way to prevent disease, but vaccinating at a time when her daughter is already “big”, or grown up, seemed strange.

Table 5. Daughter's HPV Vaccination Status

Daughter's Age & Vaccination Status	N (%)
(9-10): Ineligible	14 (46.7%)
Vaccinated	1 (7.1%)
Unvaccinated	13 (92.9%)
(11-13): Eligible	16 (53.3%)
Vaccinated	14 (87.5%)
Unvaccinated	2 (14.3%)
Total Vaccinated	15 (50%)
Total Unvaccinated	15 (50%)

Perceptions of Vaccination

Normal: “It’s just another vaccine.”

Among the 30 parents, vaccination was as a norm. The HPV vaccine was generally perceived as fitting into the already existing framework of vaccines: “*It’s just another vaccine (P14)*”. One parent’s words: “*...I agree with all the terms of vaccination (P12)*” reflects the prevailing stance on vaccination among the interviewed parents. Witnessing the benefits of previous vaccination initiatives contributed to the normalization and positive perception of HPV vaccination. Two mothers brought up the success of the campaign against polio, which resulted in the oral polio vaccine being nicknamed “*the saving droplet (P22)*”. This droplet even became the official mascot of Brazil’s PNI. Personal experience with vaccination also shaped these opinions. One mother measured the effectiveness of a vaccine by whether or not her child had become sick with the any of the targeted diseases. Through this categorization, she voiced full support for all vaccines, except for the flu vaccine since her daughter had become sick despite

being vaccinated. A second parent also perceived the flu vaccine to be less effective for the same reasoning. Regardless of these experiences with the flu vaccine, both parents believed that vaccination is important and effective. In contrast to these two parents, when voicing her trust in vaccination, another mother said she believed in the efficacy of all vaccines and specifically emphasized that this belief extended to the flu vaccine.

The general approval of vaccination continuously reemerged throughout the interviews. For example, when asked why a parent might choose not to vaccinate a daughter against HPV, quite a few participants expressed surprise at the notion that a parent would actively choose not to vaccinate the daughter. One parent stated that it would be impossible for a parent to know that the HPV vaccine is available at the health post and choose not to vaccinate his or her daughter. In agreement with this sentiment, yet another parent expressed: “...if the health posts have the [HPV] vaccine, why not vaccinate (P13)?” The following quote exemplifies the notion that vaccination generally goes unquestioned in this population: “Are there cases where parents refuse [vaccination]? A reason to refuse a vaccine for your child, gosh, I’ve never thought about this before (P16).” The opinions that “every vaccine should be taken (P25)” and “...if you don’t vaccinate, I think you are acting incorrectly (P6)” further demonstrate that vaccination is highly regarded and expected.

In general, additional vaccines were desired as several parents called for increased investment in vaccine development. New vaccines accordingly seem to be well received among the majority of these parents: “Every time there is a vaccine to be given, I always come to this health post to vaccinate them. My children’s vaccinations are all up to date. (P9).” This welcoming reaction applied to the reception of the HPV vaccine and some participants noticed that in their communities, the introduction of the vaccine was well accepted. One parent

recounted that several mothers, whose daughters had missed the in school vaccination, brought their daughters to the health post to receive the HPV vaccine. Likewise, most parents did not know of anyone who is against the HPV vaccine or vaccination in general. One parent's mother opposed vaccination, but this opinion did not change the parent's stance on vaccination as beneficial. The positive perceptions of vaccination that extended to the HPV vaccine were also shown by the fact that some parents believed the vaccine should be available to everyone and specifically, some mothers wished they themselves were eligible for vaccination. One mother asked me: *"Is it available for my age? Can I be vaccinated (P26)?"* When acknowledging the age requirements and that the HPV vaccine wasn't available when she was younger, another mother said: *"...I felt disappointed because I never got to receive the HPV vaccine (P16)."* Organizations outside of the health and education fields also help normalize vaccination in Brazil. For example, during a church sermon, the value of HPV vaccination was highlighted as one parent recounted the following: *"Even at church they've talked about it [the HPV vaccine] and have told to parents to cooperate (P4)."*

Preventative

All of the interviewed parents commented on the preventative function of vaccination. Accordingly, the significance of vaccination was often attributed to its preventative use, for example: *"It's better that you prevent a disease so I believe the vaccine is important, yes, I believe that...it's good that the vaccine was invented. The invention of the vaccine is a wonderful thing (P16)."* These thoughts about the preventative benefits of vaccination also extended to parent perceptions of the HPV vaccine: *"AIDS doesn't have a vaccine, but HPV does so let's prevent it (P11)."* The need to think about the future was intertwined within these discussions about vaccination for prevention: *"...she's taking it so that nothing happens tomorrow (P15)."*

Vaccination for some parents also might also have additional, although unknown, health benefits besides preventing the targeted disease:

“...it’s for one thing, but if you get vaccinated, perhaps the vaccine also helps with other things in your body (P21).”

““Maybe this vaccine helps prevent other types of diseases that we don’t know of and haven’t been discovered yet. There are so many diseases that we’ve never even heard of (P7).”

Opposite to the worry that HPV vaccination might incentivize risky sexual behavior, one parent said that the vaccine could increase an adolescent’s awareness of the need to prevent sexually transmitted diseases.

Although all parents believed vaccination was important for disease prevention, one parent stood out from the others by regarding vaccination as the last form of prevention. This father’s general view of vaccination is that it is a form of prevention to be utilized when other forms of prevention, such as eating well, fall short:

“That’s why you have to eat well, sleep well, feed yourself well in order to avoid vaccination. I’m telling you that the vaccine is important. It’s important but you can avoid the vaccine if you are healthy physically and mentally (P21).”

This parent’s opinion may have been influenced by his misconception that injected medicines are also vaccines. The value of vaccination for this participant appeared to be contingent on one’s health status. Contrastingly, in the case of the HPV vaccine, this same father believed that immunizing his daughter was the right choice and introduced parental responsibility into the HPV vaccination decision: *“... [she] has to be vaccinated because it’s important. If something happens, the parents are responsible for not having guided their children (P21).”*

Protective

Vaccination for protection also emerged as a theme throughout the interviews. This protection took different forms. Firstly, vaccination protected by preventing the onset of a disease, as was discussed earlier. Secondly, while prevention was the primary goal, many parents

also talked about vaccination being protective because it mediates the severity of a disease: “...because of the vaccine, the virus will come more calmly, more slowly. It won’t come as aggressively...(P2).” One mother commented on the protective role of vaccination and the inequalities in health care services:

“I’ve always thought that the best way for us to defend ourselves from all diseases is only through vaccination, but not every disease has a vaccine, only some do. I think the ideal would be to have a vaccine for all types of disease but that doesn’t exist and if it does exist, we have to pay for it and the poor can’t afford it (P5).”

Along these lines, several parents commented on the need for greater vaccine access and broader eligibility criteria.

Parents are Responsible for Preserving their Child’s Health

“The health of my children comes first.”

Preservation of a child’s health falls into the domain of parenting for all of the interviewed parents. Participants voiced that no parent wants to see their child sick and one mother said: “*Oh gosh, I would die for my daughters. I’ve already said that I would prefer it 10 times more that I get sick instead of having them get sick (P10).*” Parents only want the best for their children and aim to “*protect them from all that is bad (P3).*” This parental concern and sense of responsibility results in parents identifying themselves as having the final say in the healthcare decisions of their children. Generally, parents said that the opinions of those outside of the health field would not sway these decisions. This mother reiterated her authority over her child’s health:

“In regards to my daughters, I am the one who decides what they will or won’t do. No one changes my opinion. I change my opinion, no one changes it for me so I don’t care about what others people say. I’m very decisive. Once I decide, I stick to my decision (P24).”

Parental authority applied to girls eligible for HPV vaccination, who were described as reliant on their parents for healthcare decisions: *“...in terms of her health, I, her father, am the greatest authority over her (P1).”* Thus the decision of whether or not to vaccinate against HPV is the decision of the parent, not the daughter.

Vaccines: A Parenting Tool

Prevention of disease through vaccination was seen as an effective tool for carrying out the parental duty of maintaining health. Prevention is parental love as described by one parent: *“... parental involvement influences the child’s well-being. Prevention and care are part of love. If you take care of your child, you love. If you love, you take care of your child (P16).”*

Likewise, another parent stated that *“Those who love, vaccinate. We love our children so we vaccinate them (P3).”* Overall, HPV vaccination was not differentiated from other vaccinations: *“It [vaccination] is a precaution that every parent has with their children, not just with the HPV vaccine, but with any other vaccine (P1).”* Along these lines, some parents said that a parent’s decision not to vaccinate his or her daughter against HPV results from a lack of concern for the daughter’s health. Parents who choose not to vaccinate were described as irresponsible, lazy, careless, and responsible for bringing suffering to their children. Thus choosing to vaccinate was overall portrayed as a straightforward decision for any parent. This parent regards the vaccination decision process as obvious:

“I don’t think you need to be a genius. You don’t need to be very knowledgeable in order to understand [the importance of vaccination]...do you want your child sick? Do you want your child bedridden? Do you want your child with cancer...with a bunch of warts everywhere? If not, then this [vaccination] is the way to avoid it. End of discussion (P19).”

Sick Child, Bad Parent

This link between a parent's duty and a child's health status becomes a method for evaluating someone's parenting ability. A sick child is a reflection of a parental shortcoming. This form of parental assessment creates a situation in which a sick child makes parents feel guilty or fearful of blame. In the perspective of one interviewee, a sick daughter brings suffering to the entire family, especially to the parent who will attribute the sickness to poor parenting. The decision to vaccinate operates within this guilt/blame paradigm. For example, if her child were to one day become sick from a vaccine preventable disease, one mother said she would only blame herself for "*letting this happen*" to her daughter by not having her vaccinated. The blame is placed on the parents and leads to, as one parent stated, "*a type of guilt I don't want to experience (P12).*" Decisions to vaccinate thus mediate any future blame or guilt that would emerge from a sick child. For example, the strict adherence to the recommended childhood vaccinations provides some protection from possible blame:

"So if she does get one of these diseases, no one can tell me that I didn't keep my daughter's vaccination card up to date. I will be able to say that she is sick as a consequence of their incompetence. I would have the right to say that. This is why I prefer to always keep their vaccinations up to date. For this very reason, both to protect them and so that others don't have anything to say about me in the future (P24)."

One parent noted that the future blame could come from the daughter herself because of her dependence on her parents during the HPV vaccination age:

"Your daughter will be independent in the future. She is going to make her own choices. You make them now, but in the future, she will. Then what? What if she has sex and gets HPV? She's going to ask you: mom, why didn't you vaccinate me? Then what? (P28)"

Indirect Parental Control

The Need for Sex Education

A daughter's future independence was a recurring theme in the dialogues supporting vaccination. This independence results in a loss of parental control over a daughter's actions,

adding another layer of uncertainty to the already unknown domain of adolescent thought.

Parents had to consider not only the girl's future health state, but also the consequences of her future actions. Because of the sexually transmissible nature of HPV, a girl's sexual independence was the focus of these conversations about the future:

“You can't look at the situation and say: why vaccinate if the child won't have sex? Do I know that? Does she know that? We know and live with our daughters and everything, but we don't know their thoughts and sometimes it's completely different [from ours] (P13).”

Across the board, parents acknowledged that they only have indirect control over their daughters' sexual life. This control was primarily implemented through sex education at home, which could direct their children to approach sex more cautiously: *“I believe that an educated, knowledgeable person will be more cautious. They have a better grasp of reality. They won't fall into the careless hype (P22).”*

The importance of sex education was emphasized in many interviews and some parents commented that it is important to keep their daughters from making mistakes, especially those that they themselves had made. As one cervical cancer survivor put it: *“I had HPV because I didn't have anyone to guide me so I wasn't careful with sex. That's why I have done the very opposite with my daughters (P28).”* For others, sex education would provide protection from the outside world: *“I said: mom has never made a mistake and I don't want you to either. You have to learn how to survive because as I tell my daughter, it isn't easy living in today's world (P25).”*

The parents also emphasized the need to be straightforward and honest with their daughters and to refrain from telling *“...the stories my mother would tell me. It has to be the truth (P14).”*

Although talking about sex was considered to be less stigmatized in today's generation, some parents acknowledged that having the conversation could be embarrassing. The potential discomfort was outweighed by the benefits of preventing disease and pregnancy. Due to the

accessibility of information and images, the internet was cited by some parents as useful for directing these talks. Some parents also relied on their daughters' schools or physicians to either complement the at home sex education or provide it entirely.

The suggested age for sex education ranged from 10 to 17 years. Many parents described the ideal time not in terms of age, but in terms of the transition into becoming a *mocinha*. A *mocinha* represents a phase in between being a child and becoming a woman, which makes it similar to the American concept of girlhood. Characteristics of a *mocinha* included menstruation, sexual curiosity, and discovering one's body. The following interview excerpt portrays one daughter's fluctuating transition into becoming a *mocinha*:

“There are times when she is very childish: plays house with her sister, plays everything. Then there are times when she is very much a “mocinha”: wanting lipstick, wanting to brush her hair. There are even times when she wants high heels. There are times when she is a child and times when [she isn't]...it changes very quickly so I think that we need to be patient and not get ahead of ourselves. I think that there is a right time for everything and every child is different. There are children her age that have fully formed bodies and are already menstruating. My friend's daughter doesn't play anymore. She is more of a “mocinha” and has already menstruated, but my daughter hasn't so everything has its time. I think that we as mothers must be friends too. I consider myself a mom because I like to participate in her life so I think that when the time comes, a mom knows (P16).”

Sexual promiscuity was sometimes equated with a lack of parental guidance as described by the following quote: *“Nowadays I notice that a lot of girls are very forward, very advanced [sexually] and then I think: does her mom not talk to her (P18)?”* While the blame for a sick child was primarily considered a parental burden, some parents described a situation in which part of this blame would shift to the child. One mother commented that HPV infection and its potential consequences can result from promiscuous behavior: *“I think that all of this is a consequence of sin because if everyone had relationships the way I believe they should, with just one person, it would be difficult to get this kind of disease (P4).”* Sex education had the potential to prevent disease, but not if the daughter failed to follow the advice. From this outlook, getting

an STI “...is not from a lack of warning because we give warnings. So many people talk at school, at the health post, people talk about it [sex] everywhere so only those that want to fall into this situation (P15).” Another mother concluded that sex education can lead children to “...take better care of themselves because they think: my mom and dad explained so much, talked to me so much. What does it cost me to maintain the trust they have in me (P24)? This idea substantiates personal accountability for STIs and this same parent believed that her own daughter would “...be disappointed in herself (P24)” if she were to become infected with HPV. Thus for some parents there exists a component of personal responsibility when a child gets sick. Along these lines, most parents acknowledged that even though it is their job to educate their children, “you can’t control your child’s thoughts no matter how well you educate them (P1).”

Vaccines: Insurance for the unknown

Here the HPV vaccine is crucial for addressing these shortcomings and becomes another tool for a parent to indirectly control the child’s future. Through this interpretation, the HPV vaccine protects the parent’s conscience and reputation by protecting the child’s health. Parents stated that they did not know who their daughter would choose as a sexual partner and since you “can’t see the disease (P12)”, you don’t know who has the virus, which is why you should “at least be vaccinated (P30).” Factoring in the daughter’s unknown future state of immunity also increased the push for vaccination. Thus HPV vaccination can help alleviate parental concerns because it can “take a weight off of your mind (P21)” and “prevent against an unknown future (P4).”

The general tone from the interviews was that a child’s sexual life could not be directly controlled by parents. While several parents were aware of the argument that HPV vaccination could incentivize sexual activity, no parents regarded this as a legitimate claim. Instead, sexual

activity was presented as inevitable and thus the role of the parent was not to prevent sexual activity, but to prevent possible consequences of sexual activity.

"It [vaccination] prevents disease because no one knows what lies ahead...we don't know who is going to be their sexual partner. As much as parents care for their child, this [sex] is something that is not controllable. As much as you want to control it, you can't so it [HPV vaccination] is for this person, this girl, not to get sick in the future, to prevent disease. I think that this is the motive and there is no other. You need to prevent, take care of your child to prevent disease (P22)."

Thus HPV vaccination was considered *"...a protection for when they become sexually active, because no one is free from having their children do this [become sexually active] (P24)."*

Almost all of the interviewed parents mentioned the importance of wearing condoms for disease prevention and several also favored the use of birth control pills or injections.

Reference to the shortcomings of parental control was not confined to the future. Several parents described their control in terms of location. Once outside of the home, outside of direct parental supervision, a child's thoughts and actions become a mystery and subject to the conditions of today's generation. As one parent puts it: *"we know our children, but we know them because they are inside, living with us at home, but from the moment they leave, we don't know their actions (P13)."*

Hoje Em Dia ("Nowadays")

Almost all of the parents reflected on how things are "nowadays" and these descriptions were used to reinforce the need for vaccination as protection against growing risks and uncertainties. The world nowadays seemed out of control, as one parent stated: *"For the love of God, there are times when you feel like taking your children and raising them inside of a cubicle, a square, keeping everyone locked up so they don't have contact with this crazy world (P23)."* Two points were repeatedly highlighted among the parents. First was the notion that nowadays there are more diseases to protect against and that old ones are reemerging in stronger

forms. Some parents commented on being unable to keep up with the vast amount of diseases:

“there are so many diseases we’ve never even heard of (P7).” The issue for other parents was

not new diseases, but the return of previously common, vaccine preventable diseases:

“There are children showing up at the hospital with whooping cough, with measles...these type of diseases are coming back...chickenpox for example, we are losing children to chickenpox. This is very serious. This is something that we thought was becoming archaic, that it’s a thing of the past when people weren’t vaccinated and would die without help, children would die from dehydration...but still today babies can die from dehydration and we know there are vaccines to prevent diarrhea at the health posts. There are dehydrated children that die, babies even. Goodness, this can’t happen (P12).”

Second, parents commented that society today is more “advanced” as described by this parent:

“Today’s generation is too advanced so I think there is a need for the [HPV] vaccine. Today’s youth doesn’t care about anything. They get drugged up, they drink, all to lie with anyone. It’s much easier to do so nowadays. Everything is more visible, easier (P14).”

One mother commented that Funk Carioca, a popular genre of music in Brazil, has “*brought many girls and boys to sex (P28)*”. Parents often contrasted their own experiences with those of the adolescents of this generation. The general consensus was that children nowadays are initiating their romantic and sexual lives sooner, and sometimes carelessly, acting on “*an empty head (P17)*”. Parents referred to pregnant adolescents as justification for their perceptions of the sexual behavior of the youth. Adolescents of this generation were described as not being concerned enough with prevention. For most parents this meant not wearing condoms or being on birth control. When specifically talking about their children, some parents expressed trust in their daughters. One parent said that her daughter “*has her head in the right place (P26)*.” The source of uncertainty in these cases came from not knowing the sexual history of the daughter’s sexual partner.

The HPV vaccine once again takes on a beneficial function by acting as a safeguard to this contemporary trend among adolescents. Thus sexual activity, even risky sexual behavior, is

portrayed as existing independently of vaccination. In other words, no parents attributed these trends to vaccination. Instead, vaccination could help at least protect against some of the consequences of these “advanced” adolescents and ease some of the parents’ worries.

Males Should be Vaccinated Against HPV

All participants were in favor of having the HPV vaccine available for adolescent boys as well. Even those who did not previously know that males are also susceptible to HPV infection or viewed women as more susceptible to infection, voiced support for vaccinating boys. Interestingly, many parents stated that targeting boys would be a more effective than targeting girls. The reasoning behind such claims revealed that many parents believed that boys are more prone to risky sexual behavior and less likely to be health conscious.

Boys focus their concerns on maximizing their sexual experiences, without much thought to their sexual health according to one parent that said:

"Boys aren't concerned with who they have sex with. Today's adolescents don't think about quality, they only pay attention to quantity. It's very much like this these days. They count how many women they got with... (P14)."

Another parent had a similar perception of adolescent boys and contrasted their carelessness with the cautiousness of girls:

"They want to have fun and have sex with whoever they want so they don't think about prevention. Women, on the other hand, are more concerned with prevention: I am going to use a condom and take care of myself. This is not the case with men, all they want is to have sex (P20)."

In agreement to the previous statement, women were described as not only being more health conscious, but also being more interested in disease prevention. According to one parent, men, on the other hand, only seek healthcare services when they are out of options:

"Men don't prevent anything. Men are more afraid than women...if you come to a health post you see almost no men. There are more women around than men. Men only come when they are seriously ill and have to come because they don't want to die. They only come in these types of situations (P25)."

The interpretation of some parents is that this difference exists because women are more susceptible to disease in general and/or HPV infection. The multitude of health exams for women supported this perceived difference in disease susceptibility for one father, who commented the following:

“Women have a lot of exams, they have to undergo a lot of exams... For example, if they don’t have certain physical examinations, they don’t know if everything is okay with their breasts. Because of this women are more careful than men (P21).”

Contrary to this, men were primarily described as disease transmitters. It appeared that men were less likely to get sick and more likely to pass on disease to women. One parent stated: *“It seems like they [men] don’t get diseases as easily (P4).”* Likewise the health consequences of HPV infection seemed less severe to one parent: *“for men it [HPV] doesn’t change much because the most that they could get are those warts so it [HPV] is more harmful for women (P19).”*

Lastly, the issue of “machismo” was briefly brought up in one of the discussions about vaccinating boys. One parent believed that vaccinating boys and making them more health conscious would be a step towards addressing “machismo” in Brazil: *“I think that boys also need to have a more open mind and accept things better because our country is still very machista. I believe it is. They say it isn’t, but in reality, it is. It is machista (16).”* Another parent’s comment indirectly touched upon “machismo” in Brazil as well: *“If it [HPV vaccination] doesn’t damage their masculinity, which is their main concern, then I think they should [be vaccinated](P28).”*

Non-medical consequences of HPV infection

Non-medical consequences of HPV infection were brought up in some of the interviews. These ramifications centered on the stigma attached to sexually transmitted diseases. Some parents described the potential social marginalization that would accompany this stigma. One parent reflected on what people might say about someone with HPV infection: *“She’s a whore, a slut, these types of comments. Why did she get it [HPV]? She got it because she was being*

promiscuous. But a lot of times, that's not the case (P22)." One cervical cancer survivor noted that the stigma could also make a girl isolate herself from her social world. Another parent commented that people from all education levels and backgrounds are prone to viewing an individual with an STI through the lens of this prejudice. HPV related diseases were also said to carry social consequences. For example, a diagnosis of cervical cancer could *"interfere (P23)"* with a marriage, which might end if having children was no longer feasible.

Trust in biomedicine and government

Within the conversations about the HPV vaccine, trust in health professionals emerged as a theme. One parent relied on workers within the health field for health advice in order to avoid *"learning lies (P16)."* When discussing sex education, another parent expressed an intention to supplement the explanations a child receives at home with those of a physician. For one parent, trust in biomedicine contributed to her trust in health workers: *"...I think that medicine is evolving more and more each day, looking for disease cures. I think it's great (P18)."* This trust applied to HPV vaccination as well. According to one parent, HPV vaccine skeptics should be directed to a professional from a health post: *"...I believe in vaccines, I believe in the information so if someone tells me otherwise, I would say: I'm sorry, but you should inform yourself, look for a health professional, someone that can help inform you...(P22)."* A mother that had vaccinated her daughter against HPV received criticism from a coworker, but her faith in the health professionals kept these comments from affecting how she felt about her decision:

"She [coworker] said: 'If I had a daughter the same age as yours, I won't have taken her.' But I didn't pay attention to her comment. I ignored it and didn't care. If the doctor, the nurse, someone said that this vaccine will prevent my daughter from having the disease in the future, then it isn't going to harm my daughter (P26)."

This same mother also commented that she habitually made sure to clear up any of her health related doubts during her visits to the health post. She expressed having greater trust in the health

professionals of São Paulo than of Pernambuco, a northeastern state and her previous home. While Pernambuco seems to have physicians of different competence levels, this mother said that all of those she has encountered in Sao Paulo have appeared very knowledgeable.

Exposure to the topic of HPV at a health post incentivized one mother to accept having her daughter vaccinated: *“My daughter told me: ‘Mom, this paper is about the vaccine that is being given tomorrow.’ Since I had already seen something about HPV at a health post, I told her: ‘it’s good for you to get this vaccine’ (P17).”* Health posts thus appear to serve as credible sources of health information for these parents. In addition to a trust in health professionals, some parents also expressed trust in government vaccination recommendations. When one parent was asked about her belief in the efficacy of HPV vaccination, she expressed trust in the Ministry of Health’s TV advertisement about the campaign: *“...I saw something on TV...but I don’t really know anything about it [the HPV vaccine]...so I’m sure that if they say it is [effective], then it is (P30).”* While many parents directly voiced their trust in government officials, one parent’s commentary focused on the notion of compliance rather than trust, noting that if the government mandates a certain vaccination, then the public will comply and go to the posts to get vaccinated.

Anti-Vaccinators Lack Knowledge

When asked why a parent might choose to refuse HPV vaccination, the majority of interviewees characterized such parents as lacking something. A lack of concern for their child’s health or for disease prevention in general was identified by some parents and has already been explored in the previous sections. Another major deficit that was repeatedly brought up was a lack of knowledge. *Falta de conhecimento* or “lack of knowledge” was repeated throughout these interviews. For some parents, this deficit resulted from a lack of publicly available

information. One mother wished there was more educational outreach in the health posts that uses “*our vocabulary (P28)*” to explain HPV. Echoing this feeling, one parent articulated the need to handle health information in a “*serious and democratic*” manner by having the information “*within everyone’s reach (P19)*.” Another mother believed that the campaign did not delve deep enough into explaining HPV infection and its related diseases. Instead, the “campaign” was more of a “*call (P22)*” for HPV vaccination. Yet another mother echoed these sentiments when she commented that the parental consent form for in school HPV vaccination wasn’t informative.

Other parents directed the blame of not being informed towards parents. These parents were “closed minded”: “*...closed minded people don’t inform themselves about anything. They don’t have information about anything, they just live in their own little worlds (P23)*.” Those who might believe that their daughters wouldn’t be affected by HPV were also viewed as lacking an understanding of the reality of disease, because “*no one is exempt from disease (P12)*.” These sentiments tied back to the idea of parental responsibility for a child’s health as mentioned earlier. For one parent, vaccine refusal didn’t just result from just a lack of understanding, but from stupidity:

“They must be a bunch of idiots. A bunch of idiots that don’t want their daughters to be vaccinated. Vaccines don’t cause any problems, it’s for the good of the child, it doesn’t harm an adolescent or a child (P25).”

Closed minded parents were sometimes described as having an *antigo* culture that resulted in misconceptions about the purpose of HPV vaccination. Being *antigo* is described below by two different parents:

“I think that people who are antigo, really closed minded, they think that the vaccine incentivizes the child to have sex. How horrible! I am protecting my daughter so that when she has her first sexual relationship, she won’t get the disease, but these people think that the parent is

incentivizing the daughter to have sex. I don't see it this way, but I've heard people say these things (P24)."

"There are many prejudiced moms and dads that are from the antigo era: 'Why would I take my young daughter to be vaccinated against these things? My daughter isn't going to do anything, she isn't old enough for these things.' They seem closed minded, they don't have open minds...this seems to be the case with the parents that don't accept it [HPV vaccination] (P18)."

The second excerpt also reveals another common distinction that was present among the dialogues of these parents. Parents proposed that HPV vaccination had the potential to be misinterpreted as implying that the daughter is already sexually active. While a few parents did note that some might perceive HPV vaccination as promoting sexual activity, as in the first excerpt, this idea was brought up much less. This theme is brought up again in one mother's reflection on her initial vaccination hesitancy:

"Is he's vaccinating because she is already having sex? I don't know I think they must think this way because when they first talked about this vaccine...I myself was one of the people that thought: oh, but my daughter isn't sexually active to need this vaccine (P2)."

Both types of prejudice were associated with being something of the past and were not viewed as contemporary issues because *"today there are not a lot of ignorant people (P5)."* The openness in discussions about sex was another reason brought up for explaining this difference. The following quote encapsulates the intersecting beliefs of the need for more information, personal responsibility for being informed, and the idea of outdated sexual prejudice:

"They didn't go after it to find out what it is or anything like that. Those who have information will immediately vaccinate their daughters. I think that there should be more information, hand out more pamphlets door to door because there are people that don't go to the doctor. And there are moms that don't approve of having sexologists at school and don't want their children to participate in sex education in school (P15)."

While acknowledging that vaccination refusal might stem from a lack of knowledge, one parent also believed that despite having the necessary information, an individual might not act on this

information. It is important to reiterate that the overwhelming majority of parents did not personally know anyone against the HPV vaccine or vaccination in general.

IV. DISCUSSION

This research aimed to identify some of the distal influences on HPV vaccination decisions by characterizing the local HPV vaccination culture of a subset of parents from São Paulo, Brazil. In doing so, the strength of HPV knowledge levels for predicting vaccination was also investigated. This was the first study to qualitatively examine the meaning of HPV vaccination among parents with eligible daughters in Brazil. This was also the first study to assess whether or not there is a correlation between HPV knowledge levels and decisions to vaccinate within this population. The findings provide part of the understanding necessary for interpreting the greater than 90% coverage for the first HPV vaccine dose in Brazil.

High Levels of HPV Vaccination

At the time of the interviews, 87.5% of the interviewed parents with eligible daughters already had their daughters vaccinated against HPV. In concordance, Osis and colleagues found that 95% of the 538 Brazilian parents they interviewed, prior to the HPV campaign, would vaccinate their children against HPV if the vaccine were publically available (Osis, Duarte, & Sousa, 2014). This high coverage among the study participants is also in line with the current first dose coverage of 125% within the São Paulo municipal (DATASUS). The fact that coverage exceeds 100% can reflect an underestimation of the target population. Another consideration is that not all girls attend schools within the same municipality as their homes, therefore their vaccination may be mistakenly included in the immunization coverage calculations for the school's municipality. It is important to acknowledge that prior to the inclusion of the HPV vaccine in the National Immunization Program (PNI), only 2.43%, 2.04% and 0.38% of girls ages 10-14 had received the first, second, or third doses respectively. These percentages account for both the quadrivalent and bivalent vaccines (SI-PNI, 2013). Since these vaccines were not yet part of the PNI, they were only available through private health clinics. The dramatic increase in

coverage reflects that the HPV vaccination campaign helped mitigate some of the barriers to HPV vaccine access that stem from social inequalities. The absence of a large scale public provisioning of HPV vaccines in the U.S. likely contributes to the differences in HPV vaccination coverage rates. With that being said, HPV vaccine access alone is not sufficient for uptake if parents are not receptive to the vaccine. All of the 30 interviewed parents in my sample were accepting of the HPV vaccine and the analysis of their dialogues gives insight into the social, political, and cultural influences on this observed receptiveness to HPV vaccination.

HPV knowledge is not predictive of vaccination

Knowledge of HPV was not predictive of vaccination within the interviewed sample. Most parents had heard of HPV in passing mainly at health posts or on television, but did not have extensive knowledge about HPV. The parent with the highest knowledge level had personal experience with both genital warts and cervical cancer. Knowledge of HPV as assessed on a four point scale, was low among all parents. This finding is consistent with the studies conducted prior to the HPV campaign that also found low levels of HPV knowledge among parents in Brazil (Osis, Duarte, & Sousa, 2014; Rama et al, 2010).

Average knowledge scores did not vary much between parents with eligible daughters that had or had not vaccinated their daughter. Compellingly, half of the parents with vaccinated daughters had HPV knowledge scores of 0, implying that knowledge, in these cases, was not at all part of the decision to vaccinate. The two parents with eligible and unvaccinated daughters were not aware of the immunization campaign, but voiced support for the HPV vaccine despite having low levels of HPV knowledge. This again indicates that approval of HPV vaccination is not contingent on knowledge. Likewise, among the parents of ineligible daughters, understanding of HPV was minimal, but HPV vaccination was favored. The poor predictive

value of HPV knowledge aligns with several studies that found no association between parental HPV knowledge and HPV vaccine uptake among their daughters (Brewer & Fazekas, 2007; Davis, Dickman, Ferris, & Dias, 2004; Dursun, Altuntas, Kuscu, & Ayhan, 2009; Grabiell et al., 2013; Krawczyk et al., 2015; Lenselink et al., 2008; Perkins et al., 2010; Walsh et al., 2008). If the high vaccine uptake were to be interpreted from the perspective of a knowledge based model such as the HBM, it would appear that the study participants had high knowledge of HPV and the vaccine, which is clearly not the case. These findings suggest that the use of the HBM to target educational interventions may not be sufficient to substantially increase vaccination rates neither in this population nor in other populations.

Many parents believed that the public has little awareness of HPV. Interestingly, the majority of parents believed that HPV vaccine refusal was a parental failure and mainly resulted from this lack of knowledge. These parents emphasized the need for more HPV information, especially to educate vaccine opposers, even though their own decisions to vaccinate were not influenced by the information deficit. This same finding was present in Gottvall's study (Gottvall et al, 2013). However, an important distinction is that the type of knowledge gap described by parents was not just insufficient technical knowledge regarding HPV, but also a lack of the cultural knowledge that has normalized vaccination. This kind of knowledge includes the association of a sick child with a bad parent, which results in the guilt/blame paradigm that drives the use of a child's vaccination status to evaluate parents. Thus as Couto and Barbieri concluded, vaccination decisions hinge on the meanings of vaccination (Couto & Barbieri, 2015).

A culture of vaccination

Vaccination is normalized in Brazil and accounts for the ubiquitous support of HPV vaccination within this subset of Brazilian parents. Their dialogues reflected a prominent culture of vaccination, where the decision to vaccinate appears to be less of a decision and more of an expectation. The fact that two parents unknowingly vaccinated their daughters against HPV provides perhaps the most striking example of the deep cultural acceptance of vaccination in Brazil. The automatic “decision” to vaccinate is also exemplified by the fact that some parents had never considered the possibility that a parent might refuse HPV vaccination. The overwhelming majority of participants supported all vaccinations, although a couple mentioned having doubts about the flu vaccine, and this support extended to the HPV vaccine. Similarly, Lenselink’s study results determined that HPV vaccine acceptance was most associated to adherence to all recommended childhood vaccinations (Lenselink et al, 2008). Previous positive experiences with vaccination both on the macro and micro levels perpetuate positive perspectives of vaccines and subsequently, the normalization of vaccination. Some parents mentioned personal success stories of vaccination and others mentioned previous community benefits such as the success of Brazil’s polio vaccination campaign. The daughters’ perceptions of the HPV vaccine are also affected by and perpetuate the vaccination culture especially due to the predominately school based vaccination approach of Brazil’s HPV campaign. For example, as previously mentioned, one daughter told her mother that she wanted to be vaccinated as well after she saw her classmates being vaccinated during school.

The HPV vaccine and vaccines in general were described as normal, preventative, and protective. Other studies have also identified that confidence in the benefits of vaccination in general is associated with HPV vaccine acceptance (Davis, Dickman, Ferris, & Dias, 2004;

Dempsey, Zimet, Davis, & Koutsky, 2006; Gottvall et al, 2013; Lazcano-Ponce et al., 2001; Lenselink et al., 2008). Again, it is critical to recognize that the preventative and protective aspects of vaccination within this sample were not confined to the biomedical realm and are discussed later in further detail. Other themes in the interviews revealed a culture of vaccination. For example, several parents of unvaccinated daughters tried to have their daughters vaccinated and were disappointed to find out that they did not yet meet the eligibility criteria. Based on these behaviors and the positive perception of the vaccine, these parents will likely vaccinate their daughters once they are eligible. In addition many parents also desired greater vaccine access both in terms of the HPV vaccine and the development of new vaccines. All of the perceptions and actions mentioned above become part of a cyclical relationship that maintains the culture of vaccination from which they emerged.

Trust in Biomedicine and Government

The culture of vaccination in Brazil is linked to trust in biomedicine and the Ministry of Health, the regulating body of healthcare in Brazil. The majority of parents expressed their reliance on the healthcare professionals in the health posts for their health related questions. This dependence is tied to their trust in biomedicine. Benin et al. argue that the evaluation of biomedical information as valid is dependent on the existence of a trusting relationship between the parent and the healthcare provider (Benin, Wisler-Scher, Colson, Shapiro, & Holmboe, 2006). Trust in biomedicine extends to trust in the Ministry of Health and its guidelines. This may be partly attributed to the structure of Brazil's health system. Since healthcare is publicly provided, some healthcare workers are also government employees, thus the observed trust in both government and medicine makes sense. This is especially in terms of vaccination since the PNI is run by both the government and healthcare professionals. In terms of the HPV

immunization campaign, the Ministry of Health ran a television advertisement about the campaign and told girls and their parents to be on the lookout for the HPV vaccine at health posts or in school because “every girl is different, but all need protection (from cervical cancer)”. Trust in these messages affect how parents evaluate the validity of health information and the effectiveness of health services. In agreement, the inclusion of the HPV vaccine in Vietnam’s national immunization program fostered parental support for the vaccination due to their trust in this governmental and biomedical entity (Cover et al, 2012). The persistence of trust in these recommending bodies minimizes the need for parents to personally research and evaluate the claims because they trust that recommendations are based on credible information (Benin, Wisler-Scher, Colson, Shapiro, & Holmboe, 2006; Gottvall et al, 2013).

Although some of the specifics of HPV vaccination in terms of the targeted population and disease appeared to be in dissonance with the traditional framework of vaccination Brazil, the degree of public opposition was not as prominent as the case in the U.S. The extent of this dissonance may have been lower in Brazil since the HPV vaccine was offered through the highly trusted PNI in the absence of pharmaceutical direct to consumer advertising. However hints of this dissonance emerge in the dialogue of the mother that was hesitant about her decision to vaccinate her daughter. Vaccination at an older age did not fit into previous vaccination experiences and likely affected her hesitancy. Trust has the potential to mediate these situations of doubt in that a lack of trust could push the parent away from vaccination and vice versa.

Although the overall high trust level has proven beneficial to reaching high vaccine uptake, this degree of trust could have negative implications if the interests of the government or biomedicine were to no longer align with the public’s best interest. This trust might also keep

individuals from gaining a better understanding of the health services they receive. In this type of situation, an individual might become susceptible to accepting unnecessary treatment.

Everyone should be protected

Perceived gender differences within the realm of health and sexuality contributed to the acceptance of HPV vaccination for both men and women. The plethora of health interventions aimed at women fuels the perception that women are more prone to disease than men. Men on the other hand function as the disease transmitters in this relationship and their role was also defined as such among a sample of Brazilian students (Costa & Goldenberg, 2013). Health services have also traditionally been targeted at women in the United States, but the focus on women relates to their portrayal as “disease reservoirs” that pose a threat for men (Prescott, 2010). For some participants, the difference in disease susceptibility translated into differences in utilizing healthcare services. Parents identified women as more cautious and involved in disease prevention whereas men were portrayed as careless and reluctant to visit health post, avoiding it as much as possible. Likewise the consequences of HPV infection appeared to affect women more severely than men and consequently HPV vaccination for women is beneficial from this viewpoint. Nonetheless all participants favored HPV vaccination for boys as well as girls, which was not the case in the same sample of Brazilian students mentioned earlier (Costa & Goldenberg, 2013). This support partially originates from the idea that women are more cautious in sexual relationships. Adolescent boys especially are believed to be more likely to engage in risky sexual activity and carelessly transmit disease to vulnerable girls. Once again, the normalization of vaccination and its preventative and protective functions contributed to approval of HPV vaccination for boys. Learning that HPV has health consequences for men from the educational blurb likely further strengthened parental support for vaccinating “both sides”.

HPV Vaccination: Parental Insurance

The HPV vaccine is a form of parental insurance as is any other vaccine for these study participants. Parents described themselves as responsible for maintaining their child's health and subsequently in charge of making their healthcare decisions. Vaccination in general was seen as effective for preserving health and as a tool for exerting parental duty. A subset of Swedish parents shared this belief in parental responsibility to protect daughters from disease through vaccination (Gottvall et al, 2013). Thus a child's vaccination status is used to evaluate parents because choosing not to vaccinate is widely perceived as putting the child's health at risk. The vaccine supporters in Couto's study voiced similar beliefs of vaccination. The nonvaccinating parents also strove to preserve their child's health, but this intention translated into protection from the risks of vaccination. The non-vaccinating Brazilian parents acknowledged that their decisions jeopardized their parental reputations demonstrating again that vaccination is the norm in Brazil (Couto, 2015).

The dependency on parents for healthcare decisions also introduces the possibility that the blame for a sick child will be directed towards the parent. This is especially true in terms of vaccine preventable diseases and several parents mentioned that they choose to vaccinate in order to prevent future blame and guilt that would arise if their children were not vaccinated and later became sick. For one mother, a completed vaccination card was a symbol that she had done her part to keep her child healthy and reassured her that if her child were to become sick, she had the right to place the blame on something or someone else. Parents themselves also direct the blame for their child's sickness towards their parenting, which causes some parents to experience guilt. Parents used this blame/guilt paradigm to explain their support for the HPV vaccine. From this perspective, it seems likely that the HPV vaccine will shift part of the blame for cervical

cancer from the affected individual to the individual's parents. This transition would parallel the realignment of risk and blame for cervical cancer that resulted from the public implementation of Pap smears. As Gregg mentioned, promiscuity became a secondary risk and the blame for cervical cancer was interpreted as failure to utilize preventative health services (Gregg, 2011).

The need for vaccination to provide parental insurance is amplified by the unknowns and conditions of "nowadays". Several parents mentioned that there seems to be a greater number of diseases to protect against or a resurgence of previously controlled diseases. The unknown future health status of the child amplifies these disease risks. Parents depicted today's generation as more sexually advanced because sexual activity is starting at earlier ages. A daughter's sexual life is seen as inevitable and largely out of direct parental control. Girls will therefore become sexually active based on the social conditions nowadays and not because of HPV vaccination. This perspective also predominated among the low-income mothers interviewed in the United States (Perkins, Pierre-Joseph, Marquez, Iloka, & Clark, 2010). HPV vaccination protects against the unknown specifics of sexual activity such as with who and when the sexual activity will begin. These unknowns contribute to the possible health risks of sexual activity that parents hope won't affect their children. Sex education from home, school, or the health post was portrayed as a critical preventative tool as well. Most parents believed it is important to openly discuss how to prevent sexually transmitted diseases and pregnancy with their children in the hopes that they would approach sex more cautiously. The HPV vaccine further provides insurance by supplementing sex education as a form of indirect parental control in a daughter's future sex life. The HPV vaccine therefore adds another layer of protection from the uncertainties that can lead to sickness and subsequent parental blame and guilt.

Limitations

The conclusions from this study are limited by the size and representative power of the study participants. Although saturation was reached with these 30 participants, a larger sample size would reduce potential biases and could capture a wider range of perspectives. The study results were largely shaped by the opinions of mothers since there were only four interviewed fathers. Because sampling took place in health posts, the results also do not capture the voices of those that do not frequent or are unable to frequent health posts. Thus barriers to healthcare are not well addressed in this study. Additionally, the perspectives of parents who are against HPV vaccination or choose to vaccinate in private clinics are important for understanding HPV vaccination in Brazil, but were not present in this study. Furthermore, the study took place in São Paulo city, where the quality of healthcare is the highest in the country and among the highest in South America. It is therefore likely that in areas most affected by the health disparities in Brazil, both access to the HPV vaccine and the meaning of vaccination differ. Future studies should therefore address these issues of representation and capture a wider range of the Brazilian population in order to provide a more accurate depiction of the dialogue surrounding HPV vaccination in Brazil.

V. CONCLUSION

This study suggests that the widespread acceptance of the HPV vaccine in São Paulo can be understood by examining the culture of vaccination from which the vaccine gains more than just a biomedical identity. The strength of the PNI in mitigating socioeconomic inequalities in health increases vaccine uptake not only through access, but also through its role in the normalization of vaccination. The social, political, and cultural context in which HPV vaccination occurs determines the meaning of the vaccine to parents and consequently influences their vaccination decisions. The results show that for the majority of the interviewed parents, HPV vaccination is an act of parental love that provides both health and social insurance against the many unknowns that affect a child's health. This interpretation of vaccination is driven by the prevailing vaccination culture, which is mediated by trust in the Ministry of Health and healthcare workers and has normalized vaccination.

HPV vaccination encompasses not just issues of health, but also includes the sociocultural dimensions of parenting, sexuality, gender, and government. As hypothesized, these distal factors held more explanatory power for decisions to vaccinate than parental knowledge levels. The results indicate that attempts to understand or modify vaccination rates require the consideration of these distal factors, which are context specific.

VI. APPENDIX

Appendix A. Interview Guide

Attitudes and Perceptions of Parents with Daughters ages 9-13 about the HPV vaccine in
São Paulo, Brazil



= Interview tips



= Phrases to be read aloud

Interview conducted by: _____

Date: ____ / ____ / ____ (DD/MM/YYYY)

Interview Start Time: ____ : ____ (hours: minutes)

-START INTERVIEW-



*This interview is voluntary and you can interrupt or ask to skip a question at any moment.
Before we begin, do you have any questions?*
















Use the “Notes” space for note taking during the interview.






Notes:

Section I.

Demographic Data	
How old are you?	
Sex	
How many children (male and female) do you have?	<input type="checkbox"/> Sons <input type="checkbox"/> Daughters
Ages	Sons: Daughters:
Which of these choices applies to you?	<input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> Live together <input type="checkbox"/> Separated/Divorced <input type="checkbox"/> Widowed
What is the highest year of schooling you have completed?	
In what neighborhood do you live?	
What is your family's total monthly income?	
What is your religious affiliation?	_____ <input type="checkbox"/> Don't have one
Do you practice this religion?	<input type="checkbox"/> Yes <input type="checkbox"/> No

2nd Part

<u>Q1. Beliefs about Vaccines in General</u>
<p> <i>What are some of the things people do to prevent diseases?</i></p> <p> Probe: If vaccines are not mentioned, ask:  <i>What about vaccines?</i></p>
Notes:
<u>Q2. Knowledge of HPV</u>
<p> <i>Can you describe the first time you heard about HPV? Where, when, by whom...?</i></p>
Notes:
<p> <i>How would you describe HPV? What do you understand or know about HPV?</i></p> <p> Probe:  <i>How can someone get HPV?</i></p>
Notes:
<p> <i>HPV is a virus transmitted through skin to skin contact. The virus can cause genital warts and cancers, including cervical cancer in women and cancer of the penis in men. Both men and women can develop oropharyngeal cancers and other cancers caused by HPV.</i></p> <p><i>What are your reactions to this information?</i></p>
Notes:
<u>Q4. Social Implications of HPV Vaccination</u>
<p> <i>When parents decide to have their daughter receive the HPV vaccine, what might other people think about these parents?</i></p> <p> Probe:  <i>Whose judgment could have an effect?</i></p>
Notes:
<p> <i>And what would people think about a girl that receives the HPV vaccine?</i></p> <p>Probe:  <i>Whose judgment could have an effect?</i></p>
Notes:

<u>Q5, Q6, & Q7. Interaction of Individual and Social Knowledge</u>
 <i>What are some reasons why a parent would decide to vaccinate their daughter against HPV?</i>
Notes:
 <i>What are some reasons for which a parent would refuse to vaccinate their daughter against HPV?</i>
Notes:
 <i>Would you tell your daughter about the purpose of the HPV vaccine? If so, how?</i>
Notes:
<u>Q8. Consequences of HPV</u>
 <i>What would happen if your daughter got HPV?</i>
Notes:
<u>Q9. Opinion about vaccinating boys</u>
 <i>What do you think about vaccinating boys against HPV?</i>
Notes:

 *This is the end of the interview, thanks for participating!*

-END OF INTERVIEW AND RECORDING-

Interview end time: ____ ____ : ____ ____ (hours: minutes)

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