

ADOLESCENTS INVOLVED IN DECISION-MAKING: CLINIC CONVERSATIONS
ABOUT THE HUMAN PAPILLOMAVIRUS AND VACCINATION

by

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ABSTRACT OF THE DISSERTATION
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Thoughtful and deliberate, adolescent decision-making is not well understood. For example, adolescents and parents visit with physicians for routine health care however the extent that adolescents participate has not been satisfactorily investigated. This study used surveys, conversations, and observations of healthy adolescents, parents, and physicians discussing issues of optional vaccination against human papillomavirus infections to interrogate the gap in understanding adolescent decision-making. The decision involves if and when to receive vaccination to prevent sexually transmitted infections that potentially cause adult cancers. Thus, sexual behavior and vaccination effectiveness infuse these discussions. Survey results from several hundred 11 thru 21 year-old Black, Hispanic, and White adolescents and parents showed adolescents' older age, female gender, and suburban residence as significant predictors of vaccination acceptance; race, education, HPV knowledge, and judgments of adolescent autonomy were not. Survey conversations and observations substantiated that parents were the decision-makers. Information did not influence decisions; parents were influenced by their personal beliefs about vaccinations and sexual debut and their adolescents' age. Adolescents indicated on their surveys that they would make vaccination decisions which contradicted their survey conversations and participant-physician encounters that showed adolescents deferring the decision to their parents. During survey conversations, when

their parents were not present, adolescents posed thoughtful questions and engaged in HPV discussions. During participant-physician encounters adolescents rarely participated. Notably, if adolescents chose to speak they protested the shot and rallied to postpone it. An adolescent focused on a vaccination presents a vulnerable and asexual image. Adolescents' participation in HPV vaccination decision-making is not determined by their decision-making competence but by their social competency. Both parents and adolescents understand the sexual subtexts looming in the background and neither want those perceptions to rise to the forefront. Reformulating the manner and content of HPV discussions may increase adolescent participation and vaccination reception.

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Chapter 1: Introduction to the Research Problem

The fundamental question of how adolescents participate in health care decision-making has not been adequately investigated (this point is explored in a later section of this chapter). As a consequence, there is need for research explaining adolescents' experience of and participation in their own health care. One important benefit of this kind of work is that it can guide parents and physicians in preparing adolescents for effective participation in their own health care.

Purpose

Though adolescents are present during clinic visits, the extent to which they actually attend to, process, understand, and respond to health information provided by their physician is not fully understood. An opportunity for understanding adolescents' participation arises when physicians present optional health care procedures that necessitate some deliberation. In particular, optional vaccination preventing human papillomavirus infections is a very current, complex, and controversial health issue; it is an ideal topic for understanding how adolescents have a role in making a health care decision with their parents and physician.¹ There are practical and theoretical concerns that underlie this issue including adult apprehensions about vaccination practices, the efficacy of this particular vaccine, implications of adolescent sexual activities, and adult responsibilities for ethical medical decision-making.

HPV knowledge, vaccination views, and behaviors of adolescents and parents were examined in their clinic conversations with at an adolescent health care clinic. This primary health care setting provided a milieu to address the lack of descriptive and qualitative research on how healthy adolescents participate in health care decision-

making. In meeting this need, this study also provided an empirical and theoretical foundation for promoting and maintaining the health of adolescents.

The Papillomavirus Issue

HPV infections are the most common sexually transmitted infections (STIs) appearing in women and men world-wide. Evidence demonstrates a causal relationship between papillomavirus infections that cause abnormal tissue growth with different cancers (Palefsky, 2010). Subsequent to US Food and Drug Administration (FDA) licensure and upon the recommendation of its Advisory Committee for Immunization Practices (ACIP), the Center for Disease Control (CDC) approved and recommended vaccines for prevention of specific diseases caused by the human papillomavirus in both females and males aged 9-26 (2006; 2009). Medical authorities (e.g., the American Pediatric Association (APA) and the American Medical Association (AMA)) urge physicians to recommend HPV vaccination for all adolescents. Medicaid and federally funded programs (e.g., Vaccines for Children) cover the cost of HPV vaccination for eligible children without insurance (<http://www.cdc.gov/features/vfcprogram/> accessed February 17, 2012).

Parents decide about vaccinations for their children younger than 18 years of age. While the vaccines are safe, effective, and financially accessible, many adolescents do not receive vaccinations (Conroy, et al 2009; Kahn, Rosenthal, Jin, et al, 2008; Widdice & Moscicki, 2008). These unvaccinated adolescents may acquire the papillomavirus through sexual activity, which puts them at risk for contracting varied cancers in adulthood (Palefsky, 2010). It is likely that adolescents are unaware if they are HPV-infected. Most often HPV infections are asymptomatic and clear spontaneously

(<http://www.cdc.gov/std/hpv/stdfact-hpv.htm> accessed February 17, 2012). Other times symptoms may appear weeks, months, or even years subsequent to unknowingly contracting an HPV infection (<http://www.cdc.gov/std/hpv/stdfact-hpv.htm> accessed February 17, 2012). Consequently the salience of HPV infections and their related problems is often low and, in turn may lead to a lack of appreciation for the importance of the vaccine.

While adolescents routinely meet with physicians in primary care settings, little is known of the extent they attend to, process, understand, and respond to health information during consultations. By examining clinic conversations concerning the papillomavirus issue, fundamental theoretical and practical questions about adolescents' decision-making are grounded in how adolescents participate in their health care.

Research Assumptions

Two assumptions that guided this research study are worth mentioning.

1. Culture, history, tradition, social norms, and situation influence how each of us engage with our world.
2. Research approaches influence the data collected, thus multiple methods of data collection present different perspectives of the same event (e.g., Kagan, 2004).

Quantitative research methods produce data that can be aggregated and analyzed in various ways to illustrate participants' characteristics, knowledge and views. Qualitative research methods are an appropriate way to learn what people understand about their experiences (Carnevale, Macdonald, Bluebond-Langner & McKeever, 2008).

Observation and discussion are ethnographic methods suited to address questions of how discourse, reasoning processes, and decision-making play out in lived situations.

Both quantitative and qualitative investigative methods have disadvantages. Participants may respond in the manner they believe shows them in the best possible light, or they may respond by giving an answer they perceive the researcher wants to hear. In addition, there are validity issues with questionnaires, such as discrepancies between a survey item's intended meaning and the meaning a participant ascribes to that survey item (Richman, et al 2012). Ethnographic methods are challenged by research biases; for instance, the investigator's perspectives may interfere with obtaining participants' perspectives. For these reasons the limitations of each research method can be supplemented by the strengths of the other.

Research Questions

This study addressed the following research questions: In what ways might adolescents be involved in their own health care? How might adolescents discuss, reason, behave, and make decisions with respect to their health care with their caregivers? What influences adolescent participation in their health care decision-making? How do parents' perceptions and personal beliefs influence their health care decisions for their adolescent?

Research Approach

A mixed-method approach with a survey and observations was suitable for these research questions because the data gained from one investigative method complemented data from the other investigative method. Knowledge and attitudes were quantified with a self-report questionnaire. Reasoning processes and behaviors were identified from taped

discussions during participant observations of adolescents, their parents, and their physicians in the adolescent health clinic.

The questionnaire produced a quantitative data set of extant health knowledge of HPV and its prevention, some adolescent health behaviors, and judgments of adolescent autonomy. Ethnographic methods revealed conversations and descriptions of adolescents with parents and physicians in context. These participant-physician encounters produced rich narratives of lived health care situations describing adolescents' interactions with parents and physicians when introduced to a particular health issue.

Rationale and Significance

Adolescent health care decision-making is one issue of considerable theoretical and practical significance. Decision-making during adolescence is not well understood for issues that allow for adolescent deliberation as opposed to spur-of-the-moment risk taking decisions. HPV and vaccination decision-making allows for deliberation and is an appropriate issue to investigate adolescents' role in making health care decisions.

The HPV vaccines protect against infection from specific strains of the papillomavirus that can occur as a result of sexual activity. To be most effective, the HPV vaccines should be administered prior to becoming sexually active (Harper & Paavonen 2008). Because we presume younger adolescents to be sexually inactive, guidelines recommend that the vaccines be administered in early adolescence. Consequently, the decision to choose vaccination is made with the realization that it is in *anticipation* of the possibility of incurring specific HPV infections at some future point of sexual activity.

How healthy adolescents experience decision-making in their lives addresses issues of autonomy, agency, and self-regulation. For this reason the mechanisms of

healthy adolescents' decision-making in lived situations are theoretically and practically important. Are adolescents active or passive decision-makers? Do adolescents make clear and reasoned contributions or inattentive assertions? Do adolescents who make minimal responses do so because they lack knowledge, have no interest, or hesitant to contribute for some particular reason? This study focused on discussions about vaccination during clinic health visits which were likely to reveal different views about the decision-making process, the responsibilities of adolescents, the role of parents in medical contexts, physicians' responsibilities, the onset of sexual behavior, and so on. Such discussions provided a rich context in which to explore themes of adolescent agency, personal autonomy, evolving capacity, and decision-making processes. This study adds to our understanding of adolescent decision-making processes.

This research is also of considerable practical interest and significance for introducing health preventive attitudes and behaviors to adolescents (Healthy People, 2010; 2020). The CDC's weekly MMWR, of August 31, 2012 / 61(34);671-677, highlighted 2011 vaccination coverage results among adolescents aged 13-17 years from the National Immunization Survey (NIS)-Teen data collection (<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6134a3.htm> accessed September 24, 2012). Analyses of the NIS data revealed a continued rise in adolescent vaccination rates for tetanus-diphtheria-pertussis (Tdap) vaccine and meningococcal conjugate vaccine (MCV4), while adolescent HPV vaccination remained flat for the third consecutive year. This spurred Rear Admiral Anne Schuchat, MD, Assistant Surgeon General Director, National Center for Immunization and Respiratory Diseases (NCIRD), and Centers for

Disease Control and Prevention (CDC), to issue an August 30, 2012 communication about the nation's adolescent vaccination rates and adolescent HPV vaccination status.

Thanks to HPV vaccines, we have the prospect of preventing most cervical cancer in an entire generation of women; we simply cannot afford to miss this opportunity. Now that we can see the disappointing trajectory of uptake that “business as usual” is achieving, it is increasingly clear to me that urgent collective action is needed to alter this course. Our objectives are threefold: a) to increase initiation; b) improve completion among those who begin the HPV vaccine series; and c) reduce disparities (including geographic ones). Accomplishing these goals requires strategic and coordinated actions of each stakeholder group (<http://www.immunize.org/cdc/letter-NIS-data.pdf> accessed September 24, 2012)

Research that reveals the reasons why adolescents do not receive HPV vaccinations may provide a basis for interventions that will serve to increase vaccination reception. Research that reveals the communication process among adolescents, physicians, and parents may provide a basis for interventions that enhance adolescents' discussions with their parents and health care providers. Empirical evidence may enable physicians to match their communication and information to adolescents' desired participation in their health decision-making (Healthy People, 2010; 2020). This research study directly addressed these significant, practical issues.

Chapter 2: Literature Review

Human papillomavirus (HPV) and adolescent vaccination offers a current research platform to examine adolescent health care participation decision-making. There are practical issues of including adolescents in their health care decision-making and theoretical issues of adolescent inclusion. How adolescents participate in their own health care remains a critical issue.

Human Papillomavirus and Vaccination

Human papillomavirus is not a single virus; more than 100 strains have been identified. Many of the strains of HPV are benign to humans. The papillomaviruses get their name *papilloma* from the non-life-threatening growths some of the viral strains cause.² HPV is the most commonly-spread sexual infection among all humans. The virus' sexual transmission involves skin-to-skin contact. The high-risk ages for acquiring HPV infection are considered to be ages 20 to 24 years, with a statistically significant year to year increase in HPV viral infection starting at age 14 years (Dunne, Unger, Sternberg, et al 2007, p 815). The body's natural immune system usually overcomes and eliminates harmful HPV strains (Stanley, 2006; Widdice & Moscicki, 2008) though the mechanisms are unknown (Ault, 2006). Those harmful HPV strains that do persist are known to cause various genital, anogenital, and oropharyngeal adult cancers (Ramet, et al, 2011; Schiffman, et al, 2007).

Medical advances have demonstrated the immunogenic effectiveness of two vaccines that have the potential of dramatically halting the spread of specific high-risk HPV strains with few negative side effects (Kahn, 2005). One of the vaccines is bivalent, targeting two HPV strains HPV-16 & HPV-18 which cause 70% of cervical cancers

(Paavonen, et al, 2009). The other vaccine is quadrivalent. It offers protection against four HPV strains HPV-16, HPV-18, HPV-6, and HPV-11. HPV-6 & HPV-11 are responsible for about 90% of genital warts in both males and females (Harper & Paavonen, 2008; Palefsky, 2010). The vaccines seem to be most effective in providing protection to both females and males when given prior to the onset of any sexual activity (Harper & Paavonen, 2008; Palefsky, 2010). There has been no documented therapeutic performance for either vaccine reported (Hildesheim, et al, 2007; Stanley, 2012). Neither vaccine is live, meaning the recipients cannot acquire HPV infections from the vaccines.

Initially these vaccines were developed and licensed for HPV strains causing cervical dysplasia and cancer. It was thought that vaccinating females before they were exposed to these HPV infections would go a long way toward preventing cervical cancer in adults. Males were not part of the original vaccination program because they were not at risk for cervical cancer. Though males carried and spread these HPV infections, it seemed that they would gain no direct benefit from the vaccines. Rather, if enough pre-adolescent females were vaccinated the spread of HPV infection could be arrested and it would not be necessary to vaccinate males (Kim & Goldie, 2009). Furthermore, studies projected that public acceptance for male HPV vaccination would be too low to prove economically feasible.

The American Academy of Pediatrics (AAP), the American Medical Association (AMA), and the Society for Adolescent Health and Medicine (SAHM) recommend HPV vaccination for female adolescents (2007). The Advisory Committee for Immunization Practices (ACIP) of the Center for Disease Control (CDC) approved and recommended HPV vaccination for all female adolescents aged 11 through 26 years old in 2006. The

Food and Drug Administration (FDA) licensed the quadrivalent vaccine for administration for 11- and 12-year-old females with catch-up for unvaccinated females up to age 26 years for protection for cervical cancer, precancerous lesions, and genital warts (2006).

The prophylactic influence of these vaccines has since broadened as research studies found evidence that these vaccines also protected females against HPV infections that caused adenocarcinoma in situ (AIS), and vulva, anal, and certain head and neck cancers (Gillison, 2008). Other researchers provided evidence that the vaccines did protect males against HPV infections that caused anal intraepithelial neoplasia (AIN), penile cancers, anal cancers, and certain head and neck cancers (Anic & Giuliano, 2011; Gillison, Chaturvedi & Lowy, 2008; Palefsky, 2010). In light of this empirical evidence, the ACIP expanded its vaccine recommendation for females to include these adult cancers. In October 2009 the FDA licensed and the ACIP recommended both vaccines for HPV vaccination for all male adolescents aged eleven through twenty-one for protection against genital warts (2009).

As with other vaccines, the more people vaccinated the fewer opportunities exist for an individual to become infected; extensive vaccination affords communal protection – the so called *herd protection*. The safety and effectiveness of these vaccines is unquestionable. Two studies suggest the vaccines are safe and effective for females as young as 7 years old, though there are currently no plans to include them in the current HPV vaccination schedule (Reisinger 2007; Levin 2010). Studies also show that the vaccines are safe for women over 26 years of age yet effective only for those individual women who were not previously exposed to the specific HPV infections (Munoz, et al,

2009). Studies modeling the cost-effective use of public resources suggest that it does not make economic sense to mass vaccinate women older than 26 years for the following reasons: most likely women over 26 years old were previously exposed, are now sexually active, in a stable relationship, have few sexual partners, and thus these aged women have a low risk of acquiring HPV infection as well as a low risk of disease burden from infection (Grant, Dunne, Chesson & Markowitz, 2011; Kim, Ortendahe & Goldie, 2009).

Australia was the first nation to offer 11- and 12-year-old school-girls free HPV vaccination in 2007 (Garland, et al, 2011). Canada followed in 2007 and Great Britain in 2008. Dissemination remains varied across locals in all three countries (Colucci, Hryniuk & Savage, 2008). In January 2012 a campaign was initiated throughout Canada to include school-boys in the national funding program of HPV vaccination (CBC News Health, 2012). Though the US does not offer free HPV vaccinations, a federally funded Vaccine for Children Program covers the costs for HPV vaccinations for uninsured and underinsured adolescents under 18 years old. Shortly after CDC approval for female vaccination, numerous US state legislatures (e.g. Texas, New Jersey) considered introducing laws to require HPV vaccination for girls' to attend school (Udesky, 2007). The subsequent fervent public, political, and religious uproar obstructed such legislation mandating HPV vaccination for school entry (Lemke, 2010). HPV vaccination in the US remains private and optional; parents, not the government, decide if and when their child will be vaccinated.

At pre-licensure, public intention for HPV vaccination appeared to be high. Research surveys and interviews reported that a large percentage of parents were willing to accept HPV vaccination for their daughters (Brewer, 2007; Constantine & Jerman,

2007; Rosenthal, 2008) and their sons (Fazekes, 2008). Focus groups and individual interviews were conducted to understand the influences on parents' decisions about HPV vaccination. Parents considered expert opinions, media reports, opinions of family and friends, characteristics of their child, vaccine side effects, and medical costs in order to decide about their adolescent's HPV vaccination (Smith, 2008; Tissot, et al, 2007). These studies indicated that parents' acceptance of HPV vaccination for their daughter was related more to their views of vaccinations than to their knowledge of HPV (Olshen, et al, 2005; Zimet, Perkins, Strum, et al, 2005).

Parents' views of vaccinations were influenced mostly by recommendations. Studies in the United Kingdom and Canada reported parents agreed to HPV vaccination for their daughters upon their government's recommendation (Lenselink, et al, 2008). Parents in the United States said their family physician's recommendation was the most influential advice they followed for their child's vaccination (e.g., Caskey, Lindau & Alexander, 2009; Dempsey, Zimet, Davis & Koutsky, 2006; Rosenthal, et al, 2011; Ruffin, et al 2012). This finding explained why adolescent HPV vaccination uptake in the United States was inconsistent. Family physicians in the US did not agree on the value of HPV vaccination for adolescents. Some family physicians said they were more likely to recommend the quadrivalent and not the bivalent vaccine for HPV vaccination, to recommend HPV vaccination for females but not males, and to recommend HPV vaccination for older female adolescents rather than younger adolescents (e.g., Daley, et al, 2010).

There was another consistent research finding concerning HPV vaccination acceptance. A minority percentage of parents involved in the surveys and interviews were

opposed to vaccinating their daughters against HPV infections. There was a list of specific concerns: vaccine safety (Ruffin, et al, 2012), vaccine effectiveness, vaccine costs (Elbasha, et al, 2009), vaccine side effects (Gulati, Lazebnik, & O’Riordan, 2009), sexual disinhibition, specifically that the implication that HPV vaccination is tacit approval for sexual behaviors (Chan, et al 2007; Kahn, 2008B; Ruffin, et al, 2012). In addition, some parents resisted HPV vaccination because they believed their children received too many vaccinations (Marlow, Waller, & Wardle, 2007). Ethical issues were also mentioned among the minority’s objections to HPV vaccinations. Parents were weighing their daughter’s individual risk of infection against the public risk for contagion. Parents objected to government mandated vaccinations (e.g., Balog, 2009), and the ethics of gender-specific vaccination (Lemke, 2010).

The most contentious factor surrounding HPV vaccination emerges because HPV is an STI and is only transmitted from person to person through sexual skin-to-skin contact. Some studies confirmed that the sexual transmission of HPV infection caused parental resistance to HPV vaccination (Davis, Dickman, Ferris, & Dias, 2004; Olshen, et al, 2005); yet other studies reported that parents had no such concerns (Robbins, et al, 2010). These unconcerned parents reasoned that not being sexually active would preclude their daughters from contracting HPV and thus ensured protection from the possibility of infections and diseases (Ruffin, et al, 2012). Hence many parents maintained there was no urgency for their 11, 12, or 13 year old child to receive HPV vaccination, implying that their daughters were not sexually active (e.g., Gottleib, et al, 2009).

Many parents deny reports of widespread pubescent sexual activity. For one, many parents, adolescents, and young adults have multiple and varied definitions of

having sex (Sanders, & Reinisch, 1999; Trotter & Alderson, 2007). Many think of sex solely in terms of penile-vaginal and penile-anal intercourse (Carpenter, 2001; Hans, Gillen & Akande, 2010). Adolescent abstinence pledges act to effectively delay the onset of sexual intercourse (Hans & Kimberly, 2011) but have no association with non-coital behaviors (Martino, et al, 2008). Moreover, the rise of oral-genital contact suggests that adolescents and young adults consider such non-coital behavior as *just messing around* (Lindberg, Jones & Santeli, 2008). They do not realize oral-genital *fooling around* is an activity eligible of spreading infections (Carpenter, 2001; Hans, Gillen & Akande, 2010). Oral HPV infection is transmitted through open mouth kissing and oral-genital sex (D'Souza, et al, 2010). The possibility exists that unvaccinated adolescents engaging in oral-genital sex are potentially at risk for acquiring HPV infections. Presently, there are no empirical studies establishing a causal relationship between adolescent oral-genital sexual activities and the increase in oral/oropharyngeal cancers in the US (Tota, et al, 2011).

Concerning HPV Knowledge

There is a need to establish what relationship exists between HPV knowledge and HPV vaccination decision-making. Immediate and long-term research regarding HPV knowledge, understanding, views, recommended compliance, and educational interventions is imperative (Constantine & Jerman, 2007; National Vaccine Advisory Committee (NVAC), 2009; Sherris, et al, 2006). The NVAC (2009) emphasized that research needed to

[f]ocus on the general adolescent population as well as subpopulations (e.g., racial and ethnic minorities; youth living below the poverty level; incarcerated, substance using, homeless, and/or pregnant youth) which may be particularly

challenging to reach, educate, and vaccinate, and are therefore most vulnerable to vaccine-preventable diseases (p 279e1).

Published journal opinions, editorials, prospective surveys, interviews, and focus group discussions with parents and providers concerning their views toward HPV vaccination are informative yet limited. These studies suggest a myriad of influences on HPV vaccination uptake such as perceptions of personal/family and social norms, provider recommendations, and beliefs about vaccine efficacy and safety (Fernandez, Allen, Mistry, & Kahn, 2010). The initial HPV studies were conducted solely with parents. Parents were interviewed and surveyed about their perceptions of acceptability (for reviews see Zimet, 2005; 2006), their approval (e.g., Davis, Dickman, Ferris & Dias, 2004), their adherence to dosage, cost effectiveness (e.g., Elbasha, Dasbach, Insinga & Barr, 2009), and their low compliance. An exception among pre-vaccine licensure studies was the Canadian study that reported 87% of the adolescents sampled from an urban, Canadian, high school had never even heard of HPV (Dell, Chen, Ahmad & Stewart, 2000).

Early post-licensure studies involved females older than 18 years old, who tested positive for an HPV infection. These were retrospective interviews indicated that most of those newly HPV-infected females were proponents for vaccination; given the opportunity, they would have received HPV vaccinations (Daley, et al, 2010). Post-licensure studies only recently began including the views of the adolescents, the ones who would be most affected by accepting or rejecting HPV vaccination (Caskey, Lindau & Alexander, 2009; Chan et al, 2009; Marlow, et al, 2009; Marlow et al, 2009B). One study focused on non-infected adolescents' involvement in HPV vaccination decisions (Mathuer, Mathuer & Reichling, 2010). In that study approximately 48% (63/130) of the

participants (California high school girls in the 9th through 12th grades) said they were involved in the HPV vaccination decision. Unfortunately what constituted involvement was not explained, and thus their decision-making participation cannot be determined.

Recognition that HPV is a sexually transmitted infection that can be prevented by a vaccine is on the rise among women, especially the 18 – 26 year-old age group (Jain, et al, 2009). Unfortunately, this recognition comes with little specific knowledge of the cause, transmission, or consequences of HPV infections (Agius, Pitts, Smith & Mitchell, 2010; Hilton & Smith, 2011)). A few studies reported that adolescents who received HPV vaccination had more knowledge than those who declined HPV vaccination (Agius, Pitts, Smith & Mitchell, 2010; Caskey, Lindau, & Alexander, 2009; Mathur, Mathur, & Reiching, 2010). There are a limited number of studies involving US adolescents. Those US studies of HPV-uninfected adolescents mainly report that adolescents' acceptance of HPV vaccination is significantly influenced by their parents' acceptance and healthcare providers' recommendations (Caskey, Lindau & Alexander, 2009). Additionally, a recent systematic literature review of research articles in English found low levels of understanding of HPV among adolescents (Chan et al, 2012).

Most studies that included adolescents were focused on identifying predictors for HPV infections. Significant predictors that were found for PHV infections were poverty and being a female between 14 – 17 years of age (Kahn, Lan & Kahn, 2007). A high risk factor for HPV infections was a lack of HPV knowledge and understanding (Caskey, Lindau & Alexander, 2009). Overall, the greatest risks for HPV infection were reported to be gender (female), age (young), and sexual activity (multiple partners) (Ault, 2006).

Though risks for HPV infection can be identified, there currently is no way to predict with confidence, from any particular variable, who will actually become HPV infected. And although HPV DNA tests can reveal that a female individual is HPV-infected, there is no equivalent test for males. Furthermore, there are no serology tests that can identify whether any individual was exposed to HPV viruses.

Intervention studies that provided HPV information to parents and adolescents report participants understand more about HPV after the studying the HPV information provided. Some studies report their information interventions have no effect on parents' stated acceptability of HPV vaccination for their daughters (e.g., Dempsey, Zimet, Davis & Koutsky, 2006). Other studies report their information interventions increase participants' intentions to vaccinate against HPV (e.g., Chan, Lo, Cheung & Chung 2007; Chan, et al, 2009). One follow-up study reported low vaccine uptake (6%) of a sub-set from a group surveyed a year prior in which 66% intended to get HPV vaccinations vaccination (Conroy, et al, 2009). Unfortunately researchers seldom followed-up on their participants' vaccination intentions. Intentions don't always predict behavior (Johnston & White 2003; Stevens-Simon, Sheeder & Harter, 2005); thus further reporting on those intending to be vaccinated would be particularly informative.

The existence of HPV infections and their relationship to various cancers is a rather new public health issue. Yet now there are many sources for HPV information including media reports, internet web sites, family members, physicians, and friends. Media campaigns by vaccine manufacturers, the CDC, and public health interests encourage adolescent HPV vaccination. Radio programs, television advertisements,

newspapers, and innumerable web sites advertise cancer prevention through HPV vaccination.

Evidence suggests that such publicity has increased parents' HPV and vaccination awareness and their intent to vaccinate their children. For example, in 2007, one year after the vaccine was made available, 10% of those parents interviewed by telephone in North Carolina said their daughters received at least one HPV vaccination (Gottlieb, et al, 2009). In 2008, follow-up phone interviews found that 27% more of those parents said that their daughters had received their first HPV vaccination within the past year (Brewer, et al, 2011). The 2008 – 2009 Raising Healthy Children young adult survey reported 19% initiation of the three-dosed HPV vaccine treatment in their predominately white female sample (Manhart, et al, 2011).

HPV media coverage in various newspapers, television broadcasts and internet websites is often deficient in covering important HPV vaccination details such as disease prevention, potential harms of not vaccinating, and medical recommendations (Anhang, Stryker, Wright & Goldie 2004; Madden, 2011). A recent study involving females from 13- to 26-years old suggested that vaccine-oriented media increased their knowledge about HPV vaccine more than their knowledge about the HPV infection (Caskey, Lindau & Alexandr, 2009).

There has also been considerable media attention disputing the value of adolescent HPV vaccination (e.g. Kovacs, 2011). Commentaries cast doubt on scientific studies by arguing that the physicians and researchers who promote HPV vaccination are biased by their pharmaceutical connections (e.g., CDC, 2008; McCullough, 2009; Goldberg, 2011). Despite reputable discrediting evidence, anti-vaccination news reports

may be convincing because they are concise, coherent, and seem to be plausible interpretations of inexplicable occurrences (Reyna, 2012). For example, there has been a worrisome increase among young children of instances of two vaccine-preventable diseases, measles and pertussis (whooping cough). It occurred because concerned parents postponed vaccinations for their newborns and toddlers because reports related vaccinations to adverse, even life-threatening, effects such as Guillain-Barré syndrome and autism (Mnookin 2011). Subsequently, an influx of infection-carriers among immigrants to Los Angeles created the outbreak of measles and the spread of pertussis among the unvaccinated and thus vulnerable children (CDC, 2011; 2012).

Comparisons of adolescent HPV vaccination rates over the past few years can put some perspective on parents' HPV awareness and vaccinate intent for their children. The CDC conducts a yearly national telephone interview (the National Immunization Survey – Teen) and reports data from parents of female adolescents across the United States. The statistic of interest, that is available from the CDC reports, is the national average for HPV vaccination. Currently, this statistic is available from CDC reports of 2009, 2010, and 2011 interviews. The CDC reported that the national average HPV vaccination rate for female adolescents between 13 and 17 years of age increased from 2009 to 2011. In 2009, 44% of this target group received one or more HPV vaccinations. In 2010 the HPV vaccination average for females aged 11 thru 17 years was reported as 49% and in 2011 their HPV vaccination average was 53% (<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6033a1.htm> accessed 03-12-2012).

Adolescents in Health Care Decision-making: The Practical

The practical issue of adolescent participation in their health care is two-fold: how to involve the adolescent in a legal and ethical manner and how to involve the adolescent in a social and ethical manner.

Legal and ethical issues. Federal and state regulations guide all health care according to adult or child status. This status distinction is accorded by age (though some states differ on the particular designated age). Most often *the bright line* or *straight eighteen* defines the boundary between childhood and adulthood (Scott, 2000-2001). Health regulations are based on commonly acknowledged biomedical rights (e.g., Beauchamps & Childress, 2009). Adult status is assigned the fundamental right of autonomy. Autonomy includes the right, and the responsibility, to make health care decisions for oneself. Children's health care is based on an individual's fundamental right to beneficence. Beneficence is the duty of parents and health care providers to take action to improve and promote health and welfare. Beneficence creates a paternalistic health care paradigm in which adolescents participate as receivers of adult-made health care decisions.

Most research examining adolescents' participation focuses on adolescents with chronic illnesses (e.g., asthma, diabetes, cancer). A few other studies observed or interviewed children undergoing hospital procedures. For example, two studies in Sweden found that children participated to varying degrees and though some children were comfortable with adult control, some children felt uninformed about the health care they received (Runeson, Hallstrom, Elander & Hermeren, 2002; Runeson, Martenson & Enskar, 2007). Medical organizations have policies to include adolescents in their

decision-making for medical care and treatment and for research participation. For example, health providers are required to ask the adolescent for assent for procedures and treatments. Regrettably, this is done inconsistently and health care providers address parents as opposed to the adolescent who would receive the health treatment (Lee, et al, 2006).

There are three exceptions allowed by law for medical treatment of minors without parental consent: emergencies, the case of the *emancipated minor*, and the situation of particular health services. The first exception involves emergency situations where health care professionals are allowed to care and treat a child without parents' consent. This is based on the ethical principles of beneficence and non-maleficence and the determination that waiting for parental consent would endanger the health or life of the child. The second exception involves the status of the emancipated minor.³ An emancipated minor is legally allowed to make medical decisions regarding her care, treatment, and participation in medical research for herself and for any child she may have. The third exception allows children as young as 12 years access to certain health services because adolescents may be deterred from accessing medical care, treatment, or consultation if parental notification is required in certain circumstances (Maradiegue, 2003).⁴ These adolescents have legal access to health services for contraception, pregnancy, and care and treatment for STIs as well as for substance use and mental health issues.

Social and ethical issues. During the early 1900's, the family became a socially, psychologically, and legally respected entity (Hendrick, 1997). It became a common belief that parents and children enjoy bonds of affection or care, concern, and purpose

from sharing every-day living experiences in common residences. Society recognized parents' as having the maturity, experience and aptitude to guide their children toward developing competencies for themselves. Children needed secure surroundings to develop competently. That safety net was commonly afforded within the family context. Parents guarded their children from physical and emotional pain, harm, and suffering. The notion of the vulnerable child originated within such social family constructions. This placed parents in the unique position to know the best interests of their children and the fundamental right of beneficence emerged. So along with these parent responsibilities came the right to make decisions for their children's health and welfare (Tisdall, 2006).

Adolescence is typically a period of good health. Adolescents might face health challenges such as runny noses, fevers, headaches, backaches, cramps, broken bones, and bleeding. Indeed, they sometimes view illness merely as an interruption to their daily activities and disruption to their desired activities (Reeve & Bell, 2009). Age could limit some of the adolescent's perceptions of the physical, psychological, social, and cultural manifestations of her health, but not all of them; fundamentally the adolescent might provide information about herself of which parents are not aware. It is reasonable to expect the adolescent to discuss her health with her parents and health providers. Furthermore it is practical to involve the adolescent in her health care to the extent that she wants to be involved even in non-extenuating situations and routine health care decisions.

Health care decisions are made for various reasons. Health care decisions are made for medical treatment in direct response to some physical manifestation illness. Health care decisions are also made to take precautions against illness and in order to

conserve a state of wellness. Involvement does not require that the adolescent be the decision-maker; involvement entails participation. Five levels of participation are generally identified as (e.g., Runeson, Hallstrom, Elander & Hermeren, 2002):

1. the adolescent receives health information
2. the adolescent understands the health information
3. the adolescent speaks about the health information and adults listen
4. the adolescent's views are taken into account as to influence the health care decision-making
5. the adolescent being the main decision-maker

Irrespective of how participation is identified, it remains extremely difficult to balance children's rights, parents' rights, and maintain the integrity of the parent-child relationship while making health care decisions (Kuther, 2003). In a physician visit the adults need to ascertain how to involve the adolescents and how much the adolescent wants to participate in her health care. Parents are mindful of their responsibilities to care for their children and set the parameters for their children to participate in medical decision-making for their health care (e.g., transitioning diabetes management from parent to child, see Palmer, 2009). Pre-licensure studies showed that parents favored involving their child in the HPV vaccination decision (e.g., Brabin, Roberts, Farzaneh & Kitchener, 2006). Post-licensure parent interviews reported that daughters were involved in the HPV vaccination decision though not the primary decision-maker (e.g., McRee, Reiter, & Brewer, 2010).

Adolescents in Health Care Decision-making: The Theoretical

Practical issues concerning adult or child status, parental responsibilities, and adolescent participation in decision-making raise theoretical considerations of adolescent agency, personal autonomy, evolving capacity, and decision-making processes. Two historical themes about children pervade the theoretical issues of adolescent involvement in their health care decision-making:

1. Adolescents are seen as incompetent and lacking ability – a deficiency model of childhood
2. Adolescents are vulnerable and malleable – a Romantic (Rousseau) model of childhood

The argument against allowing adolescents to make their own health care decisions is confusing. The theoretical conceptualizations of adolescents as vulnerable and incompetent are entangled. Adolescents lack decision-making experience so they become labeled as deficient. Thus parents are socially and morally charged with their children's welfare; adolescents become labeled as dependent. When adolescents are labeled as deficient and dependent they are thought of as impressionable and malleable. Because adolescents are thought of as impressionable and malleable they become labeled as vulnerable. Adolescents labeled as dependent and vulnerable cannot make decisions that are in their best interest. Adolescents need decision-making help from their parents.

As adolescents advance in years their life experiences multiply. Because older adolescents have more life experiences they are considered to be more competent. Purportedly their accumulated experiences impart an understanding of the consequences of their behavior. Because adolescents understand the consequences of their behavior

they are accountable for their decisions. Thus age becomes the decisive factor because age becomes synonymous with having experience and experienced adolescents become labeled as competent and responsible.

A less convoluted explanation of age based decision-making competence is needed. Indeed the United Kingdom's *Gillick ruling* of a competent child attempts to discount age in deciding children's competency (1985):

The modern law governing parental right and a child's capacity to make his own decisions was considered in Reg. v. D; [1984] A.C. 778. The House must, in my view, be understood as having in that case accepted that, save where statute otherwise provides, a minor's capacity to make his or her own decision depends upon the minor having sufficient understanding and intelligence to make the decision and is not to *be determined by reference to any judicially fixed age limit* (p 25).

The *Gillick* ruling pictures a competent child as having "sufficient discretion to enable him or her to make a wise choice in his or her own interests" (1985; p 26). It seems to emphasize the cognitive, social, and emotional processing capacities involved in reasoning, choosing, and then implementing decisions. Thus decision-making competence might better be described in terms of four elements of thinking: the ability to understand what is presented regardless of the consequences of the decision, the ability to reason to come to a decision, the ability to make a decision, and the ability to understand the resulting decision (Koocher, 1990; p 69). Children of any age can be competent decision-makers and understand the responsibility of their behaviors.

Modern society does have a dual concept of children as dependent and responsible. The United Nation's definition of children's rights expresses this dilemma: "Government is torn between the notion that children are dependent on parents for well-being and the idea that individuals should take responsibility for their own actions" (Such & Walker, 2005; p 39). Thus the United Nations Convention on the Rights of the Child

introduced the notion of *children's evolving competencies* in attempt to clarify agency and adolescents' right to autonomy. Unfortunately the UN Convention does not clearly define evolving competency so this reconfiguration of adolescents does nothing to clarify the dissonance that arises from characterizing adolescents as dependent and responsible.

Adolescent Development: Autonomy and Connectedness

Adopting thinking criteria for competency creates other issues. For example, how can these thinking elements be identified or measured? Effective decision-making is learned and honed through practiced. Parent and adolescent relationships are integral influences because they afford adolescents opportunities to learn about decision-making from models, practice reasoning and choosing, and then experience consequences in the comparative safety of the family.

Parent-adolescent relationships are dynamic and at times dialectic. Adolescents are undergoing physiological and biological changes of puberty (e.g., menarche and hormones) which initiate social, emotional, and cognitive changes. They spend increasing less of their time with parents and more of their day with peers and non-family members. The adolescent's developmental task toward becoming an effective contributor in society has been touted as identity development (e.g., Erikson, 1968). Recently the adolescent's task has been re-characterized as developing multiple self-concepts involving autonomy (individuation) and connectedness (attachment). This progresses into a fluid interdependence or a push-pull between parent-adolescent. There are instances when adolescents pull away from parents (e.g., keeping friends and conversations private), while in other circumstances adolescents seek to belong (e.g., wanting parents to watch a dance performance). Parents too push adolescents toward independence (e.g., figure it out

yourself) and at other times strive to keep them close for protection (e.g., tell me about this boyfriend).

Sex Talks

Issues of autonomy and connectedness permeate family interactions as adolescent and parent re-negotiates their relationship. Even when the topic is health care, cuts, bruises, fevers, seatbelts, bicycle helmets, and vaccinations take on new configurations. In particular, parents and adolescent may find adolescent sexual maturation and romantic interests uncomfortable to discuss. Research shows parents believe it is important to talk with their child about sex, and sex talks are effective, yet that family discussions about sex are infrequent (e.g., Jaccard, Dittus, & Gordon, 2000). Parents have the perception that a child 10 – 12 years of age can discuss sex in terms of physiology and reproduction, but is not ready to talk about sexual behaviors. Interview studies found that families discuss sexual behaviors, birth control, and sexually transmitted infections after their child's sexual debut (e.g., Beckett, et al, 2010). Furthermore, parent-adolescent sex discussions are predominantly the responsibility of the mother (e.g., Raffaelli, Bogenschneider & Flood, 1998). Fathers occasionally speak about sex protection with their sons yet rarely with their daughters. Parents offer several explanations for postponing sex talks: (1) Parents do not think their adolescent is ready for sex talks; (2) Parents do not see signs indicating sexual activity or proclivity; (3) Parents believed that their adolescent showed no interest when they tried to have a sex talk the child; (4) Parents are not sure of what to say and are somewhat embarrassed by the topic (e.g., Wilson, Dalberth, Koo & Gard, 2010). Parents avoid sex talks reasoning that they would put ideas into their child's head and destroy their *innocence*.

There is evidence that contradicts parents' beliefs that their children are not ready for sex talks. The national statistics on unwanted adolescent pregnancy and STI rates indicate that adolescents are not practicing safe and healthy sex.

Frameworks for Health Decisions

Now that there is increased public recognition of HPV vaccination without specific knowledge about HPV infections (as discussed in an earlier section of this chapter), it is important to understand how adolescent HPV vaccination decision-making proceeds and to identify what factors are involved. It is important to show how adolescents are the health care recipients and parents are the decision-makers.

Health belief models (HBM) are popular. They characterize health care decision-making in terms of the individual's capability to understand and value health (e.g. Rosenstock, Strecher & Becker, 1988). Understanding health includes having knowledge of diseases, treatment options, treatment availability, and how to overcome barriers to attaining a certain health state. Valuing health includes an awareness of the possible severity of illness, personal susceptibility for illness, current health, desired health, and benefits of a certain health state. HBM models place responsibility on the individual to discover, learn, and comprehend health information, to overcome barriers to health, and to maintain healthy practices.

The responsibility of health cannot be solely in the hands of the individual. There are educational and economic achievements that impact the individual's value and understanding of health factors. Educational attainment affords the cognitive skills necessary to comprehend health information. In addition, educational attainment impacts the individual through the social capital accrued from completing successively higher

grade levels in school. Increases in social capital directly increase healthy behaviors, health management, higher occupational attainment, and higher incomes (Cutler & Lleras-Munery, 2008; Mirowsky & Ross, 2003). Economic achievements impact healthy behaviors and health management more directly. For example, adolescents from lower-class families are more likely to have a tooth pulled than have root canal that necessitates recurring dental visits (Atkins, et al, 2009). Middle-class parents advocate, utilize, and negotiate the health care system, whereas lower-class families cope with, avoid, and forego the health care system (Laureau, 2003). For lower-class families social policies can become barriers to health care. Consider the state-wide mandates that are in place for health physicals and vaccinations in order for children to attend public schools. These mandates require adolescent health visits to a physician or clinic. At minimum, parents need time off from work and a means of transportation to comply with these social policies. In this manner, health care is costly for the individual.

Social and cultural factors that encompass individuals' lives cannot be ignored. For example, if the community has no supermarket and the street lights remain broken purchasing fresh vegetables and avoiding accidents at night is an uncontrollable social barrier that sways health care choices. Laureau (2003) articulately revealed health behavior *habitus* differentiating poor and working-class families and middle-class families.⁵ Parents were seen to model and teach health behaviors differently. Poor and working-class parents gave order to their children and expected them to comply to their parental authority (e.g., wash your hands, eat your vegetables, be quiet) whereas middle-class parents modeled reasoning and negotiations and expected the same behavior from

their children (e.g., which vegetables do you want for dinner, if you help your sister with her math then I'll take your turn washing the dishes).

There is no guidance for researching healthy adolescents involved in their health care decision-making even though there are many models of adolescent of reasoning and judgment decision-making (JDM). These JDMs predominately focus on explaining adolescents' risky behaviors such as alcohol and drug experimentation, driving, shop-lifting, condom use, sexual initiation. For example, the prototype willingness model portrays adolescent's risky behavior as volitional, but suggests that it is not intentional and not usually planned (Gerrard, Gibbons, Houlihan, et al 2008). Alternatively, the theory of planned behavior (TPB) configures the adolescent's risky behavior as unplanned, peer-inspired, and contextually determined decision-making (Gerrard, et al, 2008). In both these models, the risky behavior is the focus and the adolescent's attitudes and incentives are factors that lead the adolescent-decider to the risky behavior.

There are at least three reasons adolescent decision-making models that explain adolescents' risky behavior are not transferable to health care decision-making. First, there is time for deliberation and planning during health care decision-making. Second, parents are present for their child's health care and actively make the health decisions. Third, health care decision-making is volitional and intentional. And though research suggests that risky JDMs are influenced by parent-adolescent relationships and parenting practices (e.g., authoritarian and authoritative) influences, parents are omitted from these decision-making equations because they are not physically present and are not the actual decision-makers.

Research has yet to identify the manner of the tripartite relationship between parents' knowledge, risk, and vaccination decision for their child. The challenge is incorporating the extent of parents' knowledge of their adolescents' health behaviors so the parent is able to judge their child's personal health risk and incorporate that information with disease knowledge, treatments, and health care decisions. The challenge for modeling adolescent health care decision-making is representing adolescents' health knowledge, parents' health knowledge, an adolescent's health risk, and the adolescent-parent relationship.

Since the parent is responsible to make the health care decision for her child the model should include the parent's personal beliefs and conceptualizations about the adolescent. The parent's personal beliefs are her resources that are available in her particular social and cultural milieu and are considered to adjudicate perceptions and relationships. Given this modification the responsible parent interacts with her adolescent and forms perceptions about her child, their relationship, and so forth that enable the parent to manage her child's health care. Considering the issue of HPV, a health care decision about HPV vaccination would be based on knowledge of the HPV issue and personally perceived risks of HPV infection. The adolescent participates in her health care to the extent that she communicates and informs her parent and to the extent that her parent listens to her. The adolescent-parent relationship becomes a means for adolescent health care participation as well as responsible parent management of their adolescent's health.

With respect to HPV vaccination decision-making, parents may have preconceived beliefs about if and when their adolescent commences her sexual activity

(see discussion of sex talks in previous section). A parent that believes her adolescent is on the brink of engaging in sexual activities could perceive her at risk for HPV infection and accept HPV vaccination. There are a number of reasons that a parent would perceive her child to be a low risk for HPV infection and delay HPV vaccination. A parent that believes her adolescent is not engaging in sexual activities could perceive a low risk for HPV infection and decline HPV vaccination. For example, a parent of a prepubescent child may not be able to conceptualize her child as sexual and thus may decline HPV vaccination for lack of HPV risk. Other scenarios for perceiving the adolescent is at low risk for HPV infections can be imagined. For example, a parent may not want to accept the evidence that her child is sexually active. Or, a parent may believe her adolescent won't be sexually active until she's older, goes off to college, or gets marriage.

Research Hypotheses

The studies and issues reviewed here pertain to the practical and theoretical issues of healthy adolescent health care participation. Adolescents are not lawfully competent to make the health care decision in their best interests. Parents are charged with the responsibility of health care decision-making for their adolescents. Yet the law does not preclude adolescents from participating in their health care decision-making. It remains for adults to ethically and practically include adolescents in their health care decisions. This research project examines adolescent participation in their health care. The specific hypotheses for this research project are as follows.

- Research question: How might adolescents discuss, reason, behave, and make decisions with respect to their health care with their caregivers?

H1: Adolescent's participation is minimal.

Parents make medical decisions for their adolescents.

Adolescents will respond only when asked a direct question.

- Research question: What influences adolescent participation in their health care decision-making?

H2: Socioeconomic status influences adolescents' participation in their health care.

Middle-class parents discuss health issues with their adolescents.

Lower-class parents make health care decision for their adolescents.

H3: Highly educated parents will accept HPV vaccination for their adolescents.

H4: HPV knowledge and understanding leads to accepting HPV vaccination.

Parents seek HPV information.

- Research question: How do parents' perceptions and personal beliefs influence their health care decisions for their adolescent?

H5: Adolescents' autonomy judgments influence adolescent participation.

Adolescents judged to have high autonomy participate in their health care.

Adolescents judged to have low autonomy do not participate in their health care.

Chapter 3: Study Design

While adolescents are present at their health care visit, their involvement is unknown. Hence, the extent adolescents actually attend to, process, understand, and respond to health information during their clinic visit needs interrogation. This research project focused on the adolescent experience of decision-making concerning an important health care issue. In particular, this study examined the scope of adolescents' knowledge, understanding, attitudes, and behaviors regarding the human papillomavirus (HPV) and vaccination.

This chapter describes the setting, participants, procedures, and instruments of the research project. Procedurally the research project was conceived as two separate data collection phases: first a survey and second observations of participant-physician encounters. The survey served to quantify HPV and vaccination knowledge and beliefs while participant-physician observations examined attitudes and behaviors concerning HPV and vaccination decision-making in situ. In the course of survey engagement, participants asked questions and initiated conversations about HPV and vaccinations. These survey conversations emerged as an unplanned, yet informative, third data source. Survey conversations served to bridge the two planned data sources.

Research Setting

This research study took place within an academically affiliated pediatric and adolescent medical practice in the northeast United States. This adolescent practice had a clinic site at a hospital in an impoverished city and another clinic site situated in the hospital's satellite treatment center in a nearby, affluent suburb. Patients of this adolescent medical practice reflected the region's adolescent population with one

exception; these physicians did not administer health care to the segment of the population that was uninsured and unable to self-pay for their medical care.

The city clinic was accessible by walking, driving a car, and taking a bus or train. Metered and hourly-fee parking lots were in close proximity. Security personnel were always on duty and visible at the clinic, in the hospital, and throughout the surrounding neighbor. The suburban clinic site was accessible by driving or taking a bus. Free parking was ample and no security personnel were regularly posted.

At each clinic site there was a long reception desk with two to three staff, designated patient waiting areas, lavatories, patient processing rooms, multiple examination rooms, hearing and sight examination areas, a limited laboratory to process specimens, file rooms, storage rooms, staff offices, and open work areas as well as private rooms for staff's and physicians' tasks. The clinics were populated with nurses, physicians, residents, nurse practitioners, physician's assistants, social workers, other medical specialists (e.g., general practitioners, internists, pediatricians, and pulmonologists). These health care providers used designated areas to consult amongst themselves as well as operate the multiple computer terminals available to complete tasks and reports.

The city clinic was on the third floor of a six floor medical building on the hospital campus. The large waiting room and hallways walls were painted bright yellow. Assorted yellow, white, and black floor tiles enticed young children to hop from tile-to-tile of the same color. Exam rooms were small yet comfortable. Their walls were painted light grey. They were well lit and many even had large windows. The exam rooms were

labeled “A” through “Z” for easy identification. There was no artwork on the walls though a few colorful health posters were posted.

The suburban clinic was located within a group of mixed-usage buildings that included other specialty medical offices, retail businesses, restaurants, a CVS, a bank, and townhouses. The clinic occupied a one-story wing of one of the large, red-brick buildings. An aviation theme was portrayed throughout the suburban clinic with colorfully painted murals, hanging models of planes and hot-air balloons, and whimsical plaques adorning the light grey painted walls. The three large waiting areas in the suburban clinic had ceiling-to-floor windows and carpeted floors.

The clinics were maintained well. There were plenty of chairs for patients and families in the waiting areas adjacent to the reception desk. Public lavatories were clearly marked, accessible, and clean. Waiting areas in both clinic sites were equipped with a clearly visible flat-screened television monitor suspended from the highest point on a centrally located wall. The office manager maintained control of the remote control; Cartoon Network was the preferred station. Adult-directed health literature concerning children’s health was available in racks on waiting room walls and hallways. That literature covered topics such as nutrition, nursing, safety, vaccination schedules, psychological and behavioral issues. No toys or children’s books were available in any of the waiting areas or exam rooms. Yet most all of the young patients at the city clinic site would be seen leaving with a brand new, age-appropriate book; the site’s social worker ran a reading program and distributed donated Scholastic books to the children. Patients at both clinic sites were offered a choice of two stickers for good behavior at the end of their visit.

Usually, this investigator was at the city clinic site on Mondays and Thursdays and at the suburban clinic site on Tuesdays and Fridays. Physicians had no office hours on Wednesdays. Most days the data collection occurred between 9:30 am and 5 pm. The particular physicians participating in health care during data collection depended on their work schedule. Physicians had regularly scheduled weekly hours at both clinic sites. They were normally scheduled to see eight adolescents each day. Many patients did not appear for their appointment; perhaps two to five patients a day missed their health care visits. The reasons for missed appointments were unknown, though many residents blamed the weather –sunny days as well as rain or snowstorms – for missed appointments.

During the data collection, the hospital with which this adolescent medical practice was associated underwent a government mandated change from written to electronic patient files. Beginning August 2010, computer terminals were installed in each exam and processing room for health care providers' electronic record-keeping requirements. This intervention increased patients' waiting-room time, prolonged clinic interviews, and posed logistic obstacles as well as ethical hurdles for health care providers. For example, the computer monitor was secured on the desk so the physician had to negotiate facing the patient while consulting the chart on the immovable computer screen. Part of the ethical dilemma for physicians was how to ensure privacy when anyone in the room could view confidential information on the computer monitor.

Participants

The participants in the study were adolescents presenting at this adolescent medical clinic for ill-visits and well-visits, their parents, and the health providers. There

were three female survey participants whose medical visit was specific for the intention of receiving a scheduled HPV vaccination. The sample enrolled in this study reflected the population served by this adolescent medical practice. Though the adolescents seen at the urban clinic site were more likely to reside in that city that was not always the case; patients were inclined to accept available appointments regardless of site.

Survey participants. In this geographical region of the country, only the urban area was called a city, whereas all other areas were colloquially designated as towns or townships. Indeed many of the adolescents were puzzled by the wording of the survey question asking what city they lived in (see Appendix A). Adolescents were likely to say that they did not live in a ‘city’ and some asked their parent where they lived. In total, survey participants resided in the city and 52 different suburban towns. Adolescents’ residence information was categorized into 49% city and 51% suburban town groups (see Table 1).

Enrollment was solely based on participants’ presence at the health clinics and each individual’s decision to participate. A power calculation was computed to determine the sample size needed to complete the HPV knowledge questionnaire in order to avoid the probability of a Type II error (Fleiss, Levin & Paik, 2003; Newcomb 1998). Daley and colleagues (2008) had devised and validated this HPV knowledge questionnaire with adult women but provided no information to differentiate participants as adolescents or parents. It was determined that a sample size of 168 adolescent-parent pairs would be adequately representative to ensure that survey results would reveal differences if present in the adolescent population (see Appendix C). All parents and adolescents consented or assented to participate per IRB requirements.

Physicians in this adolescent medicine practice routinely treated patients aged 11 through 21 years of age. The older adolescents aged 18 through 21 years old were legally considered responsible for their own health care decisions. Yet in practice, the older adolescent patients consulted with their parents in order to make health care decisions. While some older adolescents came to their health care visit alone, most were accompanied by their parent or legal guardian. As this information became clear, older adolescents ($n = 48$) were included in the study in order to correctly reflect this adolescent medical practice.

Tables 1 and 2 summarize survey participants' sociodemographic characteristics. The term *adolescent* is used throughout the study to refer to the participants aged 11 through 21 years. Adolescents' mean age was 15.51 years ($SD = 2.24$; $Mdn = 15$ years).⁶ For all intents and purposes, the adult accompanying the adolescent acted as would the parent and the physician addressed the accompanying adults as such. The term *parent* is used throughout to refer to the accompanying adult participants regardless whether that adult was a parent or guardian. Parents' mean age was 41.95 years ($SD = 8.83$; $Mdn = 42$ years). Take note that only 17 of the 188 accompanying parents were males, and all were the father, step-father, or legal guardian of the adolescent.⁷

Table 1 shows survey participants' race. Native American was the only 'other' race written in by participants on their enrollment sheet. There were with two female adolescents and one parent who indicated their race as Native American. Because there was a particularly low representation of Native Americans ($n=3$; less than 1%) and Asians ($n=6$; about 3%) in this study, for analysis purposes these participants were combined as category labeled *other race*.

Six of the 237 adolescents enrolled in the survey were not born in the United States. One male adolescent was born in the Dominican Republic. One of each of the five foreign-born female adolescents was born in Bulgaria, the Dominican Republic, Iraq, Romania, and South Korea.

Parents in the survey phase of the study reflected a slightly more diverse group of birth countries than their children. One hundred and fifty-three of the 188 survey parents were born in the United States and 16 parents were born in Puerto Rico. The other 21 parents were born in one of the following countries: Bulgaria, Denmark, Dominican Republic, Ecuador, Egypt, England, Ghana, Iraq, Liberia, Mexico, Monrovia, Panama, Philippines, Russia, South Korea, Trinidad, Turkey, or Vietnam.

Parents reported their child's insurance coverage. The specific insurer was not reported for about 21% of the adolescents. Medicaid and private insurance almost equally accounted for the type of insurance coverage of survey participants (see Table 1). Some parents were confused because the exact name of their insurance company was not listed. They were instructed to write in their insurance company's name which were all later identified as private HMO's insurance coverage.

Table 2 shows survey participants' education. The average grade level completed by survey adolescents was ninth grade (M grade = 9.31; Mdn = grade 10). Table 2 also shows that, on the average, survey parents were high school graduates with some post-secondary education such as a year of college or trade school. There were three parents who did not attend high school and seventeen who did not graduate from high school. Forty-four parents had college degrees and another twenty-two parents had a Masters' degree or higher.

A total of 185 adolescent-and-parent pairs (17 parents enrolled with two children), 20 individual parents, and 52 individual adolescents completed the questionnaire. There were several reasons for non-paired, individual enrollment. Individual adolescents or parents were included even if their accompanying parent or adolescent chose not to participate. More often, siblings, aunts, and other family members were at hand and volunteered to complete the questionnaire; each was enrolled if the proper IRB consent and assent processes were able to be followed.

Survey enrollment was rarely declined. Three of the parents explained that they were too fatigued from their workday to participate. Two parents agreed to participate but then refused to sign the consent form and have their personal information – specifically their name – on record; neither was enrolled. Three parents would not allow their eligible 11 year old child to participate. One 16 year old adolescent declined to participate because he did not want to take a ‘test’.

Participants in observation encounters. There were 30 total observations of adolescent-physician or adolescent-physician-parent encounters. These included observations of 26 adolescent-physician-parent sets and four unaccompanied, older adolescent males and with physicians. Table 3 describes the participants involved in these encounters. One mother and son set had completed questionnaires about three months prior to participating in this observation phase. Three mothers had also filled out the questionnaire several months prior to participating in this observation phase, although their child that was observed had not completed a questionnaire. Two additional adolescent and parent sets completed questionnaires at the conclusion of being observed with the physician.

There were no refusals for adolescent-physician and adolescent-physician-parent observations. Although in three instances the lead physician precluded enrolling a patient because the adolescent was dealing with a critical issue.⁸ One attrition occurred midway through observing the adolescent-physician-parent encounter. This parent decided not to continue participating in the study when, the physician requested to speak alone with the adolescent.⁹ This parent terminated further participation. It should also be noted that this was one of the work-fatigued parents who had declined to participate in the survey phase.

Health-care providers. A number of health care providers were active contributors to the research study during adolescent-physician and adolescent-physician-parent encounters (see Table 4). About a month into the research project, the female physician with whom this research was arranged, added a male partner to her practice. Both were board-certified pediatric and adolescent medical physicians; each had practiced medicine for over 30 years.

Because this adolescent medical practice was academically affiliated, these two lead physicians actively taught and mentored a number of medical residents and student nurse practitioners on a rotating basis. When residents or students had their rotation in adolescent medical care, the lead physicians required them to conduct the health care visit. The lead physician would introduce everybody and would ask the parent and the adolescent if it would be permissible for the resident physician or nurse practitioner student to perform the interview and examination. During the entire course of this research project only one parent objected to a resident rather than the lead physician providing the medical care (i.e., the parent described above who terminated this investigator's observations).

The health care providers in this study included the two board-certified pediatric and adolescent medical physicians, as well as three third-year resident physicians (two females and one male) and one female nurse practitioner (NP) with 17 years of experience as a school nurse (see Table 4 for descriptions). For the purposes of this research project, all health care providers are referred to interchangeably as *physicians* or *providers* regardless of their medical designation. This convention was adopted because they all provided the same HPV information and health care to the study participants. All providers consented to be observed and audio-recorded per IRB requirements.

Phase One: The Survey

The survey phase commenced in May 2010. All field work and data collection was completed by June, 2011.

The Questionnaire. Medical decision-making assumes a knowledge base of the health issue and a level of maturity involving the individual's ability to choose, plan, realize goals, and self-govern. This research phase utilized a three-page questionnaire to quantify health knowledge and maturity, as well as demographic information. Multiple items on the questionnaire asked about HPV, adolescent autonomy, and health behaviors (Appendix A). Each adolescent and parent completed the questionnaire individually.

The first section of the questionnaire was a specific HPV knowledge scale previously validated with adult females and males (Daley, et al, 2008; Daley, et al, 2010). Daley and colleagues developed this scale to assess an individual's of HPV.¹⁰ Four knowledge areas were identified: the consequences of HPV infections, the causes of HPV infections, the potential control of HPV, and the identity of HPV infections (e.g., symptoms). Table 5 presents the 22 specific HPV knowledge statements (Daley, et al,

2008).¹¹ These items could be answered correctly by a lay person with the depth of knowledge that could be obtained from reading several media articles on the topic or who had discussed the vaccine for several minutes with a physician. Participants responded to either of three choices for each item: true, false, or not sure.

The second section of the questionnaire probed participants' perceptions of adolescent maturity concerning the ability to choose, plan, realize goals, and self-govern. A series of forced-response questions sought information about adolescents' autonomy, possible health actions they might take given circumstances, and their familiarity with their family's health (see Appendix A for the actual items). The autonomy items were adapted from a scale previously validated with adolescents (Noom, Deckovic, & Meeus, 2001).¹² Noom and colleagues had adolescents respond to how well certain statements described them. Adolescents' responses were created into a score to indicate adolescent autonomy.

Because time and item consistency were constraints on this survey, two adaptations to Noom's autonomy scale were made. First, to maintain consistency throughout the survey participants continued to choose among three response choices— true, false, or not sure – for attitudinal autonomy items (instead of the original autonomy scale's 5-point Likert responses of agreement and disagreement).

Second, in effort to control the length of time needed to complete this questionnaire, a sub-portion of the original autonomy scale was utilized. That original scale contained items soliciting self-reports of adolescents' attitudinal, emotional, and functional autonomy. Noom and colleagues defined *attitudinal autonomy*, as “the ability to specify several options, to make a decision, and to define a goal,” *emotional autonomy*

as “a feeling of confidence in one’s own choices and goals,” and *functional autonomy*, as “the ability to develop a strategy to achieve one’s goal” (pp 578-581).¹³ As defined, attitudinal autonomy was the most conceptually close to the autonomy behaviors involved in health decision-making and those six items were chosen.

There was no specific research guiding the choice or wording of questions about family health awareness or situational health actions participants might take. These items were included at the request of one of the board-certified pediatric and adolescent medical physicians.

The questionnaire’s third section consisted of self-report demographic questions – birth date, gender, residence, country of birth, race or ethnicity, and educational attainment. In this section parents indicated type of insurance coverage.

The HPV vaccine is recommended in a series of three shots over a six month period. At the time of enrollment, participants would volunteer their HPV vaccination status. Whether the adolescent had received one, two or three HPV shots depended on time of their enrollment in this study and specific vaccination dosage was not pursued. Thus in this study, vaccination status for each adolescent was reported as received or declined HPV vaccination. Vaccination acceptance was high in the sample of adolescents participating in the survey phase; 67% of all survey adolescents received an HPV vaccination. Specifically, 76% of adolescent females and 44% of the adolescent males received one or more HPV vaccinations. As previously discussed (Chapter 2) the CDC reported the 2010 national HPV vaccination average for females aged 11 thru 17 years was reported as 49% and in 2011 their HPV vaccination average was 53% (<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6033a1.htm> accessed 03-12-2012).

The rate of HPV vaccination acceptance of the comparable group of female adolescents in this study was much higher. Of the 95 female adolescents aged 11 through 17 years old in this study, 73% percent had received one or more HPV shots. What factors differentiate HPV vaccination acceptance between the national sample and those in this study remain to be determined.

Survey protocol. Adolescents and their accompanying parents presenting at this academically affiliated pediatric and adolescent practice's clinics were invited to participate in research described as a study of what people know about the human papillomavirus. Potential participants were approached after they checked in for their appointment with the receptionist. This investigator introduced herself to the parent and child as conducting a research study with the adolescent's physician. First the parent was invited to participate in the research study. If the parent agreed to participate, then the adolescent was to participate. When parents and adolescents indicated that they were interested in participating in the study, the informed consent and assent processes were conducted. Then the questionnaire was distributed. There were times when office visit took precedence and intervened between the consent/assent process and the participants' completing the questionnaires. Thus, the parent might complete the questionnaire in the waiting room while the physician examined their child, and the adolescent might complete the questionnaire in the examination room while waiting for the physician to conclude some paperwork.

Debriefing occurred when participants completed their questionnaires. This is protocol in order to ensure that each participant voluntarily engaged in the research project, understood their role, and did not misinterpret any of the survey items.

Additionally, at the recommendation of one of the resident physicians who anticipated specific HPV questions, an information sheet was given to each participant at the conclusion of their participation in the study (See Appendix B).

Survey Analyses. Survey data was tallied and coded for analysis using Microsoft Excel. SAS 9.3 was used both for describing the survey data and for statistical analyses of the survey hypotheses. Chi Squares and Student's *t*'s were used to probe for differences among and influences on adolescent vaccination status. Logistic regression and quadratic regression analyses were used to identify variables influencing participants' questionnaire responses.

Survey Conversations: A Bridge

The design of this research project involved two phases: the quantitative survey phase and the qualitative observation phase. It immediately became clear that research progresses on its own accord in the field. A complication arose. The survey participants discussed the questionnaire items and how to respond to them. This investigator intervened and asked participants to complete the questionnaire independently and save their comments and questions until after they finished. Extensive conversation ensued after participants completed the survey.

It was challenging to have conversing participants during data collection. The first challenge was to convey to participants that only their physician could give them medical information and advice. Several of the participants would ask for advice and this investigator was not in a position to dispense health care advice. The second challenge arose from attempting to impose a particular research approach, which is successful in controlled situations (i.e., the laboratory), to collecting data in lived situations (i.e., the

field). An experimental psychology approach trains investigators to stay true to a prepared script because any deviations added uncontrollable variables that would bias the survey results and render them invalid. This approach is successful in controlled, laboratory settings. Conducting a survey in this pediatric clinic induced participant conversations (i.e., uncontrollable variables) outside of the investigator's script clearly demonstrating that the experimental approach was inappropriate for this setting.

Theoretically survey conversations appear to have compromised participants' questionnaire responses. Practically this investigator's swift intervention successfully postponed adolescents and parents from discussing the questionnaire items until after they completed and submitted their surveys.

Participants' scripts. Participants understood that the purpose of this survey was to accumulate information about what people knew and understood about HPV. Participants were so accommodating that in order to achieve this research goal they commented on individual questionnaire items and asked for specific information. It seemed that they adopted a common script. Their script was to comment, question, and converse in order to figure out how to answer the items and show how much they knew about HPV and issues. Thus, this investigator's presence and instructions had the unanticipated effect of inducing participants to question and converse during and after they completed the survey.

During these survey conversations participants volunteered their thoughts, views, and personal stories. Many were directly related to survey items and contributed to understanding what participants knew and believed about HPV issues. Many were constructive to the research objective of informing adolescent participation and decision-

making concerning HPV and vaccination. Thus, these survey conversations materialized as unintended although welcomed phase of this research project. Rather than invalidating survey results, these survey conversations served as a bridge between survey analyses and encounter analyses. Analyses of survey conversations provided a means to guide analyses of participant-physician encounters.

Survey Conversations Analyses. Because none of these participant-investigator exchanges were solicited or tape-recorded investigator field notes were necessary. At the first opportunity, these survey conversations were written down. Conversations were recollected, summarized, described with details of participants' statements and interactions, and annotated with investigator comments. Context was added by describing settings, body language, voice inflections, interaction patterns between adolescent and parent and between participant and investigator, and so forth.¹⁴

Analysis of survey conversations was ongoing during survey data collection and conversation summarization.¹⁵ First, a running list of ideas, or codes, was formed as each conversation summary was reviewed. For example:

- Parent would not let child participate
- Parent discussed HPV vaccination with friend
- Adolescent spoke only to parent and not to investigator
- Adolescent asked investigator "What's HPV mean?"
- Adolescent hates shots

Second, previous research findings were used to examine the survey conversations. For example, multiple studies reported that HPV knowledge was a factor for parents' HPV

vaccination decision. Thus survey conversations were examined for evidence of HPV knowledge and indications that knowledge was a factor in vaccination decision-making.

New survey conversations occurred and were summarized. Summaries were compared and contrasted and codes were revised. For example, the above codes became the following:

- Parents' views of their child connected to child's age
- Parents seeking HPV information
- Adolescent connected HPV with HIV – trying to understand the issues
- Adolescent feared shot

This continuous comparison and coding of survey conversations generated four tentative categories to describe influences of adolescents' vaccination status:

1. Sociodemographic classifications of participants
2. Participants' HPV knowledge
3. Adolescent and parent relationships
4. Perceptions of adolescent autonomy

The codes and tentative categories were used to guide analyses observations during the participant-physician encounters phase (see the following section in this chapter).

Phase Two: Participant-physician Encounters

The observation of participant-physician encounters phase started in February 2011. All field work and data collection was completed by June, 2011. The intent was to enroll adolescents and their parents between the ages of 11 to 21 years old and observe their encounters with the physician.

Observation protocol. A protocol similar to that used to enroll survey participants was used to enroll participants in participant-physician encounters. Parents and adolescents in the clinic waiting room were invited to participate in a research study jointly conducted by this investigator and their physician. The research was presented as a study of how physicians, adolescents, and parents communicate during a health care visit. Most often the adolescent was the first to agree to be observed and recorded. Though a few parents showed surprised at their child's interest in participating (i.e., by voice inflection and facial expression), they also consented to be observed and recorded. Then the informed consent and assent processes were conducted. No invitee declined enrollment in this phase of the research project. In all, there were 30 adolescent-physician or adolescent-physician-parent encounters during clinic visits. As noted in a previously, one parent opted out with her child midway through the encounter.

Observation of participant-physician encounters had no set time length. Sometimes the entire clinic interview was observed. Other times the observation entailed only of the review and discussion of the adolescent's vaccination history. This investigator's presence depended upon the individual physician's preference as well as her assessment of the particular adolescent's visit. In all observations of participant-physician encounters the issue of HPV and vaccination was discussed.

The physician in the room added a different dimension to the previous HPV and vaccination exchanges and behaviors witnessed during survey conversations. The role of observer relegated this investigator peripheral to the conversations and thus facilitated observations. Most adolescents only paid attention to their mother and the physician.¹⁶ Parents were more cognizant of others present in the room as they would glance around

the exam room during their conversations with the physician.

Each health care visit proceeded as standard for this adolescent practice.

Adolescent health care visits were scheduled as a 20 minute follow-up or ill-visit or a 45 minute complete health check-up or well-visit. The length of each session was determined by the participants in the health care meeting. It was not unusual for the physician to spend an hour or more with patients and family members regardless of the whether the visit was scheduled for 20 minutes or 45 minutes. The actual duration of an individual adolescent's involvement was determined by the individual adolescent's specific health care issues and their sequelae. The only deviation from usual health care procedures was this investigator's presence and audio-taping. The participation of particular attending physicians was determined by their individual work schedules.

Participant-physician encounters were tape recorded and this investigator wrote concurrent notes. Investigator field notes included observations and descriptions of adolescents, parents, and physicians throughout the health care visit. The audio-recordings were transcribed by this investigator and paired with related field notes. These transcriptions and observations revealed knowledge, understanding, attitudes, and beliefs of adolescents, parents, and physicians about HPV, what they see as issues involved in the preventing HPV infections, and how they wanted to participate in health care directed toward HPV.

Encounter Analyses. Written observations and transcribed audio-recordings comprised the data for the qualitative phase of this research project. Qualitative analysis was ongoing during audio-tape transcription, field note reviewing, rereading, and reassessing. The objective was to interrogate what adolescents said and did during health

consultations, specifically during HPV and vaccination consultations. The goal of investigator observations was to find indicators as to how adolescents participated in, behaved with, and reacted to the conversations, their parent, and the physician. This investigator observed and noted indices of body language, facial, glances, gestures, pragmatics, and off-hand comments. As the course of the health visit preceded these indices exposed adolescent-parent relationships.

Previous research, the codes and tentative categories from survey conversation analyses, and factors identified from survey analyses that had significantly contributed to adolescents' vaccination status were used to examine the survey conversations. For example, previous research indicated that HPV knowledge was a factor in vaccination decision. Analyses of the surveys found that HPV knowledge was not significantly related to adolescent vaccination. Thus the codes concerning HPV knowledge were guides for examining participant-physician encounters. These two codes

- Parents' spoke about HPV
- Adolescent asked specific questions about HPV – what is it?

produced these two questions asked of the participant -physician encounters:

- What did parents say about HPV?
- What did adolescents say about HPV?

Answers found in the participant-physician encounters gave rise to other questions:

- Did adolescents speak?
 - To whom?
 - Were adolescents asking questions?
- Who made the decision about HPV vaccination?

Codes were revised and re-applied to survey conversations

- Parents' responses to HPV information from physician
- Adolescent heard of HPV but knows nothing about it

Comparisons and contrasts of coded statements and observations occurred within and between survey conversations and participant-physician encounters. In this manner there was a dialogue between survey conversations and encounter observations. When no new codes and categories emerged, observations of participant-physician encounters ended.

Chapter 4: Knowledge, Attitudes, and Health Behaviors: A Reckoning

Adolescents' HPV vaccination status is the health behavior outcome of interest.¹⁷

Adolescents and their parents completed separate questionnaires during their health care visit to their physician's office that focused on HPV knowledge, sociodemographic classifications, and behaviors that might influence their HPV vaccination decision. This chapter presents results from analyses of that survey. The analyses explored theoretical relations between the participants' HPV understanding, autonomy ratings, sociodemographic classifications, and whether adolescents received or declined HPV vaccination (see chapter 2 for specific hypotheses).

Adolescents' Vaccination Status

A significantly greater number of the 237 adolescents surveyed at this medical clinic received ($n=158$) an HPV vaccination than declined ($n=79$) an HPV vaccination ($t = 21.73$; $df=236$; $p < 0.0001$). There were 167 female and 70 male adolescents participating in this survey. A greater number of female adolescents ($n = 127$) were vaccinated than were male adolescents ($n = 31$). Similar numbers of male adolescent received vaccination ($n = 39$) and declined vaccination ($n = 31$) though more female adolescents were vaccinated ($n = 127$) than were not vaccinated ($n = 40$).

Adolescents' HPV Knowledge and Their Vaccination Status

The HPV Knowledge Scale items on the survey assessed adolescents' knowledge and understanding of the identity, causes, consequences, and controls of HPV.¹⁸ What adolescents know and understand about HPV is represented by their HPV knowledge scores summarized in Table 5. The composite HPV knowledge score satisfied the needs for operationalizing HPV knowledge for adolescents involved in the survey.¹⁹ Table 6

arranges adolescents' HPV knowledge scores with respect to various sociodemographic groupings including age, gender, race and residence.

Several factors were considered as influencing HPV knowledge scores.

Regression analyses with age, gender, and an age-gender interaction showed that age and gender significantly predicted HPV knowledge scores (see Table 7). Older adolescents and older female adolescents had higher HPV knowledge scores. Table 8 shows the results of regression analyses with race (Hispanic compared to White adolescents; Black compared to White adolescents; other ethnicities compared to White adolescents), residence (city compared to suburbs), and parents' education added to age and gender as predictors for HPV knowledge was significant. Age remained a significant predictor of HPV knowledge scores while gender became a marginal predictor of HPV knowledge (female adolescents had more knowledge than male adolescents). In addition Hispanic and White race showed to be marginally predictive in that White adolescents compared to Hispanic adolescents had higher HPV knowledge scores.

Figure 1 shows adolescents' HPV knowledge with respect to their age. It appears that HPV knowledge scores dropped sharply from ages 11 to 12 years, then steadily increased until age 16 years and levelling off. This apparent trend may be spurious, attributable to statistical error as well as biases by small sample sizes at specific ages. Yet as a group, adolescents 18 years and older had a mean correct HPV knowledge score of 52% and adolescents under 18 years of age had a 39% mean correct HPV knowledge score (Table 6).

Female adolescents' mean HPV knowledge score was 45% correct; male adolescents' mean HPV knowledge score of 34% correct (see Table 6). But comparisons

of HPV knowledge between female and male adolescents are tenuous because there were a larger number of female adolescents than male adolescents involved as survey participants.

Notably, there was no significant difference in HPV knowledge scores between adolescents who received HPV vaccination and those who declined HPV vaccination (see Table 9). There was no significant difference in the HPV knowledge scores of female ‘adolescents who received and female adolescents who declined HPV vaccination; nor was there a significant difference in the HPV knowledge scores of male adolescents who received and male adolescents who declined HPV vaccination (see Figure 2).

Adolescents’ Autonomy and Health Behaviors and Their Vaccination Status

The HPV vaccination decision might be related to how adolescents perceive themselves as decision-makers determining and managing their behaviors in general. The several items on the questionnaire intended to assess adolescents’ self-management were highly related and combined into an operationally defined autonomy score (see Appendix 8 for Cronbach alphas).²⁰ Thus the autonomy score incorporated self-reports of adolescents’ ability for deciding and choosing as well as thinking about what actions to take and doubting actions taken.

Correlational analyses examined possible relationships between adolescent autonomy scores and several sociodemographic classifications (see Table 10). Adolescents’ age and autonomy scores were significantly correlated. Figure 3 shows participants’ autonomy scores with respect to their age. Autonomy scores appear to rise sharply from ages 11 to 13 years and then level off. This apparent trend may be specious, attributable to statistical error as well as biases by small sample sizes at specific ages.

Adolescents' age, education, and autonomy scores are significantly correlated (see Table 10). Notably, logistic analyses showed that adolescents who declined and received HPV vaccination did not significantly differ in their autonomy scores (see Table 9).

Analysis also revealed a marginally significant relationship between adolescents' autonomy scores and their HPV knowledge scores ($r=0.1159$; $p=0.0747$). Furthermore, age, education and HPV knowledge were significantly related. Thus it is possible that these correlations result as a corollary to the participants' age because older participants are in higher grade levels (have more education), have higher HPV knowledge scores, and have higher autonomy scores than younger adolescents.

Adolescents responded to three survey items concerning their health behaviors (see Table 11 and Appendix A):

1. I trust the doctor with my personal information [item1 survey page 2]
2. I will decide if I will get the HPV vaccination [item 6survey page 2]
3. I am going to get a vaccination shot for HPV [item 15 survey page 2]

Over half of the adolescents (59%) responded that they would make the decision about getting the HPV vaccination and intended to get the HPV vaccination (53%) while 89% of the adolescents said that they trusted their physician (see Table 11). These three survey items were examined as possible health behaviors that related to adolescents' autonomy. Table 10 shows that adolescent autonomy scores were significantly correlated with survey items I TRUST (i.e., Trust) and I WILL DECIDE (i.e., Decision-maker). Table 10 also shows that Decision-maker was significantly correlated with age, autonomy, Trust, and I AM GOING TO (i.e., Intent) and participants' age was found marginally correlated with Intent and Trust. Furthermore, adolescents' vaccination status was significantly

correlated to their being older, having more education, intending to receive an HPV vaccination, as well as the adolescent reporting to decide about HPV vaccination (see Table 10).

Parent Influences on HPV Vaccination

Parents who took the survey responded to the same HPV knowledge items and the same autonomy items given to their children. Parents' survey responses were examined with reference to their child's age and gender and how they might be related to adolescents' HPV vaccination status.

Parents' HPV knowledge. Parents' HPV knowledge might affect their children's HPV vaccination status. What parents know and understand about HPV is represented by their HPV knowledge scores summarized in Tables 6; mean percent correct responses are shown. Correlational analyses, involving all parents' responses, showed significant response correspondence among the 22 HPV survey item responses so as to conduct all subsequent analyses using the composite score of all 22 survey items (see Appendix 8 for Cronbach alphas). Parents' HPV knowledge scores were significantly correlated with their children's HPV knowledge scores ($r = 0.30145$; $p < 0.0001$).

Parents' HPV knowledge scores were not significantly different in relation to their child's age or gender. Figure 2 shows a trend of parent HPV knowledge scores increasing from their child's age of 11 years up to 14 years, and then leveling with respect to their child's age thereafter. This apparent trend may be specious, attributable to statistical error as well as biases by small sample sizes at specific ages.

Regression analyses examined multiple predictors of parents' HPV knowledge scores (see Table 12). Three sociodemographic characteristics significantly predicted

parents' HPV knowledge scores: adolescent's Hispanic race, insurance type, and parents' education were significant predictors, whereas adolescents' age, gender, Black and other races, and adolescents' residence were not significant. Parents of White adolescents as compared to parents of Hispanic adolescents, parents that have private insurance for their child, and parents with more education had significantly higher HPV knowledge scores.

Notably, parents' HPV knowledge scores were not significantly related to whether their child declined or received an HPV vaccination (see Table 9).

Parents' perceptions of their child's autonomy. The HPV vaccination decision might be related to parents' perceptions of their children's decision-making behaviors. The several items on the questionnaire intended for parents to rate their child's self-management were highly related and combined into an operationally defined parent autonomy score (see Appendix 8 for Cronbach alphas).²¹ Thus parents' autonomy scores incorporated ratings of their children's ability for deciding and choosing, as well as thinking about what actions to take and doubting actions they have taken.

Correlational analyses showed that parents' perception of their child's autonomy was not related to their child's age, gender, education, or who will decide about HPV vaccination (see Table 10). There was a marginally significant relationship between adolescents' trust of their physician and parents' judgments of their child's autonomy. The uniformity of parents' autonomy scores across their child's age is shown in Figure 3. Parents' perception of their child's autonomy was significantly related to their child's self-judgments of autonomy. Inspection of Figure 3 suggests that a difference between parents' and adolescents' autonomy scores between parents and their 11 and 12 year-olds. Because of small sample sizes at these ages this interpretation is questionable.

Notably, there was no significant difference in parents' autonomy scores with respect to their child's HPV vaccination status (see Table 9).

The Decision-maker

Parents responded to the health behavior item: *I will decide if my child will get the HPV vaccination*. Over two-thirds of the parents (80%) said that they would make the decision about getting the HPV vaccination (see Table 11). Regression analysis showed that their child's age had a significant effect on parents' responses to being the decision-maker about HPV vaccination and parents' HPV knowledge scores were approaching significance (see Table 13). Thus parents of younger children were more likely to assert they were HPV vaccination decision-maker than were parents of older children. There is a weak suggestion that parents with higher HPV scores, presumably having more understanding of the HPV issues, will make the HPV vaccination decision. Further investigation of this relationship is warranted.

Juxtaposing parents' and adolescents' responses to this decision-maker item reveals an interesting phenomenon. Both parents and their children considered themselves to be HPV vaccination decision-makers. Notably, responding regarding the intention to be the decision-maker about HPV vaccination that would be offered was not related to HPV vaccination status (see Table 9).

Other Influences on HPV Vaccination

Several other sociodemographic characteristics were examined as influences on adolescents' vaccination status (see Table 14). The regression analysis showed adolescents' education, race, report of a previously bad reaction to a vaccination, parents' education, and adolescents' insurance type were not predictive of getting an

HPV vaccination. Adolescents' age remained a significant predictor of their HPV vaccination status (i.e., as adolescents age they were more likely to be HPV vaccinated). Curiously, adolescents' residence was a significant predictor. Though at this juncture, it is not clear why adolescents in the city were less likely to be vaccinated than those in the suburbs. Further research is needed.

Reckoning Survey Findings

A combined total of 425 adolescents and parents individually completed surveys. Statistical analyses revealed a few significant and one marginally significant factor that influenced HPV knowledge, assessments of adolescents' autonomy, and HPV vaccination decisions. Adolescent's gender, age, and residence were significant predictors of their vaccination status.

Survey results address portions of this study's research hypotheses.²² The hypothesis (H1) concerning adolescents' participation cannot be determined from the survey analyses. Both adolescents and parents reported that they would make vaccination decisions.

Analyses of survey responses provided intriguing findings regarding the hypothesis (H2) that socioeconomic status influences how adolescents participate in HPV vaccination decisions. Parents' education, usually considered a proxy for socioeconomic status, was not significantly related to their child's HPV vaccination status. This also refutes the hypothesis (H3) that highly educated parents will accept HPV vaccination for their adolescents was not substantiated. Parents' education was not significantly related to their child's HPV vaccination status. Though there was substantially no difference in parents' education when comparing those residing in the city and with those residing in

the suburbs (see Table 2), there were a greater number of parents with a high level of education in the affluent suburbs (see Table 2) and a greater number of adolescents residing in the suburbs were vaccinated than those residing in the city. At this juncture there is no data to disentangle parents' education and their adolescents' HPV vaccination status. What particular differences exist between city and suburban residents that affect their HPV vaccination status is speculative at this juncture (this issue is explored in a later section of this chapter).

The hypothesis (H4) that HPV knowledge and understanding leads to accepting HPV vaccination was refuted. Neither adolescents' nor parents' HPV knowledge scores were significantly related to adolescents' HPV vaccination status.

Analyses of survey responses did find HPV knowledge differences. Adolescents averaged 40% correct HPV knowledge responses while their parents averaged 57% correct HPV knowledge responses. Adolescents averaged 51% correct responses to the question HPV is an STI. Older adolescents had higher HPV knowledge scores than younger adolescents. Female adolescents had higher HPV knowledge scores than male adolescents. Hispanic adolescents and their parents had higher HPV knowledge scores than White adolescents and their parents. Parents with more education and whose adolescents are privately insured had higher HPV knowledge scores than those with less education and Medicaid insurance.

The hypothesis (H5) that adolescents' autonomy judgments influence adolescent participation was refuted. Neither adolescents' nor parents' autonomy judgment scores were significantly related to adolescents' HPV vaccination status.

Analyses of survey responses found autonomy judgment differences.

Adolescents' perception of their autonomy increased with age, conversely their age was not related to their parents' perception of their autonomy. These analyses of autonomy scores show that decision-making is unrelated to HPV vaccination status because parents and adolescents autonomy scores were not significantly correlated though not significantly related to HPV vaccination status; thus there is no support for the hypothesis (H5) that adolescents judged high in autonomy would receive HPV vaccinations. Class distinctions of adolescent-parent decision making cannot be deciphered from the survey analyses.

Some of these statistical findings need to be considered cautiously. For example, gender and age differences in adolescents' HPV vaccination status may be a function of time of study enrollment. A significantly larger number of female adolescents than male adolescents received HPV vaccination than declined vaccination. This may be a consequence of government policy. Female HPV vaccination was recommended in 2005 and private insurance companies as well as Medicaid paid for their vaccinations. Over four years lapsed before male adolescent HPV vaccination received the same recommendation and insurance coverage in October 2009. Thus male adolescents did not have the same vaccination opportunities as female adolescents prior to enrolling in this study.

It is difficult to interpret the adolescents' intention to receive HPV vaccination. Intention refers to some future action and not a current situation. Yet it may be that adolescents interpreted the survey item concerning their intention to receive the HPV shot as whether they actually had received or had not received the HPV shot. The results

showed that adolescents who responded *true* to the Intent item (112/237) had actually received the HPV vaccination (103/126), whereas of the adolescents who responded *false* to the Intent item (16/237), the same number of adolescents actually received (8/16) and declined (8/16) the HPV vaccination.

The most striking and important result emerging from the statistical analysis of these participants' survey responses is that HPV knowledge scores did not predict whether adolescents received or declined HPV vaccination. HPV knowledge was assumed to be the necessary foundation for health care decision-making. Age was not hypothesized to be an influencing factor for HPV vaccination. Yet age was consistently a significant predictor of HPV knowledge scores, autonomy judgments, and HPV vaccination status. Further examination of how age influences HPV vaccination decision-making is warranted.

Chapter 5: Survey Conversations

Adolescents and their parents at their physician's office were surveyed to quantify their knowledge, understanding, and views regarding HPV and vaccination.

Inadvertently, this particular survey protocol added another aspect to his research project. Reading the items evoked extemporaneous conversations. Adolescents and parents conversed, asked questions, made comments, offered opinions, and told stories. This chapter examines survey conversations as a window into adolescents' HPV knowledge, vaccination attitudes, and health care participation. Parents' survey conversations are also considered in this chapter because parents' knowledge, beliefs, and attitudes regarding HPV and vaccination affect adolescents' participation.

There were two types of survey conversations: survey exchanges and post-survey conversations. Survey exchanges refer to comments and questions participants made in the process of responding to the questionnaire. When these occurred participants were told that their questions would be answered after they completed the questionnaire. Because all participants complied the integrity of their survey responses was retained. Post-survey conversations derived from participants delaying their questions and comments. Both types of survey conversations are analyzed in this chapter.

Adolescents' HPV Knowledge

Survey analyses found that adolescents in this study had moderate knowledge and understanding about HPV. Survey conversations suggested differently. Survey conversations suggested that adolescents' written responses may have been without their genuine understanding of HPV and vaccination Examination of these conversations indicates adolescents had little knowledge about HPV. There are five points of comparisons to consider.

First, when adolescents were asked to enrol in this research study, many said they did not know about HPV. For example:

- Marla: Hello, my name is Marla. Dr. Gate and I are doing research about what people know about human papillomavirus – HPV. Will you fill out a survey?
Ms. Langston: I don't know anything about HPV. I'll do it if it's fast.
Marla: Sure. Thanks.
- Marla: Hello, I'm Marla. Will you fill out a survey also?
Drake Zegan: I don't know anything about it.
Marla: That's ok. That's why Dr. Gate and I are doing research about what people know about human papillomavirus – HPV. We want to find out so we are better at discussing it with others.
Drake: Ok. What do I have to do?

Adolescents typically said they knew nothing about HPV, yet they agreed to take help out and take the survey. Adolescents seemed to participate whole-heartedly. Survey completion took about 10 minutes, depending on how long it took the adolescent to read and sign the IRB forms. A common question followed when they completed the questionnaire: *Can you tell me what I got wrong?* Post-survey conversations provide evidentiary support that adolescents were motivated to assist and perform as best they could.

Second, because adolescents were motivated they probably behaved resourcefully to respond to items on the questionnaire. For example, adolescents could have gleaned HPV information from the study's enrolment process. The phraseology of the invitation to participate was one source for the denotation of the acronym *HPV*. Another source was the IRB consent/assent form each participant read and signed because it contained the written title of the research study – *Surveying Adolescents' and Parents' Understanding of the Human Papillomavirus* – as well as phrases explaining that the acronym HPV

stood for a *human papillomavirus*. Knowing that HPV is a virus may have been gained solely by enrolment in this research project.

Third, some adolescents directly asked about the acronym HPV after they started reading the questionnaire items. For example, there were frequent comments about the meaning of the three letters H-P-V and asked “What’s HPV?” Some adolescents asked this question repeatedly:

- Carol Reynolds: What’s HPV again?
- Tabitha Janis: What does the ‘H’ stand for? Human?

Fourth, adolescents could have made connections among the questionnaire items as they took the survey. For example, adolescents could have correctly identified HPV as a virus by associating the letters with HIV. One post-survey conversation supports this type of behaviour. Ms. Lundy and her 14 year-old son, Ellis, discussed how he knew about HPV:

- Ellis: Well, from the test I figured out it was related to HIV and AIDS.
 Marla: HPV is not related to HIV or AIDS.
 Ms. Lundy nods her head in agreement with me.
 Ellis: I can’t remember the word. It’s like gonorrhoea and syphilis are called.
 Marla: You mean STI sexually transmitted infection?
 Ellis: Yean, STD.
 Ms. Lundy: When I was young they called it VD, then STD, and now it’s called STI. Same thing.

As Ellis stated, HIV is a widely recognized acronym for a virus that may be sexually transmitted. Given that multiple items on the questionnaire refer to STI’s (see Appendix A) adolescents could have guessed answers by associating among the survey items responses. Questionnaire item #2 refers to HIV/AIDS and item #7 asks about herpes. Reading these items could have influenced adolescents’ subsequent responses. The correct response rate for 16 of the 22 questionnaire items was under 50%, however 74%

of the adolescents surveyed answered *True* correctly to Questionnaire item #9: HPV IS A VIRUS and 51% answered *True* correctly to Questionnaire item #16: HPV IS AN STI (see Table 5).

Fifth, several post-survey exchanges reveal that adolescents were unfamiliar with the health terminology or the health experiences that were mentioned in the survey. For example:

- Mary Kay Castor: I don't even know what a pap smear is.
- Angelina Folletta: What's a genital wart?
- Rhea: I don't know this. What's this?
 Ms. Persia: We haven't gotten to that chapter yet. We're still working on getting you settled and focused in school. Then we'll talk about this.
 Rhea: How do you know about this? Is this about boys n' stuff? I don't do none of that.
 Ms. Persia: We will talk about sex soon.
 Rhea: I don't even like that word. I don't do that stuff.

Other adolescents made comments about themselves as they read the items. Their comments indicate their lack health care knowledge as well as their dependency on their parents.²³ For example:

- Dallas Graham: I don't know [if received HPV shot].
- Mona Keebler asked her mom: Did I get the HPV shot?
- Selma Murray asked her dad: Did I get the HPV shots?
 Mr. Murray [looked toward me]: She doesn't pay attention.
 Selma shrugged her shoulder and smiled at her dad.

Taken together, these analyses of survey exchanges show that adolescents had minimal knowledge and understanding about HPV. In these survey exchanges adolescents asked questions, revealed reasoning processes, and demonstrated comprehension deficits with regards to colloquialisms, vocabulary, and background

knowledge (specifically health experiences) that plausibly influenced their HPV knowledge scale scores. These survey exchanges also show that some enrollees were very skilled in test-taking which possibly masked their true HPV understanding.

Adolescents' Vaccination Attitudes

In stark contrast to their limited HPV knowledge, many adolescents held strong views about vaccinations. Many post-survey conversations were about getting a shot. Those who did not want a vaccination were exceedingly vocal to all in the room:

- Wilma Flint: I don't like shots.
- Brad Garnett: I don't like shots. The needle is too big.
- Adina Arce: Shots hurt. I'm scared.
- Blaire Smith: I had a bad reaction.

When adolescents protested against getting vaccinated, parents, physicians, and nurses were sympathetic. They explained the benefits of vaccinations to the theretofore silent adolescent. Dissenters were unmoved and adamant. Some recalcitrant adolescents tried to hold back tears. Others shook visibly. These adolescents insisted that would have another bad reaction and from the pending vaccination. Yet parents remained firm in their decision that their child be vaccinated. Some remonstrative adolescents hung their heads down and seemed resigned to the inevitable shot. Here is an example:

- Ms. Smith: She's afraid of shots. Blaire: My stomach was upset last time; my arm hurt. Then I passed out.
[Nurse Nightingale came in and administered second HPV shot and a HepA shot.] Ms. Smith: Don't look. Turn your head.
Nurse Nightingale: Good job. It's all over.
Blaire: This time it didn't hurt. I didn't feel anything!

Notably, no adolescent vocally requested the HPV vaccination when their parent declined the vaccination. It was all about the shot. Adolescents who vocally protested

vaccination assessed the vaccination in terms of the immediate pain and discomfort that the shot would bring. Needles hurt before; a needle today would hurt again. Proximal pain and discomfort trumped any thoughts about future protection. This attitude displayed by dissenting adolescents superseded their understanding that vaccinations were preventative health care against fatal diseases.

Adolescents' Health Knowledge Engagement

Survey conversations are important for their content and also for what the act of conversing represents. Because adolescents repeatedly asked for relevant information, their lack of HPV knowledge became apparent. On the other hand, such questioning behavior also revealed their need or desire for HPV knowledge. Having a conversation about HPV suggests that adolescents were interested in the health information and how it applied to them. For example, adolescents would comment aloud as they read items:

- Angelina Folletta: I don't know any of these words.
- Parker McManis: I have a lot of *Not Sures*.
- Tyos Alvarez: Can HPV be cured?
- Donald Weston: What is this?
- Wilma Flint: I don't remember this.
- Elena Donne: HPV is that shot.
- Renee Donne: Oh, that Gardasil shot.

Some post-survey conversations concerned specific knowledge inquiries:

- Veronica Bailey: What's a genital wart look like?
- Gunther Gunn: Males get HPV? Is it like herpes? Can it be cured? Can you get it from poor hygiene? Aren't I too old for the shot?
- April Messina: So how do you get it?

Parker, Tyos, Veronica, Gunther, and April would not have been able to pose the specific knowledge questions had they not read the items and thought about them. These adolescents engaged with the presented health information even to the extent of seeking more explanations. Even though health information was presented within an anonymous survey and did not address their personal situation some adolescents asked seemingly general questions about HPV transmission and symptom identification that could be applicable to their personal situation. A few adolescents thanked this investigator for answering their HPV questions.

HPV vaccination was a frequent topic of post-survey conversations. Adolescents (and parents, discussed in a later section of this chapter) typically volunteered their vaccination status, some in a way that revealed how they participated in the HPV vaccination decision. For example, during post-survey conversations, Ida Pascal, Ruth Trump, Stella Senate, and Turner Price professed awareness and involvement in the health care decision-making.

- Ida Pascal: I heard my boyfriend [Gunther] talking to you in the waiting room because he talks so loud. Dr. Gate told me about HPV and the shot before [today]. I didn't get the shots. I'm going to practice safe sex and just be careful.
- Ruth Trump: I talked about this to my girlfriend today at lunch. She couldn't understand why I had the shots. She won't get them because she said they're too new. I can't understand why she wouldn't get shots that prevent cancer. My mother and I talked about the HPV shot and she definitely wanted me to get it. It made sense and so I wanted it too.
- Stella Senate: My doctor before I started coming here recommended the HPV shot before I go to college. I did my own research. I'll get the shot before I go to college.
- Turner Price: I'm getting the shot today.
Marla: Oh. What made you decide?

Turner: Because he [Dr. Commodore] said I should get it. He said it was good for me to get.

These post-survey conversations indicate that these adolescents sought, gathered, and discussed HPV information. Though different vaccination decisions were ultimately made, adolescents had discussions with mothers, friends, and physicians and collaboratively made their decisions.

In contrast, the post-survey conversations Parker McManis and Paulette Suero reveal that these adolescents were less involved.

- Parker McManis was thoughtful: “I’m pretty sure. Is this the one you get three shots? Then I did it.”
- Eighteen-year-old Paulette Suero thought aloud about the HPV shot, going back and forth recalling her health visits until she finally decided that she had all three vaccine doses. Paulette reasoned that since her little 13-year-old sister just got her first shot, she must have had all three HPV shots.

There are at least two interpretations of Paulette’s and Parker’s struggles to remember about their HPV vaccination. Perhaps their uncertainty came from a lack of concern about their own health. It follows that adolescents who would be unconcerned about their health would pay little attention to health care and information. Alternatively Paulette’s and Parker’s uncertainty about their vaccinations came from a continued dependency on their parents. It follows that dependent adolescents would pay little attention to health care and information.

The behaviors and attitudes these adolescents demonstrated in their post-survey conversations compare with how adolescents responded to the decision-making item on the questionnaire: I WILL DECIDE ABOUT THE HPV VACCINATION (see Table 11). Fifty-nine percent of adolescents responded that they would decide about the HPV vaccination and 79% of parents responding that they would be HPV vaccination deciders. Post-

survey conversations demonstrate that there were adolescents who participated in their health care by collaborating with others and there were adolescents who were uninvolved.

Parents HPV Knowledge

Parent post-survey conversations revealed a wide range of parental HPV knowledge, from those who were quite knowledgeable to those who knew little to nothing.

For example:

- Mr. Steele: I don't know as much about HPV as my wife knows; she's a nurse's aide. She knows more.
- Ms. Dunlop: It's that cancer shot?
- Ms. Morgan: My friend just had surgery for cervical cancer. And this other friend of mine knows someone who told her they know someone who burnt off their warts.
- Ms. Meade: I just passed my nurses' exam a few months ago. I should know this.
- Mr. Graham: I should know this; my wife told me about it. She's a nurse at the hospital.

When they completed the questionnaire many parents started conversations. Some parents asked specific questions. Some parents asked for the correct answers. For example:

- Ms. Donne: Can you tell me what I got wrong?
- Ms. Janis: I just want to get everything right.
- Mr. Mott: I can't believe I got two wrong.
- Ms. Messina: How long have they been giving the shot? How do you know if it's going to prevent HPV? I didn't know they were giving it to boys. I heard if you've already had sex they want you to get the shot within a certain period

of time. What effects are there from the vaccine?

These examples of post-survey conversations indicate that HPV knowledge was important to parents. One mother strongly expressed her perspective about knowing:

- Ms. Castillo: I believe in finding out as much as possible about what is out there. Its education. There is so much out there. You never know. Some people think its voodoo. Voodoo to know. But I don't.
Josephine [Her daughter appeared uncomfortable and interjected a qualification]: My mom is mixed up with her English. She means that her friends believe that something bad happens to a kid. There are bad affects if a kid gets vaccinated. But my mom doesn't believe this. Not to be educated is not a good thing.

Even parents opposed to HPV vaccination exhibited an interest in finding more out about HPV. Multiple incidents occurred. For example, when Ms. Becker was invited to participate, she requested to look at the survey. Ms. Becker skimmed the questionnaire.

- Ms. Becker [looking at her daughter [Ellen]:“Let's do it together. You do one and I'll do one.”
After completing the consent/assent process they received the questionnaire and started reading and responding.
Ellen: What's human papillomavirus?
Marla: I can't tell you until after you've filled out the questionnaire.
Ms. Becker finished the survey before Sally. Ms. Becker handed me the papers. She sat back down in her chair, crossed her arms, and waited; her face expressionless; her body quite still. I too sat quietly.
Ellen finished, handed me her papers and she asked me again “So what's human papillomavirus? What's HPV?”
As I answered her questions I glanced back and forth from her to her mother. I noticed that Ms. Becker looked directly at me with an unreadable expression on her face; not moving, her body straight and stiff. After my explanation I asked Ellen “Do you have any questions?” Ms. Becker abruptly stood, did not look at me, and said to her daughter “Let's go.” Ellen rose and her mom herded her out the exam room. I stood and thanked them for participating, and realized I was saying “Thank you” to their backs as they walked out through the exam room door.

Surely Ms. Becker did not want to have a conversation about HPV. Yet it appeared that she seized the opportunity of this survey study to gain information and to expose her daughter to the same information. At her mother's behest Ellen filled out the

questionnaire. Ellen engaged the issue and became interested in understanding HPV as evidenced by her question about HPV. Furthermore, Ms. Becker allowed Ellen's question and this investigator's response. But Ms. Becker then prevented further discussion about HPV with an abrupt departure.

Other survey conversations show that parents were prompted for more HPV information because they took this survey. Parents asked for clarification about the HPV shot. For example:

- Ms. Roberts: Nobody told me I could get this shot to protect my daughter from cancer! Can you tell me more about it?
Marla: This information sheet will explain more about the vaccine, but its best you discuss it further with Dr. Commodore.
Ms. Roberts: Thank you. I will!
- Ms. Langston: I don't know anything about HPV. I'll do it if it's fast.
Marla: Sure, a few minutes. Thanks.
I handed Ms. Langston the consent forms to complete.
Ms. Langston: I'm leery of what they put in the shot. I want to know what they're giving her; I want to know everything that goes into her body.
Then she Ms. Langston: started filling out the questionnaire.
Ms. Langston: This is easy. That doctor just discussed the HPV shot but didn't tell me anything. You told me more in this survey than the doctor did. I just want to end this visit and go do my own research.

Post-survey conversations provide evidence of the importance of specific HPV knowledge for parents' vaccination decision-making. Some parents, like Ms. Becker, took advantage of opportunities to discuss the topic with this investigator, a layperson. Dr. Gate, knowing that Ms. Becker was adamantly against the HPV vaccination, was surprised when she heard that both mother and daughter participated in the survey. Although Ms. Langston had refused HPV vaccination for her 12 year-old daughter and Ms. Roberts wanted the HPV vaccination for her daughter, both were forthright about

their need for further HPV and vaccination information. Ms. Langston intended to do her own research and Ms. Roberts would question the physician.

Contrary to survey results, parents' post-survey conversations revealed that HPV knowledge was important to them. But similar to survey results, parents' post-survey conversations revealed that their HPV knowledge did not predicted their vaccination decisions. Parents like Ms. Castillo and Ms. Roberts, who acknowledged the importance of obtaining HPV knowledge, wanted the HPV vaccination for their child; parents like Ms. Langston, who admitted little HPV knowledge and wanted more, declined HPV vaccination for their child. Other parents declined vaccination for their child by deferring their child's health care to their spouse. Mr. Mott explained: "I have to discuss it with my wife. She's a nurse. She has some concerns."

Parents Parenting

Parents did not question their role as vaccination deciders; neither did their children. Here are two examples:

- Ms. Tapper: I'll decide.
June: She'll decide [pointed toward her mother].
- Marla: Why did you decide to receive the Gardasil shot?
Ms. Garnett: Because Dr. Whitman said it was important and it would protect him [nods her head toward Brad].
Marla: Are you okay with getting the HPV shot today?
Brad Garnett: If she says so [pointed toward his mother].
Ms. Garnett: He's getting the shot.

The responsibility of protecting their child influenced parents' HPV vaccination decisions. Post survey-conversations demonstrated that parents were mindful of protecting their adolescent from a number of possible threats. Parents named four risks in survey conversations: cancer, sexually transmitted infections, adverse reactions to

vaccinations, and the unknown. Cancer was a considerable risk.

- Dawn [speaking to her mother]: You had cervical cancer, right?
Ms. Myers: No, I had precancerous cells removed but never had full blown cancer. You don't know anyone who's had cervical cancer.
Ms. Myers: [speaking to Marla]: I had 3 portions, 3 different times removed from my cervix. My kids were getting the shots. I didn't want them going through what I've gone through. They didn't have a choice.
- Ms. Zegan: I think that's what my mom died from. Now I remember reading in the papers. That's about HPV. I am worried about my children. If it's in our genes; in the family. I take my daughter to the general pediatricians and no one told me or talked to me about this. They never said anything. I'll do anything I can to prevent my kids from getting cancer.
- Ms. Arce: I saw a commercial and I wanted the shots for my daughters. I didn't even discuss it with my sister and I discuss everything with her.
Marla: So that's what made you decide?
Ms. Arce: Why not? If I can prevent all this? I want to. Just watching the commercial was enough for me to decide. Then I brought them here to the doctor's and she said 'yes'. Both my daughters got all three shots. I think Adina was nine.

Sexually transmitted infections were acknowledged risks.

- Ms. Nikolis: She [my daughter] had all her HPV shots when she was nine. Before I started coming here [to see Dr. Gate]. You never know what kids are gonna do today. You've got to protect them.
- Ms. Elmer: I brought him here [the clinic] for an examination and tests. This [HPV] is one more thing to find out.
- Ms. Messina: We had a conversation, a little talk. But now we have to talk about this more. Now that I've found out she's active.

Previous adverse vaccination reactions were pronounced as risks.

- Ms. Giagunto: My daughter is afraid of shots 'cause she fainted once.
- Ms. Sharriott: She had a real bad reaction to that first shot. Her arm swelled really big. She had a bad fever.
- Ms. Wade: My daughter had a reaction when she got the second shot. Her eyes reddened and swelled. I wouldn't let her get the second one.
Cherokee: It wasn't cause of the shot, and the doctor so.
Ms. Wade: Her eyes puffed up at night when she got the shot.

Cherokee: No, it was the night before at my friend's house. . . .

The unknown was a risk.

- Ms. Vance: It's interesting; my sister has a daughter about the same age and was surprised that I gave my daughter the shots. My sister wasn't giving the shots to her daughter. My sister said it's too soon. My sister doesn't trust it. I just believe I should protect my daughter from cancer.
- Ms. Barber: I always ask my own doctor what to do. My doctor told me not to let Renee [my daughter] get the shot. He don't believe in vaccinations.
Marla: Why are you here at this clinic?
Ms. Barber: I needed to bring her here to see the doctor and get meds 'cause my doc can't treat her.
Marla: Oh, he's your gynecologist?
Ms. Barber: He's a chiropractor. He can't treat her because she's too young.
Marla: Oh.
Ms. Barber: He's against all these shots including the HPV shot. She may actually get the disease or worse from the vaccination. She's getting HepA but I'm not convinced it's good idea.
Marla: But doesn't your daughter need vaccinations in order to attend school?
Ms. Barber: My doctor says I can get around that. I can sign papers so she can go to school without those shots the government says to get. My doctor says so.

Another factor frequently materialized in parents' survey conversations. Parents named their child's age as a reason for their vaccination decision. The age of their child required no further explanation.

- Mr. Mott: I didn't know they were giving it to boys. We were just having this discussion last week. Actually my wife and her sister were talking about HPV and Gardasil. My brother-in-law and I were there 'cause we had just finished dinner. My wife's against it and her sister is for it. My wife is a nurse and she thinks it's too new to decide. Fortunately our daughter is too young to have the shot. She's only 16 years old.
- Ms. Stein: I have been considering it. I talked with Dr. Gate and I have some concerns about heart issues. There was talk about heart problems. I talked with my husband about it. She's 15 so I guess now's the time to decide.
- NP Decker: Do you want Lonnie to receive an HPV shot today?
Ms. Horvath: No. I had this discussion with my own gyn. My gyn said Lonnie was too young for the shot. The vaccine was too new to give to her.

Further evidence of an age factor was demonstrated in parents' selective consent to their adolescent's participation in this survey project. As previously mentioned, adolescents were willing to participate in the HPV survey. Very few parents prevented their child from participating, but those that did seemed to restrict their child according to the child's age, not the child's gender. One mother allowed her 14 year old daughter but not her 11 year old son to complete the survey.

- Katrina's mother was filling out the survey as Nurse Nightingale was giving Katrina a flu shot. After she received the shot, I asked Katrina if she would you fill out the survey. Katrina did not speak. She nodded her head affirmatively, walked toward me, and reached for the survey in my outstretched hand.
Ms. Langston looked directly at me and said loudly: She isn't doing it!
Marla [to Katrina's mother]: Oh, ok.
Katrina backed away from me to stand near the exam table. Ms. Langston watched her daughter's retreat before turning back to complete the survey.
- Marla to Leslie: Would you fill out the survey?
Ms. Kunmar: Leslie doesn't know anything about HPV.
Leslie: Yes I do. She [Dr. Gate] told me about it 'cause I got the shot today.
Ms. Kunmar: We're in a hurry so she can't fill it out.

These parents behaved according to their responsibility to protect their child. In this survey situation, the perceived danger appeared to be the information in the questionnaire. For example:

- Ms. Quinn: Yes. We'll do it. Morgan slowly read her assent form while her mom rapidly read her consent form, initialed each page, and began answering the questionnaire.
Ms. Quinn: I read it. It's okay for you to do. Just initial each page.
Morgan: Mom you have to sign here. Morgan pointed to where on the assent form and her mom signed.

These are examples of parents protecting their children because they perceived that health information contained in the questionnaire that referred to sexual health and behaviour was a threat to their children. Ms. Langston prevented her daughter, Katrina, from even looking at the questionnaire. Ms. Kunmar had completed the survey so she

was aware of its content. By explaining that they were in a hurry, Ms. Kunmar prevented her daughter Leslie from being exposed to health information that referred to sexual infections and activities. Though Ms. Quinn allowed her 12-year old to participate she initially protected her daughter by previewing the questionnaire before allowing Morgan to even see it. Ms. Becker also previewed the questionnaire before deciding that she and Ellen would both fill it out. These behaviors suggest how serious parents took on their responsibilities of protecting their children even to the extent of shielding them from perceived informational threats in the form of sexual health information.

HPV and vaccination was an issue wrought with emotion for many parents. It appeared that parents exercised their right to make health care decisions because they acknowledged their responsibility to safeguard their child. The child was seen as vulnerable and in need of protection from possible physical and informational health dangers. Parents assumed the decision-making role and their children allowed their parents to do so. The reasons for adolescents' acquiescence to parents' decisions are not revealed in these survey conversations. Perhaps adolescents realized they did not understand the issues involving HPV infections so they accepted their parents' protection. This interpretation suggests the absence of adolescent agency. Alternatively, it may be that adolescents yielded the decision-making role to their parents in order to avoid sex discussions with them. This interpretation suggests the presence of adolescent agency.

Adolescent-parent Exchanges

Parent-adolescent relationships were revealed in many of their survey conversations. In the following examples adolescents do not exhibit agency or an interest to be vaccination decision-makers.

- After Ms. Dietch agreed to have her daughter, 16 year old daughter vaccinated she paused in mid-statement, turned, and asked her daughter's opinion.
Ms. Dietch: Dolores Are you ok with getting an HPV shot today? You know you have SAT's tomorrow. I don't want it to interfere.
Dolores: I'm ok. I just want to get it over with.
- Seventeen-year-old Noah Sherlock shrugged his shoulder and stated: I don't know if I've had a Gardasil shot or not. When I go to the doctor my mother decides what I should get. If I get a shot, I guess I need it.
- Ellis: Am I going to get an HPV shot today?
Ms. Lundy: Yes, if the doctor will give it to you.
Ellis had his head down and shook it slightly in negation.
Marla: Are you ok with shots? Getting an HPV shot today?
Ellis: Sure. I don't care. If she wants me to.

Statements like Ellis's, Noah's, and Dolores's offer confirming evidence that adolescents continue to be dependent on their parents to make their health care decisions. Noah seemed quite comfortable in abdicating his health care decision-making to his mother, while Ellis seemed acquiescent and resigned to doing whatever his mother decided. Both abdicating and submitting to parental control suggests an absence of adolescent agency.

What does a parent think their adolescent knows? There were parents like Ms. Amhera who said "He doesn't know anything about HPV." There were parents like Ms. Kunmar, for example, who were oblivious to their child's HPV knowledge despite agreeing to have them vaccinated. Leslie told her mother "Yes I do [know about HPV]. She [Dr. Gate] told me about it 'cause I got the shot today." Other the other hand, there were parents who thought their children were knowledgeable about HPV because of they had previously received vaccinations.

- Ms. Janis: They [daughters] know about it; they got all their shots here.
- Tyos Alvarez: Did I get the HPV shot?
Ms. Alvarez: You got all three shots. Don't you remember we talked about this?

There were parents who thought that HPV was taught in health class. For example, Mr. Graham asked his son about learning HPV in health class at school and was surprised that he had not.

- Mr. Graham: So your health ed class came in handy?
Dallas shrugged and shook his head no. He asked: What's HPV?
Mr. Graham: Well, if you don't know, that's why this is a survey.

It may be that parents like Ms. Kunmar prefer to believe their child is innocent and vulnerable and does not have sexual knowledge. It may be that adolescents and parents, like the Alverezs and Grahams, had misconceptions about their children's experiences (e.g., having the HPV vaccination, health class at school). They apparently believed the experiences were informative; their child's survey exchanges proved them wrong. The reasons why parents' might be unaware of their child's HPV knowledge are undeterminable from these survey conversations.

What does a parent think their adolescent does? Adolescent and parent perceptions of each other are integral to their relationship and successful health care as well. For example, one parent welcomed the opportunity this survey offered to inform her son and get him vaccinated against HPV infections. Unfortunately their parent-adolescent relationship prevented the mother's well-placed intentions. Their survey exchange became uncontrollable when Ms. Morgan urged her son to ask questions. He refused.

- Ms. Morgan: Ask the lady [this investigator] questions.
Barton: I got none.
Ms. Morgan: Yes you do; ask her.
Barton: No!
Ms. Morgan: Go on ask.
Marla: It's better that you discuss this with the physician.

The exchange between mother and son became increasingly agitated and loud, morphing into an argument that continued to heighten when the mother insisted that her son gets the

HPV shot. Barton said “no.” Ms. Morgan said aloud “I want him to get the shot. He’s a football player. All those girls throwing themselves at him. He needs protection.” Barton ignored his mother and completed the questionnaire. The survey encounter ended.

It appeared that Barton did not want to discuss HPV. As previously suggested, adolescents might avoid having sex discussions with their parents. Parents might also avoid having sex talks with their children. Even though the Morgans had conversed, it appeared that they were not communicating and misread each other. Indeed, this adolescent-parent exchange suggests a complicated way that adolescent autonomy might influence vaccination decision-making. Barton’s mother perceived that her son was vulnerable to HPV infection because he might be enticed into sexual encounters. Barton exercised his autonomy by consistently refusing to be vaccinated.

Another parent-investigator exchange led to an adolescent-parent exchange that undoubtedly influenced the parent’s vaccination decision. Fifteen-year-old Albert Ercolino sat on the exam table, his unfinished questionnaire was on the clipboard in his hand.

- Albert: I don’t know anything about HPV.
Marla: That’s ok; that’s why we’re doing this survey.

Ms. Ercolino: Didn’t you have this in health class?

Albert shook his head no.

Ms. Ercolino looked down and continued with her survey.

When Ms. Ercolino completed her survey, she turned her head toward me and asked: What about a shot for boys?

Marla: Yes, boys do get the shot. It’s been approved since October 2009.

Ms. Ercolino: Well, my son’s too young. He will get it at 19.

Marla: I understand. It’s best for you to discuss that with the physician.

Ms. Ercolino: When he goes off to college. That will be the time. We’re not getting the shot now.

Marla: Sure. That’s good. It’s most effective when given prior to beginning sexual activity.

From where I was quietly sitting I could observe both mother and son simultaneously. Sitting in her chair, legs crossed at the knee, Ms. Ercolino began re-reading the survey on her clipboard. She looked over at her son. Ms. Ercolino [speaking to Albert]: You know anyone who was having sex? Albert looked up from his papers making eye contact with his mom but said nothing. They kept eye contact for what seemed to me to be a full minute. I studied Albert body language. His feet dangled off the exam table where he sat. Clipboard in one hand, pen in the other. He didn't move any his body. After some time Albert nodded his head in affirmation ever so slightly. He resumed flipping through the papers on his clipboard. The room was quite for some time.

Ms. Ercolino [speaking to Albert]: “Boys or girls?” Albert looked up again and starred at his mother. He didn't answer; his mother stared back at him for a few moments. I watched Albert not moving or speaking. I heard Ms. Ercolino speak again.

Ms. Ercolino [speaking to Albert]: “Both?” Again Albert stared at his mother for what seemed to be forever. Then he nodded slightly, shrugged his left shoulder, and turned promptly to the clipboard in his hand. Albert continued with the final survey page. His mother and I sat silently. She seemed to avoid looking at me. Dr. Gate knocked and walked into the exam room. I gathered the forms, thanked Albert and his mother, and exited.

After the clinic visit, Dr. Gate related that Ms. Ercolino had changed her mind about the HPV shot for her son. In previous visits Ms. Ercolino had wanted to wait until Albert went to college. Today she decided to have the nurse administered the HPV shot to her son. Clearly the survey conversation provided new information; Ms. Ercolino recognized that Albert's potential for sexual activities was more imminent than she had supposed. With this realization she decided to acknowledge Albert's autonomy and for that reason decided to accept HPV vaccination for Albert now at 15 and not delay until he becomes 19 and goes off to college. For his part, Albert did not object.

The evidence from these examples suggests that parent-adolescent relationships were influences on HPV vaccination decisions. The adolescent decided (consciously or unconsciously) to reveal sexual behavior (e.g., Barton and Albert). The parent (usually

the mother) decided to acknowledge her child's revealed sexual activities in various ways such as trying to have a conversation (e.g., Ms. Trump and Ms. Ercolino) and bringing her for a physical examination and discussion with the physician (e.g., Ms. Elmer and Ms. Messina). Furthermore, these adolescent-parent exchanges suggest that parents were making HPV vaccination decisions and not collaborating with their children.

Categories

In comparison to analyses of survey data, analyses of survey exchanges, post-survey conversations, and adolescent-parent exchanges revealed an alternate view of participants' HPV knowledge and vaccination attitudes. In survey conversations adolescents showed minimal understanding of HPV and vaccination and subsequently displayed a range of interest for HPV issues often asking questions of this investigator. On the other hand, parents showed a wide range of understanding of HPV and vaccination and frequently engaged in extensive conversations with this investigator. Furthermore, parents' survey conversations showed their desire for information even though their HPV knowledge did not always predict their HPV vaccination decision.

Three categories emerged from comparing, contrasting, and coding participant-investigator, parent-investigator, and adolescent-parent-investigator exchanges and post-survey conversations: *Vaccination decision influences*, *HPV knowledge*, and *Relationship*.

Vaccination decision influences. The category Vaccination decision influences is comprised of the variables of parent influences, vaccination beliefs, and adolescent's age. Parents reported discussions about HPV with family, friends, and physicians that were influential. Even when parents explained their HPV attitudes to their children,

parents did not report asking their child's opinion about her health care. Though adolescent survey conversations suggest that they collaborated with parents in making HPV vaccination decisions, parent survey conversations suggest that parents did not discuss HPV issues with their children. Thus, survey conversations are not helpful in addressing the hypothesis (H2) that adolescents' decision-making attitudes influence their vaccination status.

Many parents reported the age of their child as a factor for deciding about HPV vaccination; parents behaved as if age was a sufficient explanation. Parents' intentions for their children's HPV vaccination were based more on issues of vaccination than on issues of HPV. Adolescents bemoaned the pain from former vaccinations and eschewed subsequent vaccinations. Adolescents' protests did not influence decision-making although parents' acknowledgement of their child's previous adverse reaction did influence vaccination decisions.

HPV knowledge. HPV knowledge is a category in itself. Similar to the survey results, survey conversations did not support the hypothesis (H2) that HPV knowledge determined HPV vaccination decisions. Parents' professed HPV knowledge did not always coincide with their vaccination decisions. Yet parents' survey conversations did establish that HPV knowledge was important to them.

Survey conversations provide evidence that many parents were deciding about HPV vaccination for their child outside of the clinic visit. Parents discussed HPV and vaccination with friends, family, and other physicians, as well as with this investigator. Their' survey conversations clearly demonstrate that parents had thought about and discussed HPV and vaccination with family, friends, and physicians prior to participating

in this research project. There were other parents who, admitting they had no knowledge of HPV, stated they preferred to do their own research and not rely on the physician's recommendations.

Survey conversations also make it clear that few adolescents had thought about HPV or discussed vaccination prior to participating in this research project.

Relationship. Relationship is a category with two indices parents' perceived responsibility and adolescents' sexual comportment. Health care decision-making was the parent's responsibility. Parenting responsibilities are reflected in their vaccination decisions. Parents accepting HPV vaccination were protecting their vulnerable child from HPV infections and possible adult cancers. Parents declining HPV vaccination were protecting their vulnerable child from possible vaccine harm or from exposure to sexual information. Some shot-fearing adolescents tried to take advantage of their parent's sense of responsibility. They attempted to avoid a vaccination by acting vulnerable and appealing to their parent to protect them from the pain.

The factor labeled adolescents' sexual comportment is a complicated relationship. Two aspects were requisite of the relationship: sending a message and receiving that message. Sending a message: the adolescent made a decision (consciously or unconsciously) to communicate to her mother. Receiving that message: her mother decided to pay attention to the message or not to pay attention. The adolescent revealed a level of autonomy through his message (whether they were statements, behaviors, or body language) which required that his mother recognize and acknowledge that comportment as vulnerable and dependent or autonomous and agentic.

For example, those adolescents who made the decision to be silent and completely still during HPV conversations had allowed their mothers to perceive them as naive and dependent; mothers decided against HPV vaccination. Even protesting adolescents remained naïve and vulnerable in their attempts to abort their vaccination based on their fear of shots and not the HPV issues that concerned parents and physicians. Alternatively, if the adolescent made the decision to be responsive and disclosing during HPV conversations and if his mother made the decision to receive and recognize her son's contributions as a message of his autonomy and vulnerability for infection (i.e., his sexual comportment), then his mother decided to have him vaccinated against HPV infections. In either scenario the adolescent was not the vaccination decision-maker; the adolescent decided on the message. Mom decided about receiving the message and about HPV vaccination.

Analyses of survey conversations have provided mixed findings regarding the hypothesis (H3) that adolescents participate in HPV vaccination decisions. While participating in this research study adolescents attended to, gathered, and processed HPV, vaccination, and health information often when alone with this investigator. In the presence of their parent, adolescents would inquire what HPV stands for however few adolescents participated in HPV conversations.

Chapter 6: Adolescent-physician-parent and Adolescent-physician Encounters

Understanding how healthy adolescents attend to, process, comprehend, and respond to health information during their medical visits remains low. To address this research gap adolescent-physician-parent and adolescent-physician encounters were observed and audio-recorded in the course of adolescent visits to the adolescent medical clinics. Specific attention was given to discussions of HPV and adolescent vaccination as a focal point for insight into adolescent decision-making

Physicians' perspectives on adolescents, parents, and their role in adolescent health care set the tone of the adolescent medical visit and their views and attitudes served as potential contextual influences for adolescents' discourses. This chapter's analysis focuses on what physicians said to adolescents about HPV and vaccination and how adolescents reacted and responded. Adolescents' decision-making is addressed through examining their statements and behavior during these exchanges. Parents' behaviors and responses are examined in relation to their child's participation and decision-making during these encounters.

The Physician in the Room

Adolescent health care visits followed a prescribed script, yet each was unique to the adolescent's needs. The physician orchestrated the health care visit according to the agenda of a well-visit or sick-visit yet allowed for the adolescent's and parent's input and concerns to take precedence. Each physician approached the clinic interview characteristically. For example, Dr. Barry Commodore conducted his clinic interview with trigger questions from what he termed "the old *Five-Boxes* (Medical, Home, School/Activities, Peers, and Romance) because everybody lives in five boxes."

Alternatively, Dr. Golda Gate preferred using the *HEAD* method to guide her clinic interviews (Home, Education, Activities, and Dreams). Irrespective the preferred script, the physician's pace was unhurried, calibrated to prompt participant responses in order to inquire, collect, and impart appropriate health care, health information, and encourage compliance.

This particular academically affiliated pediatric and adolescent medical practice provided *patient-centered medicine* for their adolescent patients and their families. In patient-centered medicine the family is regarded as experts in their own health. The adolescent is not cared for separately, rather she is considered a part of a larger entity which is her family. Furthermore the adolescent is considered the expert of her own health. There are specific steps during the health care visit that establish the adolescent and her family to be controllers of their own health. As Dr. Commodore explained:

- I've had 35 years of doing this. I start out each visit with parents and their adolescent acknowledging them and introducing myself. "Glad to see you; glad that you're here. I'm a physician, but I'm also an adolescent physician and we adolescent physicians talk about things. We'll talk together for a while, the three of us. I'm also going to try to talk with your child alone. For two reasons; one, because she's going to talk to a physician herself as an adult, and this is good practice. She might as well get started. And two, there may be things she feels uncomfortable saying in front of you. I will keep what she says to me private; unless it will harm her." Then I ask the parent: "Is that all right with you?" Parents here at this facility have always agreed; they have never said no. Parents say no at other places, but not here. Not yet.

Initiating communication pathways, ensuring confidentiality, encouraging respectful relationships, and establishing who is in control over health care was a key component for these physicians in order to provide appropriate health care according to each patient's needs. New patient, Asante Diamond's previous physician retired. As he waited for Dr. Gate to return to the exam room with his medical records Asante shared his

thoughts about her procedures.

- Marla: So this is just like a regular check-up?
Asante: Well my doctor usually don't do this. Um, I just go dere and . . .
Marla: Unhuh . . .
Asante: . . . and see what's wrong with me. But . . . I mean I don't sit there for a longtime.

Though on the surface Asante's statement seem to focus on the length of his visit, with his comment "my doctor usually don't do this" Asante acknowledged the extensive review of his medical history that Dr. Gate was doing was more than just giving him an illness diagnosis. This physician visit was a new experience for the 16-year-old and he was processing it by focusing on the time.

These adolescent physicians believed in the value of HPV vaccination for their individual patient's health and for herd protection.²⁴ The issue of HPV was discussed with almost all patients.²⁵ Vaccination review and discussion during adolescent-physician and adolescent-physician-parent encounters varied in length. Physicians adjusted their discourses about HPV and vaccination depending on their familiarity with their patient and family. The discussions were short as three minutes or as long as ten-plus minutes.

Dr. Commodore maintained that in many instances "Gardasil was an easy sell." He described a visit earlier in the day with a patient, a male, who just turned 18, and his mom. "I told him and his mom that 'HPV is an STI and we've been giving Gardasil to protect against it to girls. Do you know about it?' Mom said 'Yes.' I told them 'We're now giving it to boys. Do you want it?' Mom and son said 'Yes' in unison. So the nurse gave it to him. It was that easy." Dr. Commodore offered HPV information and the shot was accepted.

Another adolescent-physician-parent encounter presented an entirely different

scenario because the mother appeared to assume a supportive role to her son.

- Dr. Commodore: Then the other shot I want to talk about [coughs] is called the human papillomavirus vaccine, or HPV. Have you ever heard of HPV?
 Ruben: Yeah, I don't know what it is though.
 Dr. Commodore: Ok. HPV is a virus, obviously, 'cause it's human papillomavirus. ...
 Um, it's a virus that, um, causes cancer of the cervix in women. Do you know what the cervix is?
 [Ruben shakes head no.]
 Dr. Commodore: You wouldn't ... did you ever hear of a womb? Uterus?
 Ruben: Ok [shakes head yes]
 Dr. Commodore: It's the entrance from the vagina into the uterus. It's the opening. And women . . . that's why the women leading death, cancer death in women, is cancer of that thing. And it's a virus infection that's transmitted by sex. So we have been giving this shot to kids; it's recommended for girls 9 to 26 years old. And it's now recommended for boys as well.
 Ms. Kahn: I didn't know boys had got it too.
 Dr. Commodore: Yes, it's recommended. I can give you information about it. It's recommended for boys. And the reasons, the virus, the vaccine . . . prevents most viruses that cause this cancer . . . and it also; the virus also causes warts. And there are warts you can get from having sex. On your penis; your penis, women's vagina. And those warts are, to put it mildly [said with emphasis] icky.
 Ruben: I can imagine. Unhuh.
 Dr. Commodore: And so this also prevents you from getting those. And it prevents you from transmitting the virus to women. And so, my question to you is, would you be interested in getting this? Its three immunizations; one now, one in two months, and one four months after that. It is, uh, the only side effect that we've come up with is, um, tender arm, for a day . . . for which you can take Tylenol.
 Ruben: Unhuh.
 Dr. Commodore: And there's been no negative effects. There's been no reports of any bad reactions on all. . . Women have been doing it for like seven or six years. . . But guys have only been getting it for a little over a year and we've had no, no problems. Would you be interested?
 Ruben: Yes.
 Dr. Commodore: Ok. All right.
 Ruben: Ok.

Ruben's responses demonstrated that he attended to, processed, and deliberated on the health information the physician presented. His behavior supported Dr. Commodore's belief that 'properly' informing patients and parents about Gardasil and its advantages for cancer protection would assure a favorable reception.

Though Dr. Commodore believed that properly informing patients and parents will assure a favorable reception, he described other occasions when the adolescent “vetoed HPV vaccination and discussion.” Dr. Commodore related an encounter: “For example, I asked this fellow, an 18 year old, three times. And each time he said ‘No, not interested.’ He stopped the conversation. He wouldn’t listen to anything I had.” Yet stopping the conversation didn’t preclude further discussion of the same topic at subsequent visits. The physicians in this practice would tell patients “We will revisit this topic next time.”

- Dr. Whitman [Speaking to Ms. Caruso]: So it's just one of those vaccines that will help . . . prevent cancer in whoever. . .
 Ms. Caruso: Ok.
 Dr. Whitman: . . . In the future. . .
 Ms. Caruso: Ok. . .
 Dr. Whitman: So you can think about it
 Ms. Caruso: Yeah, we can talk. . .

Dr. Gate advocated individualized, family-centered care. She varied her approach when presenting HPV and vaccination based on her familiarity with the situation, the patient, and the family: “I think it has a lot to do the, with who they are, the willingness, the situation.”

- Dr. Gate: So let’s see. Ok. So the only thing that Zane hasn’t had that we’re now recommending for guys just like we did for girls...for about a year now, about a year, is the Gardasil vaccine.
 Ms. Chamberlain: Is that like a series of them?
 Dr. Gate: It’s just like hers [Zane’s sister Sydney]. The series starts, so he’ll get the first today... [Zane coughs] . . . and then the second in two months, and the third, six months from today. So, if you could just sign there...
 [Dr. Gate offers permission form to Ms. Chamberlain. She signs the form.]

In this encounter, Dr. Gate’s HPV and vaccination presentation appeared instructional: today the adolescent would receive an HPV vaccination; sign here. Ms. Chamberlain and her son complied. Dr. Gate mentioned to several adolescents and their moms that they

“had discussed HPV and Gardasil last year.” Parents remembered those prior discussions.

For example:

- Dr. Gate: Ok. All right. She’s our good reader. All righty. Sooo . . . ummm . . . I know last year we talked about the Gardasil vaccine...that, all that good stuff . . . and now the Gardasil vaccine has new indications so it’s not only a vaccine to prevent against cervical cancer but now we realize that it actually prevents other kinds of cancers as well...the um,... lower GI tumors, and throat cancers that are also caused by the HPV virus.
 Ms. Swanson: Unhuh
 Dr. Gate: Yeah, you know but the thing you both probably heard about Michael Douglas.
 Ms. Swanson: Right.....
 Dr. Gate: His throat cancer is actually HPV related. So we’re not just giving it to girls any more, we’re giving it to guys as well.
 Ms. Swanson: Yeah, I heard, I did a little research on that but we’re still...
 Dr. Gate: Ok.
 Ms. Swanson: We still haven’t decided, but I mean . . . but we have time . . . There’s no best . . . I don’t know. . .
 Dr. Gate: Ok.
 Ms. Swanson: Unhuh
 Dr. Gate: Do you have a brochure?
 Ms. Swanson: Yes,
 Dr. Gate: [unclear]
 Ms. Swanson: Is there a current one, a newer one?
 Dr. Gate: [Turning and speaking to Marla] You want to get the um . . .
 Marla: Yeah, I’ll go get it for you.
 Ms. Swanson: That gives me indications what you were just saying here?
 Dr. Gate: Yeah, you know we have actually that web [Turning again and speaking to Marla] Do we have that thing you know from the science museum? Do you want to pull that?
 Marla: Yeah...I can pull that.
 Dr. Gate [Speaking to Ms. Swanson]: There’s actually this really neat video tape that was produced in the . . . of the Natural Museum History of New York that did just did . . . [Dr. Gate turned and looked at Myranda] the science is what the doctors need [Laughter from all because Myranda had said earlier that she wanted to become a doctor.] Yes, but that’s what I would look at. If you watch it will teach you about the viruses can cause cancer. Which is pretty remarkable...that they were able to study that. So that’s what I would look at.
 Ms. Swanson: Ok.
 Dr. Gate [Speaking to Myranda]: Because it will teach you a lot about the virus itself and how it’s related to. . . So any way, the reason to think about it, sooner than later, because you’re fourteen now, is that the peak response to

the vaccine is right around now. And then from here on out your response to the vaccine starts to come out, to go away

Ms. Swanson: Oh, ok.

Dr. Gate: So we try to maximize the efficacy of how well it works. And this is the period of time where the vaccine is, is perfectly suited for this age group.

Myranda: Ok.

Dr. Gate: Not that you will use it now, but you'll get the maximum benefit now, and that it will be there for you later.

In this encounter, Ms. Swanson stated she has researched the issues and was still considering their options. Nonetheless Dr. Gate pressed the issue, offered a newer brochure and suggested a web site explaining the current viral research underling HPV vaccination.

The following two encounters demonstrate how Dr. Whitman adapted her HPV and vaccination presentations to her patients. In the first adolescent-physician encounter she focused on disease prevention emphasizing the immediate prevention of genital warts that HPV infections cause.

- Dr. Whitman [Speaking to Adam Fielder]: The other, there is some benefit of boys somehow. With the shot is it's a virus. A virus which causes cervical cancer in women. What can it cause in boys? It can cause warts. Do you know what warts are?
Adam: Unhuh.
Dr. Whitman: Ok. And that's not pretty. You know it's not dangerous, but it's not pretty.

In this second adolescent-physician encounter Dr. Whitman's appealed to the 18 year-olds' relationship responsibilities. She focused on Doug's commitment to his girlfriend and his ability to protect her from becoming HPV infected and possibly developing cervical cancer.

- Dr. Whitman: The third thing is the Gardasil vaccine. Ok? Now that is, primarily... you've heard about that?
Doug House: Unhuh
Dr. Whitman: Primarily it's for women. Ok?
Doug: Hmm.

Dr. Whitman: And that's how they advertise it, that it's for women.

Doug: Hmm.

Doug: Definitely.

Dr. Whitman: It's a virus. It protects you against a virus that can cause cervical cancer in the woman. Ok. You have a partner. Ok. You have your girlfriend. And you have [unclear] So, um, so the thing is, when you get that vaccine, it protects HER primarily against cancer. Ok?

Doug: Definitely.

Dr. Whitman: Ok. So that's one thing you are doing for her.

Doug: Oh, yeah.

Dr. Whitman: Ok? The other thing is that it also helps YOU in a way because that virus can cause cancer in women. In men it can cause warts.

Doug: U Unhuh

Dr. Whitman: Ok. Do you know what warts are?

Doug: Sure.

Dr. Whitman: Ok. That's really not something you want to [unclear]. So it will help you not get that. Ok?

Doug: Ok.

Dr. Whitman: So, cancer is a big thing and if can get a vaccine that can protect you against cancer, or your girl against cancer, it's worth it

Doug: Unhuh

Dr. Whitman: Side effects, you know it's a shot, we spoke about that. It will give you some pain; you will be sore. Ok. But you're getting other shots, so you'll be sore anyway.

Doug: Ok.

Dr. Whitman: Any questions?

Doug: Uh, no.

Dr. Whitman: Now the HPV, the Gardasil is a set of three shots. Ok. So one shot you'll get today, the other one will be in two months, and the third one will be four months after the second one.

Doug: ... the second one. Ok.

Dr. Whitman: Ok. So when you come in for your next appointment, you don't have to, when you come in for your shot, to finish your series.

Doug: Unhuh

Dr. Whitman: You don't have to see the doctor. Just call in and say you want a nurse appointment for your shot. And they'll it will be a quicker visit. We don't have to do all of this. Ok. And then you'll come in, we give the shot and you're out of here. Ok?

Doug: Ok.

Dr. Whitman: All right?

Doug: All right.

Dr. Whitman: Any questions?

Doug: No. No.

Dr. Whitman: And we will give you information about all these things that we spoke about.

Doug: Ok.

Dr. Whitman: And you can read up also about the HPV. It's on the Internet. And we'll give you the information. Show it, show it to your girlfriend and you can tell her what you are doing it for her. So, one more thing, right?

[Laughter]

Doug: Yeah [Laughter].

Dr. Whitman: All right. So you will get the shot.

Doug: I'll get it.

These sensitively and carefully worded HPV presentations reflect the physicians' view of the importance of HPV vaccination as well as their acquaintance with their patients. Dr. Gate referenced Myranda's hope to become a doctor and she framed her comments to Ms. Chamberlain knowing that Zane's sister had previously received HPV vaccinations. Dr. Whitman focused on supporting Doug and his relationship with his girlfriend. With some young male patients, Dr. Gate and Dr. Whitman emphasized the immediate protection against warts. Taken together these encounters illustrate that much of the physician's discourse was directed toward engaging the adolescent's participation in the vaccination decision.

Adolescent Responses and Reactions

There were fourteen adolescents who sat silently staring, made no outward response, or continued fiddling.

- Dr. Gate: It's just like hers. The series starts, so he'll get the first today...
[Zane Chamberlain coughed, continued to look at the floor and stroke the 'peach fuzz' on his chin with no acknowledgement of the discussion around him.]
- Dr. Franklin: The other thing was for the HPV vaccine . . . umm, we want . . .
uh, about that vaccine, its Gardasil . . .
[Calvin did not move from his position of leaning on his mother; sitting in his chair, his head on laid on his mother's lap and his mother stroked his head.]

Zane and Calvin they did not appear to react or even attend to the discussion in progress.

Other silent adolescents appeared indifferent. For example, Sandy Kennedy sat on the

exam table swinging her legs while occasionally looking at her sister Marsha sitting across the room on the floor fiddling with her fingers; Kenyatta Carter looked at his hands; Damon Abbot clutched a spiral notebook and stared at Dr. Commodore; J.J. Haruki and Horatio stared at a nondescript place on the wall across the room. The few adolescents who appeared to be attentive to the HPV presentation refrained from entering the adult conversation. For example, Cyrus Briggs kept his eyes on his father; and Julio Hanson, Myranda, Bella Burch, Ga'briel Chandler watched their mother converse with the physician.

At times the physician spoke directly to the adolescent and asked him to decide about HPV vaccination. These adolescents were more likely to respond because the physician maintained direct eye contact and directly included them in the discussion. Little, if any, back-and-forth dialogue occurred between adolescents and physicians about HPV, Gardasil, or vaccination. Only two adolescents the physician answered with one complete sentence, albeit a short sentence:

- Dr. Commodore: Have you ever heard of HPV or Gardasil?
Ruben Kahn: Yeah, I don't know what it is though.
- Dr. Whitman: Have you ever heard of HPV or Gardasil?"
Adam: I think so.

Most adolescent kept their replies to simple utterances (such as *Yes* or *Yeah*, *No*, *All right*, *K*, *Okay*, or a grunt *Unhuh* or *Um*) or gestures (such as head nods, or shoulder shrugs).

- Dr. Commodore: And there's another immunization out now called HPV or Gardasil. Have you ever heard of that?
[Luther Celek nodded his head yes.]

There were six adolescents who replied with such monosyllabically utterances. Four of those adolescents Carlos, Curtis Foles, Trent Court, and Doug were 18 year-olds in

unaccompanied clinic visits; Trindon Ellerbe and Jasper Hubbard were there with their mother. Dr. Commodore offered his thoughts about adolescents' sparse replies:

- Marla: There are a lot of 'yes' and no responses. Not a lot of discussion going on.
Dr. Commodore replied: That's all you can expect from a 14 year old boy.
Marla: But you get them to talk to you, to tell you their story.
Dr. Commodore: Yes, but with vaccinations it's different. They listen to what I have to say and they respond yes or no. That's it.

Such lack of dialogue in adolescent-physician encounters is striking in contrast to the numerous post-survey conversations of adolescents and parents with this investigator. Evidence presented from participants' post-survey conversations demonstrates adolescents expressed interest in understanding more about HPV (see Chapter 5).

Adolescents' Vaccination Attitude: It's a Shot!

Conversations about the vaccination, the shot, did occur during the physician visit. Nine adolescents displayed swift and pronounced reactions when they realized a shot was imminent. Adolescents responded with through their body language. One adolescent held his head in his own hands; another buried his head on his mother's shoulder. Leg-bobbing up-and-down on the floor increased and hair fiddling intensified. These adolescents all-of-a-sudden perked up. There were several adolescents with ardent responses about getting the shot. They were concerned specifically about the shot itself: "Where do I get it?" or "It hurts?"

- Asante Diamond: Where dat shot go? In my arm?
Dr. Gate: Yep. It goes in the arm.
Asante: Ok.
- Thatcher Lee: Is it like a flu shot vaccine?
Dr. Gate: Yeah. It's a shot. Yeah.
Thatcher: In the arm?
Dr. Gate: In the arm. All right. But we're not going to do it today.
Thatcher: Yeah, I know. I know some shots are like here [points to buttocks]

Dr. Gate: Yeah, but not those, not those. We rarely give those [shots in the buttocks].

Thatcher: Yep.

- Dr. Gate: The main side effect is that it hurts.
Ms. Haruki: It hurts?
J.J.: Is it a sharp hurt?
Dr. Gate: Yeah, it's like every other shot, you know. . .
J.J. [Turning to his mom]: I told you.
Ms. Haruki [Speaking to J.J.]: Stop it!
- Curtis Foles: I was gonna, actually [unclear] I um... kinda don't wan to
um... so....I'll hold off on that...
NP Memorial: Well, just because it makes you sore.
Curtis: [unclear] In fact I kinda don't wanta, cause I.....
NP Memorial: He's a body builder.
Curtis: Yeah, I go to the gym. ... I gotta.
Marla: Ok. So you think that the shot's going to hurt?
Curtis: What? Nah, it's just like, you know, after a while you're gonna feel that, you know?
NP Memorial: Well, yeah. It's in the muscle and when you're reachin up an all you know any shot will that...
Curtis: Yeah, that's what I'm sayin...
NP Memorial: But it does prevent other problems then with your arms, so...
Curtis: Ok, I'll get it next time.

Other adolescents emphatically protested, pled "Why?" to their mother or displayed exaggerated antagonistic behavior.

- Ga'briel Chandler: I just don't like shots!
- Marsha Kennedy: I didn't even want to look when Sandy [sister] got her shot. I hate shots!
- Ms. Rice: Yes, can we get it today? [Ms. Rice shook her head in affirmation and fist-pumped her right hand while actually doing a little jump. Quinton walked over to his mother and put head on mother's shoulder, like he was hiding his head in her shoulder.]
Ms. Rice: "Are you 14?"
Quinton shook his buried head back-and-forth on his mother's shoulder.
Ms. Rice: "I have to Facebook this moment!" [She reached in her left pocket.]
Quinton: No. [He mumbled very softly and reached his hand out to stop her.]
- Wyatt Anderson: No! [Wyatt covers eyes] Why am I getting a needle today?
Ms. Anderson: It's necessary.

Wyatt: But why? I want to see you get a needle.

[Wyatt swings his feet in a circle rapidly. He is sitting on the exam table and his mom is sitting in the chair. Wyatt looks at his mom. Mom looks at Wyatt.]

Wyatt: I don't want a shot!

Ms. Anderson: Do you want to have a party in July?

In contrast to this strong evidence that adolescents just did not like vaccinations, three privately told this investigator that they were reconciled to shots.

- Sandy Kennedy [Marsha's sister]: Shots don't bother me now. Now I like to watch them giving me the shot.
- Kenyatta Carter: I don't care...I'm not afraid of shots, so it doesn't make a difference.
- Trindon Ellerbe: No...I don't know... It's that... I remember as a kid I used to get scared of them, of shots...

Nevertheless, whether the adolescent's statement was an objection to shots or a subjection to the shot, these responses to a vaccination convey that the adolescent was attending to the discussion even while refraining from speaking about the HPV health care issue.

Adolescents as Decision-makers

The majority of adolescents observed were not likely to attend to participate in the HPV vaccination decision even if directly confronted with the decision about HPV vaccination. Five adolescents voiced acceptance of the HPV vaccination while the other 25 adolescents conceded the vaccination decision to their parents. Consider the following encounters where Damon, Bella, Thatcher, and Horatio conceded the vaccination decision to their mothers while Adam and Ruben (discussed in an earlier section of this chapter) and made the vaccination decision with their mothers.

- Damon slouched on the exam table leaning his back against the wall. He kept his 'hoodie' on and clutched a notebook to his chest, fingering the spiral. Damon complained that he was hungry and his mother said he had to wait.

Damon was sullen. While Dr. Commodore presented HPV and vaccination Damon maintained eye contact despite the indifference his body language projected.

Dr. Commodore: Would you be interested?

Damon Abbot: Ask her.

Dr. Commodore: I'm asking you.

Damon: I don't care.

... ..

Dr. Commodore: I can I could put you down for a nurse visit. Come back and get it.

Ms. Abbot [speaking to her son]: You want to do that? So you can...

Damon: I don't care. You guys figure that out.

Damon ceded to his mother verbally. When pointedly addressed, Damon refused to participate. When pressured by Dr. Commodore to make a decision Damon professed indifference and withdrew.

Fourteen-year-old also Horatio Caruso refrained from entering the HPV conversation and ceded the decision to his mother in a different manner. Dr. Whitman introduced the HPV virus as causing cervical cancer. Ms. Caruso made perfunctory remarks which allowed the physician to continue talking about the consequences and transmission of HPV infections as well as vaccination prevention.

- Dr. Whitman: ...in against HPV... virus, which is a virus which causes cervical cancer in women, in women.
Ms. Caruso: Unhuh
Dr. Whitman: Most commonly, it can cause genital warts in men and women; Ok? Now the thing with um, HPV is, you can get it with intimate skin contact. You don't need sexual contact.
Ms. Caruso: Unhuh
Dr. Whitman: You can have direct skin contact, Ok.
Ms. Caruso: Unhuh
Dr. Whitman: So it's just one of those vaccines that will help prevent cancer in whoever
Ms. Caruso: Ok.
Dr. Whitman: ... In the future...
Ms. Caruso: Ok...
Dr. Whitman: So you can think about it
Ms. Caruso: Yeah, we can talk...
Dr. Whitman: Ok.

Ms. Caruso: ...he's fourteen...we have some time...
 Dr. Whitman: Ok . . . All right...Great...Any questions so far?
 Horatio: Well just about coughing...
 Dr. Whitman: Ok...
 Horatio: Sometimes when I'm running

Horatio contributed nothing to the discussion and actually changed the topic when pointedly asked if he understood about HPV 'so far'. Horatio's response was an abdication of decision-making to his mother; he withdrew.

Another adolescent-physician-parent encounter also shows an adolescent ceding the decision to her mother. Though Bella participated in the conversation monosyllabically her behavior demonstrates compliance to her mother's decision.

- Dr. Gate: Uh, and the other one is the Gardasil vaccine, the HPV vaccine...
 Ms. Burch: Yeah, which we [my daughter and I] have discussed...
 Dr. Gate: Ok.
 Ms. Burch: ... and we're going to hold off on that for a little while
 Dr. Gate: Ok...
 Ms. Burch: We're just more comfortable...
 Dr. Gate: Yeah, and I think that's fine. The vaccine is completely safe.
 Ms. Burch: Right.
 Dr. Gate: Um, and the efficacy is best around this age.
 Ms. Burch: Ok.
 Dr. Gate: ... twelve, thirteen...
 Ms. Burch: Yeah.
 Dr. Gate: ... is when we recommend it...
 Ms. Burch: Right.
 Dr. Gate: ... because it just works better when the immune system is perfectly primed to make...
 Ms. Burch: Ok.
 Dr. Gate: ... the immune response around now.
 Ms. Burch: Yeah.
 Dr. Gate [looking toward Bella]: ... and then, you know, you don't need the vaccine ... you don't need the immunity from the vaccine until sometime later, but ...
 Bella: Unhuh...
 Ms. Burch: Right.
 Dr. Gate: ... it's there for you, best, if you get it early. [unclear]
 Ms. Burch: Yeah, we're still gonna hold off. We're just more comfortable.

Bella's mother took the lead and replied to the physician's statements. When Dr. Gate pointedly addressed Bella, her response was compliant with her mother's script.

Contrariwise, two male adolescents were observed to stray from their mother's script during their adolescent-physician-parent encounters. Both youngsters engaged the physician with questions.

- Dr. Gate: So, I'm going to do your exam. I'm going to give you some privacy. Before we do that, um, he's had just about all the vaccines except one that we're recommending now for males.
 Ms. Lee: Oh...
 Dr. Gate: And that's the Gardasil vaccine is recommended now for males. Um, because we recognize that the cancer the HPV causes is not just a female cancer. Like at first we were just giving the vaccine to prevent against cervical cancer, but now we recognize that there are all kinds of cancers in the throat, in the lower GI system that are also caused by HPV. So we think that we can get a better control giving it as well to guys and girls. Like Michael Douglas is infected with throat cancer, the kind of cancer that he was just um, was treated for was classified as HPV. So we're going to recommend that vaccine. So if it's ok with you?
 Ms. Lee: Um, not today. I have to talk to my husband about it.
 Dr. Gate: Ok. All right. Good. Um, so and we do it generally, again, around twelve, thirteen...
 Ms. Lee: Is that three, three stage ... given...
 Dr. Gate: So, yeah... same, same as the girls.
 Ms. Lee: And it's the same for boys, age, age-wise you can never ...know...
 Dr. Gate: We usually do it twelve, thirteen. Yeah, we can do it all the way up to age twenty-six. But it's...
 Ms. Lee: Yeah.
 Dr. Gate: ... again, it's sort of one of those things...
 Thatcher: Is it like a flu shot vaccine?
 Dr. Gate: Yeah. It's a shot. Yeah.
 Ms. Lee: We're not going to do it yet. I have to talk to dad.
 Dr. Gate: Yeah. Ok.
 Thatcher: In the arm?
 Dr. Gate: In the arm. All right. But we're not going to do it today.
 Thatcher: Yeah, I know. I know some shots are like here [points to buttocks]
 Dr. Gate: Yeah, but not those, not those. We rarely give those.
 Thatcher: Yep.

Though Thatcher ceded the HPV vaccination decision to his mother, Thatcher joined the HPV discussion with questions for Dr. Gate. Even though both his mother and Dr. Gate

reminded him that he was not getting the HPV vaccination, Thatcher continued questioning. He had attended to the conversation and solicited clarification about how he might be affected by the vaccination.

Adam Fielder also sought answers from the physician about the vaccination and not about the HPV infection. Ms. Fielder had agreed to have her son receive the vaccination to prevent acquiring and spreading HPV infections. Adam's initial silence was an indication of compliance to his mother's decision; after all, his younger sister had received hers already. Then Adam posed a question.

- Adam Fielder: I have a question about it...
 Dr. Whitman: Yes.
 Adam: Will I be able to get the vaccination uh, later say over the summer instead of now?
 Dr. Whitman: Unhuh.
 Ms. Fielder: It's...
 Adam: I have volley ball. And the regional tournament for volleyball
 Dr. Whitman: Sure...
 Adam: I have volleyball and I don't want to have a shoulder.
 Ms. Fielder [Laughing]: He doesn't want sore arms.
 Dr. Whitman: Ok. So then you wouldn't want the Hepatitis A as well?
 Adam: No. Not immediately.
 Dr. Whitman: Ok. So...
 Ms. Fielder: But we can come back. It's not a problem. Because he doesn't have any objection, I would love to go ahead and do the Gardasil too.
 Adam: I would like to have it. Just not right now.
 Dr. Whitman: I understand...
 Adam: I want to wait until the season's done.
 Ms. Fielder: Yeah. We don't want to have any volleyball problems.
 Dr. Whitman: Ok.

Adam's behavior demonstrated that he attended to, processed, and deliberated on the health information the physician presented. Ms. Fielder showed her support of her son's participation in the decision-making by repeating his concerns.

Ruben decided and Adam managed to defer vaccination. Ruben decided and participated by accepting vaccination. Adam acceded and participated by deferring

vaccination. Because of their mother's behavior, Ruben's and Adam's voices are heard. Yet proper information exchange is an inadequate explanation for what occurred during the adolescent-physician-parents encounters of Damon, Horatio, Bella, and Thatcher. Damon, Horatio, Bella, and Thatcher ceded HPV vaccination decision-making to their mother, though Damon's and Horatio's behavior was quite different from Bella's and Thatcher's. Damon, acceded by statement and Horatio acceded by changing the topic. Bella acceded by confirming her mother's statements. Thatcher complied and participated by inquiring about vaccination.

The behavior of these adolescents illustrates part of what is undeterminable about adolescent health. It is known that adolescents are likely to allow their parent to do the decision-making. The reason for their acquiescent behavior remains undetermined. Perhaps they acquiesced from lack of understanding or lack of interest. Because their voices are not heard, we do not know the extent of their health knowledge. Lacking knowledge adolescents may not be aware when their health is compromised or at risk. This is a problem.

Health care providers treated adolescents aged 18+ years old as adults. When they appeared for their health visits these older adolescents were expected to make their own decision about the HPV vaccination.

- Dr. Commodore: Would you be interested in getting the shots?
 Carlos Hanson: Yeah! I don't want no warts on my genitals! I don't want warts on my genitals!
 Dr. Commodore: So you'd be interested?
 Carlos: Yeah!
 Dr. Commodore: Ok.
 Carlos: But will it affect me in any type of way?
 Dr. Commodore: No. No. The only thing it does is that we've seen so far, there have been no bad side effects recorded from anybody who gets the shot.
 Carlos: Um, my body...

Dr. Commodore: Except for just the sore arm for a day.
 Carlos: What do you mean that...?
 Dr. Commodore: It just hurts for a day?
 Carlos: It hurts?
 Dr. Commodore: Yeah, it goes away after a day or so . . . Ok?
 Carlos: Unhuh.
 Dr. Commodore: Its three shots. One now, one in two months, and then one four months after that . . . You willing?
 Carlos: Yep.

Carlos immediately agreed to receive the vaccination and then questioned Dr.

Commodore. Further discussion ensued and the physician acknowledged the legitimacy of his claims and was able to satisfy his concerns. Carlos demonstrated his interest in managing his health and his competency for decision-making.

In another encounter the older adolescent miscommunicated his intentions and was reluctant to manage his health care without parental guidance.

- NP Memorial: Now we're talking to guys all about guys and girls about various vaccines, one in particular. The vaccine we're going to talk about is for the human papillomavirus you heard about probably in high school?
 Trent: Yes.
 NP Memorial: Yes. Do you know what it does?
 Trent: No, not really.
 NP Memorial: Ok. In females it causes cancer in the uh cervix. And men are the carriers. In both sexes it can cause human papillio.... human papillomas. Right. Genital warts. Which are in a woman ... on her ... vulva and in a man it, you know, would be on his penis. AND, those are not pleasant to have.
 Trent: K.
 NP Memorial: So, the uh shot is a three shot series. You can have. . .
 Trent: Right.
 NP Memorial: . . . to prevent that.
 Trent: All right.
 NP Memorial: Ok. Do you have any questions?
 Trent: No.
 NP Memorial: No?
 Trent: Ok.
 NP Memorial: You're ok!
 Marla: Are you going to get it?
 Trent: Huh?
 Marla: Are you interested in getting the shot?

Trent: Um... I think.... can I wait? Or likelike can I wait? Or do I have to get it now?

NP Memorial: We can give you uh information on it.

Trent: Yeah, can I do that?

NP Memorial: Un hmm. And then you can make the decision

Trent: Yeah.

NP Memorial: ... by the next time you are here..... whatever...

Trent: Yeah. Great. I'll do that.

Trent appeared to accept the vaccination. Then this investigator interjected and asked him directly if he agreed to accept HPV vaccination. Trent balked and then he asked permission to decline the shot. He shortly acknowledged that "My parents told me not to get anything I don't have to. So I have to talk to them about this [HPV vaccination]."

Trent continued conversing with NP Memorial. He related that he once auditioned for a commercial that he now realized was about HPV. They both talked animatedly about auditions and how that particular one progressed.

Trent and Carlos participated in their clinic interviews and demonstrated deliberation and engagement with HPV issues. Carlos made his own decision upon his physician's recommendation and Trent deferred the vaccination decision in order to consult his parents. They participated in their health care making different decisions; their voices were heard.

Taken together, these adolescent-physician and adolescent-physician-parent encounters clearly demonstrate that adolescents' decision-making was not uniformly similar. However, most clinic discussions regarding HPV and vaccination were long physician narratives with sporadic, brief adolescent responses. An adolescent decided, an adolescent acceded, an adolescent submitted when their parent interceded, and an adolescent deferred in order to confer with his parents. Some adolescents did question their physician. These adolescents were preoccupied with the nature of the shot and not

the vaccine or the issues of HPV. Fundamentally, these adolescents' behaviors and statements are evidence for their selective attention to the immediacy of the vaccination.

Unspoken

Explaining the need for HPV vaccination by emphasizing cervical cancer prevention intentionally shifted attention away from the sexual transmission of HPV and yet unintentionally shifted attention from the infected carrier to the female recipient.

Some parents reacted with surprise at the offer of HPV vaccination to their son: Ms.

Rivera: "I didn't know boys had got it too!" Ms. Fielder had a lengthier discussion with the physician:

- Dr. Whitman [Looking directly at Adam]: We offer, and I might have mentioned it, that we offer Gardasil. Have you heard about that?
Ms. Fielder: I do! And they give it to boys?
Adam: I think so.
Dr. Whitman: Ok. So its, its, primarily it prevents cervical cancer in girls. Right? That's probably what you've heard. Right?
Ms. Fielder: Shana's had it. She's had all the doses.
Dr. Whitman: Yes, it's a series of shots and you need to get all of them. Now the way, the issue why we offer it to boys is because . . .
Ms. Fielder: They carry it!
Dr. Whitman: Exactly. They, they're the ones who will give it to girls.
Ms. Fielder: Interesting.

An emancipated minor. The HPV and vaccination conversation during the adolescent-physician-parent encounter changed when the 16 years-old adolescent was a father. Julio Hanson and his mother presented for an ill-health check with Dr. Gate because they were concerned about his contact with his new-born son. The baby boy's mother lived a few blocks away from where Julio lived with his mother; they attended the same high school. Dr. Gate reviewed his health chart and vaccination records. Dr. Gate presented a brief explanation of HPV cancers in guys and girls, mentioned Michael Douglas, and explained the effectiveness of the Gardasil vaccine. Dr. Gate then finished

with a rhetorical question: “So we’re going to recommend that vaccine. So if it’s ok with you? Sign here.” Ms. Hanson signed the form. Julio received his first HPV vaccination.

After the visit was completed Dr. Gate commented:

- Dr. Gate: That’s family centered!
 Marla: Yeah, yes. So you have to judge who you’re talking to.
 Dr. Gate: You know, like I don’t have to tip-toe around the fact that they’re having sex is out there because he’s a dad.
 Marla: Yes, I see.
 Dr. Gate: He’s already a father; it makes a difference.
 Marla: That’s true. It does make a difference.

Though Julio may be considered an emancipated minor, he showed little evidence of decision-making capabilities for his own health care. Julio was with his mother at the physician’s for an ill visit, a behavioral acknowledgment of his ill health, willingness to receive health care, and responsibility of protecting his son from illness. Ms. Hanson’s behavior indicated that she was concerned and wanted to protect her son and her grandson from illness. Julio attentively listened to Dr. Gate, yet said nothing. Ms. Hanson, by attentively listening and then signing the vaccination permission form per Dr. Gate’s instructions, communicated that she wanted to protect her son from any future health harms.

Julio ceded the HPV vaccination decision-making to the physician and his mother. Admittedly, Julio was a new father with newly acknowledged responsibilities and his physician visit demonstrated his understanding of his own need for health care. In contrast, his submissive participation in this ill-visit with his mother and physician did not demonstrate that fatherhood was evidence for his decision-making capabilities for his own health care.

Sexual subtext of HPV and vaccination. Every physician in this study behaved

in a socially acceptable and ethical manner. Their conversations and behavior were professional when they discussed the causes, transmission, and consequences of HPV. They referred to activities and used words that are typically avoided in public conversations in a professional and sensitive manner. Physicians used word depicting sexual activities: intercourse, oral sex, physical intimate contact, skin-to-skin contact, and sexually transmitted disease. Physicians also named specific body parts: the cervix, womb, vagina, anus, genitals, and penis. The subtext of HPV conversations evoked sex and alluded to the adolescents' prospective sexual activities.

One parent directly commented on the sexual context of HPV when she claimed to have had “sex discussions” with her 12 year old daughter: Ms. Burch stated “we're pretty open about discussing sex and sexually transmitted diseases.” Bella neither confirmed nor denied her mother's claim that they openly discussed sex. Bella is typical of the adolescents observed in participant-physician encounters; adolescents are silent. Ms. Burch is atypical of the parents observed in participant-physician encounters; parents talked around the issue of sex. For example, Horatio Caruso's mother seemed to grasp the sexual context of the issue because she mentioned Horatio's age as a factor in her decision to decline HPV vaccination at the present time. By focusing on her son's age, Ms. Caruso alluded to sexual activities and avoided using sex words. She rationalized: “he's fourteen; we have some time.” Ms. Caruso suggested that Horatio's sexual debut would be at a later age. One parent was frank about viewing HPV vaccination as involving sexual activities: Ms. Cash: “I don't even want to think of him like that right now.”

Adam Fielder replied when Dr. Whitman directly questioned him. He spoke his mind only to request that the vaccination be postponed because of his upcoming volleyball game (see above). Adam is typical of the adolescents observed. Adolescents did not speak about sex or allude to sexual behaviors. Yet there is evidence that adolescents reacted to the sexual subtexts of the HPV issue from the not always subtly ways adolescents responded when the physician described the sexual transmission of HPV. Consider the following two examples:

- Dr. Washington: So orally you can get um oral warts, or whatever. Its most commonly used cause genitally you can get cuts, something really serious like cervical cancer, or something more benign or but very irritating genital warts. [Ga'riel starts laughing quietly.] So by the vaccine, it's a three... course, a three course vaccine, um... first month, two months from now, and then six months from now. And you will be protected against the worst, like the worst kind. Are you guys interested?
Ga'riel: I don't know. [Still laughing]
Ms. Chandler: [speaking to Ga'riel] Why you laughing?
Ga'riel: I don't know.
Dr. Washington: Do you want to think about it?
Ms. Chandler: Yeah.
- Dr. Commodore presented HPV information and looked directly at Cyrus Briggs. Cyrus said nothing, looked at his father and avoided eye contact with Dr. Commodore. Mr. Briggs did all the talking. Cyrus opened his eyes wider and looked away from his dad and down on the floor when Dr. Commodore spoke about the oral transmission of HPV.

Ga'riel could not stop herself from laughing and Cyrus's eyes widened. Attentive as these adolescents seemed, neither voiced an actual opinion, offered information, or asked a question. They remained out of the discussion.

The examples above indicate a sexual undercurrent to HPV clinic conversations. If the adolescent typically avoided talking about sex in front of her parents it follows that she would not participate in a discussion with obvious sexual innuendos. Yet the adolescent might not be attending to the particulars of the HPV discussion. The totality of

the physicians' message – that the HPV vaccine is preventative and most effective prior to initiation of sexual activities – might not be perceived and understood. If the adolescent attended to and processed the physician's message she could have said "Let me get the shot now" and that would imply that she was not sexually active. Thus, the sexual undercurrent in HPV clinic conversations is a barrier to adolescent participation in vaccination decision-making and ultimately health care.

Categories

The analyses in this chapter of adolescent-physician and adolescent-physician-parent encounters during clinic HPV vaccination discussions generated four categories: *HPV knowledge, Sex, Decision-making, and Adolescent health behavior.*

HPV knowledge. HPV knowledge is a category in itself. The adolescents observed in encounters with their physician appeared to have little knowledge and understanding of HPV issues. Six adolescents had heard about HPV or Gardasil but said they knew nothing about it. Five adolescents said they had not heard about HPV and the other eighteen gave no response. When presented with information about HPV two issues were raised: the vaccination and the vaccine's effects. Seven adolescents were concerned about the vaccination, the shot itself. Six adolescents voiced concern about the pain from a vaccination and two delayed the HPV shot until after an athletic event. Two others were interested in where on their body the shot would be administered. Carlos was the only adolescent who raised a question about the vaccine itself. He was clearly interested in preventing warts yet turned his focus to possible adverse effects from the vaccine might have on his body.

Specific vaccine information was important to one older adolescent, who understood the consequence of genital warts and readily accepted HPV vaccination. None of the others were observed to talk about the information the physician presented. These adolescents appeared to have little HPV knowledge and showed little interest in acquiring and understanding HPV infections and concomitant issues. Yet it remains difficult to determine the extent of the adolescents' HPV knowledge and understanding because twenty-two of the adolescents observed spoke little or not at all.

Parents were dissimilar in their knowledge and understanding of and interest in HPV and vaccination. Some parents were receptive, some were impassive, and some refused to listen to physicians' HPV information and recommendations.

Sex. Sex emerged as a category of importance and avoidance. HPV exchanges were minimal; the physician did most of the talking. It may be that adolescents and parents did not want to discuss the HPV issues because of the sexual sub-context. Parents did not want to think of their child as sexually active and children did not want to give their parents an opportunity to do so. Thus, sex was alluded to in coded terms of age and gender. Age was mentioned as an indicator for sexual debut. Gender was thought to be a barrier to HPV vaccination because male adolescents cannot contract cervical cancer. In this manner parents avoided directly discussing sex and considering their child's sexual debut and thus imagining his sexual activities. Adolescents avoided sex discussions by not entering speaking or by not participating in the HPV vaccination decision.

Decision-making. Another category Decision-making is comprised of the agentic and decision-making behaviors. The adolescent-physician and adolescent-physician-parent encounters presented above can be examined for evidence of adolescent health

care decision-making capabilities. Some statements and behaviors demonstrated continued parental dependency such as Damon who ceded his decision-making to his mother, Quinton and Calvin who buried their heads on their mothers. Even Trent's behavior exemplified continued dependency. Trent shortly acknowledged that his "parents told me not to get anything I don't have to. So I have to talk to them about this [HPV vaccination]." Trent's subsequent disclosure qualifies what had appeared initially to be autonomous health care decision-making. Trent deferred vaccination because he was instructed to do so by his parents, not because he wanted to confer with his parents about HPV vaccination. The latter interpretation describes cooperative decision-making, whereas the former interpretation describes relinquishing decision-making and continued dependency on parents. Thus, adolescent decision-making was wide-ranged. A few made decisions alone; some made decision with their parent. Most avoided decision-making through deferring or submitting to their parents.

Adolescent health behavior. The category Adolescent health behavior expresses how adolescents attended to, processed, and participated in their clinic consultations. Most adolescents did not speak during HPV discussions. Yet many adolescents protested their vaccination. The vaccination shot was foremost in the minds of adolescents if they previously had a bad reaction to a vaccination. The protesting adolescents participated by asking questions and discussing the vaccination. As such these adolescents' statements did show a level of thoughtful reasoning though it was reasoning about the vaccination and not HPV issues. For example Asante inquired where on his body the shot was given; Thatcher tried to understand by comparing the vaccination to a flu shot; Adam understood that the pain was considerable and suspected it would interfere with his

playing sports; Carlos was concerned about adverse effects beyond the pain from the shot. This reasoning behavior is evidence that some adolescents engaged in their health care and contributed to health care decisions. Furthermore, though some parents encouraged their child's health-care participation either actively or passively, other parents actively discouraged their child's participation.

The analyses in this chapter of participant-physician encounters contribute four important findings regarding adolescent participation in discussions and decision-making for HPV vaccination. First, adolescents' behaviors indicate an awareness of what's transpiring during their health visits (Adolescent health behavior). Second, adolescents have different ways of yielding HPV vaccination decision-making to their parent, usually their mother (Decision-making). By yielding adolescents appear to pay little attention (Adolescent health behavior) to the specific HPV information discussed (HPV knowledge). This provides some indication that the adolescent is not participating. Third, some adolescents vigorously protest getting a vaccination (Adolescent health behavior and Decision-making) specifically declaring their distress is due to the imminent pain from the shot. This provides some indication that the adolescent is capable and willing to participate (Adolescent health behavior) and make decisions (Decision-making) but chooses not to participate in HPV discussions. Fourth, the unspoken subtext of adolescent sexual comportment might be a factor. Parents state their child's young age (Sex) permits them to postpone HPV vaccination decision-making and refrain from HPV discussions. Ultimately the perceptions of parents regarding their children and the adolescents' perceptions of their parents may be the best predictors of HPV vaccination decision-making.

Chapter 7: Discussion

How adolescents participate in clinical health care visits was examined. This research study focused on human papillomavirus and vaccination to provide evidence of how adolescents attend, process, understand, and respond to health information.

The health issue of human papillomavirus and its prevention guided this research. Physicians typically discussed the issues of HPV with parents and adolescents during their clinic visits. Adolescent participation in discussions and decision-making for HPV vaccination is opaque. First, adolescents' behaviors indicate an awareness of what's transpiring during their health visits. Second, adolescents have different ways of yielding HPV vaccination decision-making to their parent, usually their mother. By yielding adolescents appear to pay little attention to the specific HPV information discussed. This provides some indication that the adolescent is not participating. Third, some adolescents vigorously protest getting a vaccination specifically declaring their distress is due to the imminent pain from the shot. This provides some indication that the adolescent is capable and willing to participate and make decisions (Decision-making) but chooses not to participate in HPV discussions. Fourth, the unspoken subtext of adolescent sexual comportment might be a factor when parents state their child's young age permits them to postpone HPV vaccination decision-making and refrain from HPV discussions. It may be that the sexual sub-context of HPV infections contributed to mother's perceptions of their adolescent's sexual comportment and perceived vulnerability. The reasons that adolescents cede HPV vaccination decision-making are conjecture at this juncture.

Analyses of questionnaires, survey conversations, and participant-physician encounters yielded three insights toward understanding how adolescents participate in

health care decision-making.

1. Adolescents were receptive to health care information; they understood and responded to the information presented.
2. Parents and adolescents did not rely on the information to make their health care decisions.
3. Adolescents' participation in this health care setting was governed by their relationship with their parent.

Participation

In this study, merely a few adolescents showed concern about genital warts asking what they were, what they looked like, and agreeing to a vaccination to prevent them. Adolescents did not discuss other HPV issues. Yet they talked adamantly about the vaccination; adolescents refused shots because of their fear of pain and their conditioned aversion. Adolescents had selectively attended to this particular detail, the vaccination, and focused on the immediate pain and soreness from receiving a shot.

Fundamentally, adolescent protestations and resistance to vaccination are evidence that adolescents processed the HPV vaccination discussion and participated in their health care decision-making.

Almost half of the California high school girls in Mathuer, Mathuer & Reichling's (2010) study reported that they were involved in deciding about HPV vaccination unfortunately their level of involvement was not described. The adolescents in this research study demonstrated different levels of participation. All seemed to receive HPV information. Others understood the HPV information spoke out and were heard during HPV discussions; their views were taken into account and many influenced the HPV

vaccination decision.

HPV Knowledge

The results of this research project showed that participants recognized HPV yet had moderate to minimal knowledge of the issues involved. Furthermore, their knowledge and understanding of HPV and vaccination was not significantly related to their vaccination decision.

Public recognition of HPV and Gardasil has risen yet public HPV knowledge is consistently incomplete (Chan, et al, 2012; Daley, et al, 2010). In this research study parents identified information sources as family, other physicians, and friends; adolescents noted they had seen television commercials about HPV. Seventy-four percent of the adolescents surveyed and eighty-four percent of the parents surveyed recognized that HPV is a virus. Sixty-two percent of the adolescents and seventy percent of their parents surveyed knew that there is a vaccine that may prevent HPV infection. These are encouragingly high recognition rates. Slightly more than fifty percent of the adolescents surveyed knew that HPV is an STI and that condom use may prevent warts. Regrettably, more detailed knowledge about the causes, consequences, and how to control HPV was consistently lower among the adolescents surveyed. Their parents had somewhat more specific HPV knowledge. A little over seventy-one percent of the parents surveyed understood the relationship between HPV, pap smears, and cervical cancer. Notably, there was no relationship between HPV survey knowledge scores and adolescents' HPV vaccination reception.

Taking the HPV knowledge survey prompted adolescents and parents to engage with the HPV issue. For example, during survey conversations adolescents frequently and repeatedly sought HPV information; their parents and shared their personal experiences

and tended to explain their decisions. Contrariwise during participant-physician encounters physician spoke at length about HPV and vaccination parents responded appropriately and few adolescents even spoke. If adolescents spoke they spoke about the inoculation itself such as where the shot was given, how painful it would be, can it be postponed.

Parents frequently commented about male HPV infection. Parents' had knowledge that HPV caused cervical cancer which excluded male susceptibility to HPV infection. Consequently, parents seemed surprised that males could get HPV infections.

Adolescent-parent Relationship

Adolescents' attention to vaccination pain suggests a different adolescent agenda than that of disease (i.e., infection and cancer) prevention. Adolescents' focus on the immediate painful effects of receiving a vaccination reflects their moral outrage; parents are supposed to protect them from harm and pain, not subject them to it.

However adolescents had additional concerns that motivated their HPV participation. Adolescents were concerned with relationship maintenance. Adolescents knew that their parents perceived them to be sexually naïve and uninvolved. Adolescents strove to maintain this perception. It follows that one resolution for adolescents to was to relinquish HPV vaccination decision-making to their parents and avoid discussions of sex.

Many adolescents refrained from HPV discussions, deferring and ceding decision-making to their parent. This was their tactic to avoid discussing their personal comportment with parents as they navigated their autonomy. Parents also strove to maintain a relationship and worked toward balancing parent control and adolescent

autonomy. Part of these negotiations between adolescents and parents was to separate and yet remain attached; this required an information balancing ritual (Bakken & Brown, 2010). Both understood that information boundaries between them were in flux. So by focusing on the vaccination inoculation the adolescents in this study were able to ignore or avoid the issue of HPV contagion through sexual activity; they were able to circumvent discussing their personal comportment, and keep their sexual activities private. Adolescent strategies of protesting shots and deferring and ceding decision-making helped them to keep their activities (sexual and otherwise) private and avoid sex talks with their parents.

In different ways, sexual behavior was the unspoken influence on adolescents and parents during HPV vaccination conversations. Because HPV is an STI, some parents reasoned that not being sexually active precluded contracting HPV and ensured protection from the possibility of HPV infections and consequential adult cancers (see also Ruffin, et al, 2012). For example, a few parents stated that they and their child had discussed sex and neither had any difficulties having the discussion. In contrast, their children were silent; they did not confirm or contradict their parent's ascertain. Hence there were parents who maintained there was no urgency for their 11- and 12-year old, or even their 13-, 14-, or 15-year old to receive HPV vaccination (see also Gotlib, et al, 2009).

Parents, adolescents, and young adults have multiple and varied definitions of *having sex*. The nonverbal reactions of some adolescents when physicians mentioned oral sex provides further evidence that adolescents control what their parent knows about what the adolescent does. These adolescents had processed the details of the HPV

discussion and perhaps realized that their private behavior had left them vulnerable to HPV infection yet remained unwilling to enter the discussion. Adolescents regulated their participation based on relationship maintenance.

Perceptions

Parents' attitudes, their views of vaccinations, and world experiences appear to be the main influences on their HPV vaccination decisions. Some parents reasoned they were protecting their child from disease by accepting HPV vaccination while other parents reasoned they were protecting their child from adverse or unknown (the vaccine was too new) vaccine reactions by declining HPV vaccination. Both acceptance and decline of HPV vaccination were perceived to be preventative, though against different risks.

Some parents seemed surprised that the physician was recommending vaccination for their sons. Parents literally paused and thought about the implications of male HPV infections. When they understood that males could get HPV infections they were forced to consider how HPV infections were transmitted. Making that connection leads parents to contemplate their child as sexually active or at minimum acknowledge their child as capable of sexual behavior. Such considerations and thoughts re-image the child from vulnerable, pure, and innocent to independent, un-childlike, and sexually knowledgeable.

A frequent parent comment concerned the timing of receiving the HPV vaccination; that is when their child would need the shot. If the adolescent was not sexually active the shot was unnecessary. Parents seemed to regard their young children 11, 12, or 13 years old as sexually innocent, thus sexually inactive. Some parents even resisted thinking of their 14 or 15 year old children as sexually active. It seems that parents' notion of vulnerability precluded their adolescents as being sexually active.

The notion of childhood innocence could have been the reason why some parents did not allow their young children to participate in the survey because the extent of adolescents' knowledge could influence parents' HPV vaccination decision. If parents perceived their child had knowledge about HPV knowledge then the parent's perception of their child's innocence was challenged. Thinking of their child as sexually active would be to admit their child's innocence was lost. Parents could implement their role of protecting their vulnerable and innocent child who displays minimal HPV knowledge by declining HPV vaccination.

What Does Age Got To Do With It?

Perceptions pervade this issue, both parent perception of the child and adolescent perception of the parent. Parents, usually the mother, made the bulk of the HPV vaccination decisions. This is evidenced by adolescents' minimal participation during clinic conversations of HPV and vaccination. Mothers accepted their responsibilities for their children and their children's health. A few mothers acted to protect their children they perceived as vulnerable to physical harm, the vaccine. Mothers reported that their intentions for their child's HPV vaccination were based more on issues of their child's age than on their knowledge and understanding of the HPV and vaccination. It appears that age is used as an euphemism to refer to sexual knowledge and activities. Thus, parental decisions reflected their perceptions of their child's autonomy and sexual maturity. Mothers had preconceived notions of the age when their child would become sexually active and it was these notions that directed their HPV decisions. Hence mothers postponed HPV vaccination. Mothers acted to protect their children they perceived young of age, vulnerable and exposed to a loss of innocence (sexual knowledge). Thus, in

several ways parents' perception of their adolescent in terms of social maturity and sexual development affected HPV vaccination decision-making.

Tables

Table 1

<i>Sociodemographic Classifications of Survey Adolescents</i>						
	All adolescents (n = 237)		Adolescent females (n = 167) (70%)		Adolescent males (n = 70) (30%)	
Age in years						
Mean	15.51		15.65		15.17	
Median	15		16		15	
SD	2.24		2.31	(78%)	2.04	
Younger: 11 -17	189	(80%)	130	(22%)	59	(84%)
Older: 18 - 21	48	(20%)	37		11	(16%)
Race						
Asian	6	(3%)	5	(3%)	1	(1%)
Black	74	(31%)	51	(30%)	23	(33%)
Hispanic	93	(39%)	74	(44%)	19	(28%)
White	62	(26%)	36	(22%)	26	(38%)
Native American	2	(1%)	2	(1%)		
Residence						
Urban = City	115	(49%)	75	(45%)	40	(57%)
Suburban	122	(51%)	92	(55%)	30	(43%)
Health insurance						
Medicaid	82	(34%)	47	(28%)	24	(35%)
private	92	(39%)	61	(36%)	23	(33%)
self-pay	10	(4%)	5	(3%)	4	(6%)
other	4	(2%)	3	(2%)	1	(1%)
not reported	49	(21%)	52	(31%)	17	(25%)

Table 2

Survey Participants' Education

Grade completed	Adolescents n (%)			Parents n (%)		
	City	Suburbs	Totals	City	Suburbs	Totals
4 th	-	1	1 (<1%)			
5 th	4 (67%)	2 (33%)	6 (3%)			
6 th	8 (42%)	11 (58%)	19 (8%)			
7 th	15 (60%)	10 (40%)	25 (11%)			
8 th	18 (47%)	20 (53%)	38 (16%)			
9 th	16 (55%)	13 (45%)	29 (12%)			
10 th	20 (47%)	23 (53%)	43 (18%)			
11 th	15 (41%)	22 (59%)	37 (16%)			
High school graduate	13 (50%)	13 (50%)	26 (11%)	13 (76%)	4 (24%)	48 (25%)
Some post-secondary	6 (46%)	7 (53%)	13 (6%)	31 (65%)	17 (35%)	37 (20%)
Associate/technical degree				24 (65%)	13 (35%)	19 (10%)
College graduate				10 (53%)	9 (47%)	44 (23%)
Master's or higher degree				6 (14%)	38 (86%)	20 (11%)
Other ^a				4 (20%)	16 (80%)	20 (11%)
Totals	115 (49%)	122 (51%)	237	91 (48%)	97 (52%)	188

^a This category includes 3 parents who indicated that they had no high school education and 17 parents who indicated only some high school education.

Table 3

Sociodemographic Classifications of Adolescents in Participant-physician Encounters

	All adolescents (n = 30)	Adolescent females (n = 7) (23%)	Adolescent males (n = 23) (77%)
Age in years			
Mean	15.17	14.43	15.39
Median	15	14	15
SD	1.7	1.62	1.67
Younger: 11 -17	26 (86%)	7 (27%)	19 (73%)
Older: 18 - 21	4 (14%)	-	4 (100%)
Race			
Black	9 (30%)	2 (29%)	7 (33%)
Hispanic	3 (10%)	-	3 (28%)
White	18 (60%)	5 (71%)	13 (38%)
Country of birth			
United States	29 (97%)	7 (24%)	22 (76%)
Middle Eastern country	1 (3%)	-	1 (100%)

Table 4

Health Care Providers Involved in Participant-physician Encounters

Title	Gender	Race	Name assigned	Number of encounters
Board-certified lead physician	female	White	Dr. Golda Gate	12
Board-certified lead physician	male	White	Dr. Barry Commodore	8
Third-year resident physician	female	Indian	Dr. Walthea Whitman	3
Third-year resident physician	female	Hindi	Dr. Georgia Washington	1
Third-year resident physician	male	White	Dr. Benjamin Franklin	3
Nurse practitioner	female	White	NP Delaware Memorial	3

Note. The male third-year resident physician was born in Egypt. All other providers were born in the United States

Table 5

Survey Adolescents' and Parents' HPV Knowledge Scale Responses

Category and item	All adolescents (n=237)			Parents (n=188)		
	True	False	Not Sure	True	False	Not Sure
About the Cause of HPV						
There are many types of HPV [1]	46.01	8.86	44.30	46.81	11.17	41.49
Only females get HPV [6]	21.10	47.26	31.22	24.47	49.47	25.53
HPV is a virus [9]	74.26	5.06	20.68	84.04	2.66	13.30
HPV is spread on toilet seats [15]	17.30	26.16	56.54	5.32	61.70	32.98
HPV is an STI [16]	51.48	10.55	37.97	64.89	12.77	21.81
You can get HPV thru poor personal hygiene [19]	22.78	20.68	56.54	9.57	55.85	34.57
About the Control of HPV						
Antibiotics can cure HPV [3]	22.36	36.29	40.51	18.09	46.81	35.11
Once you get HPV you always have it [10]	35.02	23.21	41.77	40.96	19.15	38.89
A vaccine may prevent HPV [11]	62.45	9.28	28.27	70.21	6.91	22.87
HPV can be cured [14]	28.27	23.21	48.10	22.34	35.64	41.49
HPV may go away by itself [18]	7.59	46.41	45.99	6.38	67.55	26.06
You can decrease the chance of transmitting warts during intercourse [21]	23.21	26.12	50.63	42.02	25.00	32.45
Using a condom will decrease the chance of transmitting warts [22]	52.74	12.66	34.60	61.17	11.70	27.13
About the Consequences of HPV						
HPV causes HIV/AIDS [2]	16.03	37.55	46.41	5.85	64.89	28.72
HPV can cause abnormal Pap smears [5]	32.07	6.75	60.76	71.81	2.13	25.53
HPV causes herpes [7]	10.97	30.38	58.65	15.43	42.02	42.55
HPV affects your ability to get pregnant [8]	37.13	13.50	49.37	46.28	16.49	37.23
HPV causes genital warts [12]	22.78	16.88	59.92	37.77	17.02	45.21
HPV causes cervical cancer [17]	44.30	9.28	46.41	72.87	3.19	23.94
About the Identity of HPV						
You can always tell if someone has HPV [4]	3.80	67.51	28.27	2.13	77.66	20.21
You can have HPV without knowing it [13]	70.46	3.38	25.74	77.68	1.06	21.28
Even if you do not see a wart, you can transmit HPV [20]	49.47	7.59	42.19	54.79	11.175	34.04

Note. Items are presented in categories their order of appearance on the questionnaire in brackets. Mean percent responses are shown and correct responses bolded.

Table 6

Survey Adolescents' HPV Knowledge Scores

Parameter	Number of adolescents	Mean % correct HPV knowledge score
All adolescents	237	41%
11 – 17 years old adolescents	189	39%
18 – 21 years old adolescents	48	52%
Female adolescents	167	45%
Male adolescents	70	34%
Black adolescents	74	36%
Hispanic adolescents	93	50%
White adolescents	62	35%
Other (race) adolescents	8	41%
City (urban) adolescent residents	115	35%
Town (suburban) adolescent residents	122	48%

Table 7
Regression Results: Age and Gender Predictors for Survey Adolescents' HPV Knowledge Scores

Predictor	df	SS	MS	F	Pr > F
Type I					
Adolescents' age	10	23538.65736	2353.86574	5.58	<.0001
Adolescents' gender	1	5182.32389	5182.32389	12.29	0.0006
Adolescent's age X gender	9	8886.48878	987.38764	2.34	0.0155
Type II					
Adolescents' age	10	12854.71675	1285.47168	3.05	0.0012
Adolescents' gender	1	808.22239	808.22239	1.92	0.1677
Adolescents' age X gender	9	8886.48878	987.38764	2.34	0.0155

Note: The intercept in the model was -24.02197. The R^2 for the overall model was 0.292158; $F(20,236) = 4.46$, $p < .0001$.

Table 8
Regression Results: Sociodemographic Predictors for Survey Adolescents' HPV Knowledge Scores

Predictor	<i>b</i>	<i>b</i> SE	<i>t</i>	Pr > <i>t</i>	Standardized estimate
Adolescents' age	3.83680	0.79002	4.86	<.0001	0.32502
Adolescents' gender	-6.07121	3.36975	-1.80	0.0733	-0.12108
Black	-2.33027	4.21666	-0.55	0.5812	-0.04579
Hispanic	7.76157	4.53331	1.71	0.0886	0.16382
Other (race)	-3.25145	9.76823	-0.33	0.7396	-0.02476
Adolescents' residence	3.83019	3.74224	1.02	0.3075	0.08218
Parents' education	1.21200	1.13584	1.07	0.2874	0.08449

Note: The intercept in the model was -24.02197. The R^2 for the overall model was 0.2452 $F(7,184) = 8.21, p < .0001$.

Table 9

Predictor	E	SE	Wald χ^2	Pr > χ^2	Point Estimate	95% Wald Confidence Limits
Adolescents' age	0.2793	0.1032	7.3249	0.0068	1.322	1.080 1.619
Adolescent will decide about HPV vaccination	0.5641	0.3606	2.4474	0.1177	1.758	0.867 3.564
Adolescents' autonomy judgments	0.0329	0.0686	0.2298	0.6317	1.033	0.903 1.182
Adolescents' HPV knowledge score	-0.0126	0.00801	2.4846	0.1150	0.987	0.972 1.003
Parent's HPV knowledge score	0.00249	0.00641	0.1508	0.6977	1.002	0.990 1.015
Parents' judgments of adolescents' autonomy	0.0398	0.0584	0.4636	0.4959	1.041	0.928 1.167
Parent will decide about HPV vaccination	-0.3864	0.4595	0.7070	0.4005	0.680	0.276 1.672

Note: The intercept in the model was -3.5376. For all predictors df=1. The Wald χ^2 for the overall model was 17.0882; df=7; $p < .0168$.

Table 10
Correlations: Survey Participants' Autonomy Judgment Scores, Health Behavior Responses, and Sociodemographics

Variable	1	2	3	4	5	6	7	8	9
1. Adolescent's Age	-								
2. Adolescents' Gender	0.09121	-							
3. Adolescents' education	0.93678***	-0.11283 [†]	-						
4. Adolescents' autonomy score	0.32212***	-0.01955	0.30389***	-					
5. Adolescents' intent to receive vaccination	0.12613 [†]	0.02224	-0.12716 [†]	-0.05567	-				
6. Adolescent will decide about vaccination	0.43886***	-0.05737	0.45465***	0.27400***	-0.31100***	-			
7. Adolescents' trust of physician	-0.11665 [†]	-0.03865	-0.11215 [†]	-0.19634**	0.14564*	-0.22219***	-		
8. Parents' judgment of adolescents' autonomy	0.7120	-0.06928	0.03227	0.28689**	-0.09727	0.10632	-0.14908	-	
9. Parent will decide about vaccination	-0.6876*	0.02642	-0.17472*	0.05926	-0.02050	-0.01346	-0.09663	-0.05377	-
10. Adolescents' vaccination status	0.20697**	-0.30738***	0.18938**	0.05854	0.31306***	0.16964**	-0.10331	0.11765	-0.06422

Note. All adolescents n = 237 are included. * $p < .05$; ** $p < .01$; *** $p < .001$; [†] p is marginally significant

Table 11
Survey Adolescents' and Their Parents' Health Behavior Responses

Responses (%)				
Health behavior	True	False	Not Sure	
Adolescent survey item				
Trust				
I trust the doctor with my personal information [1]	212 (89%)	21 (9%)	4 (2%)	
Decider				
I will decide if I will get the HPV vaccination [6]	139 (59%)	37 (15%)	61 (26%)	
Intent				
I am going to get a vaccination shot for HPV [15]	126 (53%)	16 (7%)	95 (40%)	
Parent survey item				
Trust				
I trust the doctor with my personal information [1]	180 (96%)	3 (1%)	5 (3%)	
Decider				
I will decide if my child will get the HPV vaccination [5]	149 (80%)	15 (8%)	24 (12%)	

Note. Statements are presented in categories with their order of appearance in brackets.

Table 12

Regression Results: Predictors for Survey Parents' HPV Knowledge Scores

Predictor	<i>b</i>	<i>b</i> SE	<i>t</i>	Pr > <i>t</i>	Standardized estimate
Adolescents' age	1.10829	0.83854	1.32	0.1880	0.07745
Adolescents' gender	-0.32560	3.57482	-0.09	0.9275	-0.00536
Black	6.83132	4.47311	1.53	0.1285	0.11073
Hispanic	20.55619	4.85064	4.24	<.0001	0.35792
Other (race)	5.61544	10.37015	0.54	0.5888	0.03528
Adolescents' residence	2.22572	4.06813	0.55	0.5850	0.03940
Parents' education	5.69053	1.24027	4.59	<.0001	0.32724
Adolescents' insurance type	-8.44480	3.81603	-2.21	0.0282	-0.14789

Note: The intercept in the model was 13.58873 (13.52736). The R^2 for the overall model was 0.4252 $F(8,176) = 16.27, p < .0001$.

Table 13

Predictor	E	SE	Wald χ^2	Pr > χ^2	Point Estimate	95% Wald Confidence Limits
Adolescents' age	-0.2569	0.1071	5.7566	0.0164	0.773	0.627 0.954
Adolescents' gender	0.3777	0.4564	0.6849	0.4079	1.459	0.596 3.569
Adolescents' autonomy judgments	0.0595	0.0823	0.5224	0.4698	1.061	0.903 1.247
Parents' HPV knowledge score	0.0140	0.00846	2.7222	0.0990	1.014	0.997 1.031
Parents' judgments of adolescents' autonomy	-0.0583	0.0819	0.5064	0.4767	0.943	0.803 1.108
Adolescent's residence	0.0299	0.4925	0.0037	0.9515	1.030	0.392 2.705
Black	0.1462	0.4838	0.0913	0.7625	1.157	0.448 2.987
Hispanic	1.0689	0.6548	2.6654	0.1026	2.912	0.807 10.509
Other (race)	-0.1243	1.3044	0.0091	0.9241	0.773	0.627 0.954
Parents' education	0.2065	0.1657	1.5534	0.2126	1.459	0.596 3.569

Note: The intercept in the model was 3.4186. For all individual predictors df=1. The Wald χ^2 for the overall model was 22.1687; df=10; $p < .0143$.

Table 14

Predictor	E	SE	Wald χ^2	Pr > χ^2	Point Estimate	95% Wald Confidence Limits
Adolescents' age	0.6275	0.2787	5.0712	0.0243	1.873	1.085 3.234
Adolescents' gender	-1.5186	0.3901	15.1549	<.0001	0.219	0.102 0.470
Adolescents' education	-0.3380	0.2737	1.5247	0.2169	0.713	0.417 1.220
Adolescents' residence	-1.0641	0.4521	5.5388	0.0186	0.345	0.142 0.837
Black	-0.6117	0.4875	1.5744	0.2096	0.542	0.209 1.410
Hispanic	0.2678	0.5361	0.2495	0.6174	1.307	0.457 3.738
Other (race)	-0.1145	1.0340	0.0123	0.9119	0.892	0.118 6.768
Adolescent reported previous bad vaccination reaction	-0.2085	0.2770	0.5666	0.4516	0.812	0.472 1.397
Parents' education	-0.0809	0.1368	0.3499	0.5542	0.922	0.705 1.206
Adolescents' insurance type	-0.1827	0.4206	0.1886	0.6641	0.833	0.365 1.900

Note: The intercept in the model was -5.3729. For all predictors df=1. The Wald χ^2 for the overall model was 29.0662; df=10; $p < .0012$.

Table 15

Vaccination Status of Adolescents Involved During Participant-Physician Encounters by Age, Gender, and Race.

	Vaccination status		
	Received n (%)	Declined n (%)	Postponed n (%)
All adolescents			
11 – 17 years old (n=26)	15 (58%)	10 (38%)	1 (4%)
18 – 21 years old (n=4)	3 (75%)	-	1 (25%)
11 – 21 years old (n=30)	18 (60%)	10 (33%)	2 (7%)
Female adolescents			
11 – 17 years old (n=7)	1 (14%)	6 (86%)	-
18 – 21 years old	-	-	-
11 – 21 years old (n=7)	1 (14%)	6 (86%)	-
Black	-	2	-
Hispanic	-	-	-
White	1 (20%)	4 (80%)	-
Male adolescents			
11 – 17 years old	14 (74%)	4 (21%)	1 (5%)
18 – 21 years old	3 (75%)	-	1 (25%)
11 – 21 years old	17 (74%)	4 (17%)	2 (9%)
Black	6 (86%)	1 (14%)	-
Hispanic	-	3	-
White	9 (70%)	2 (15%)	2 (15%)

Illustrations

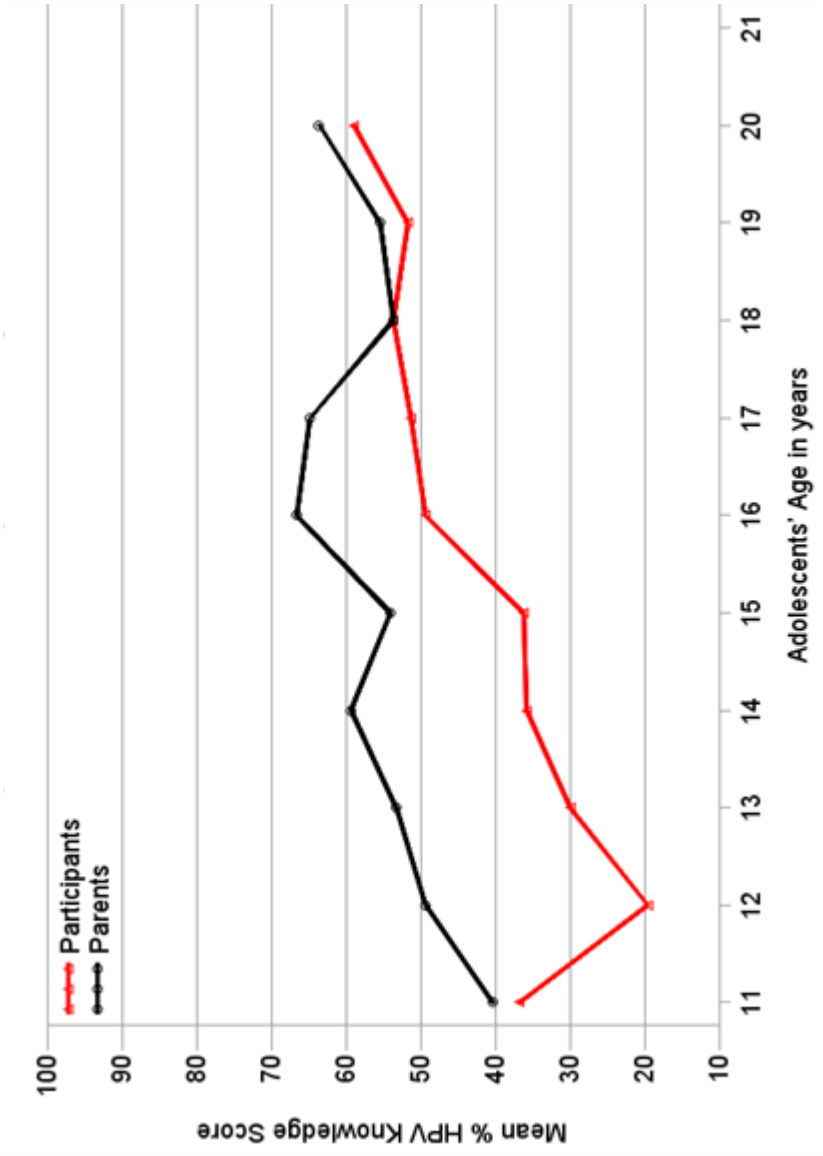


Figure 1: Survey Adolescents' & Parents' HPV Knowledge: Compares Mean % Score by Adolescents' Age

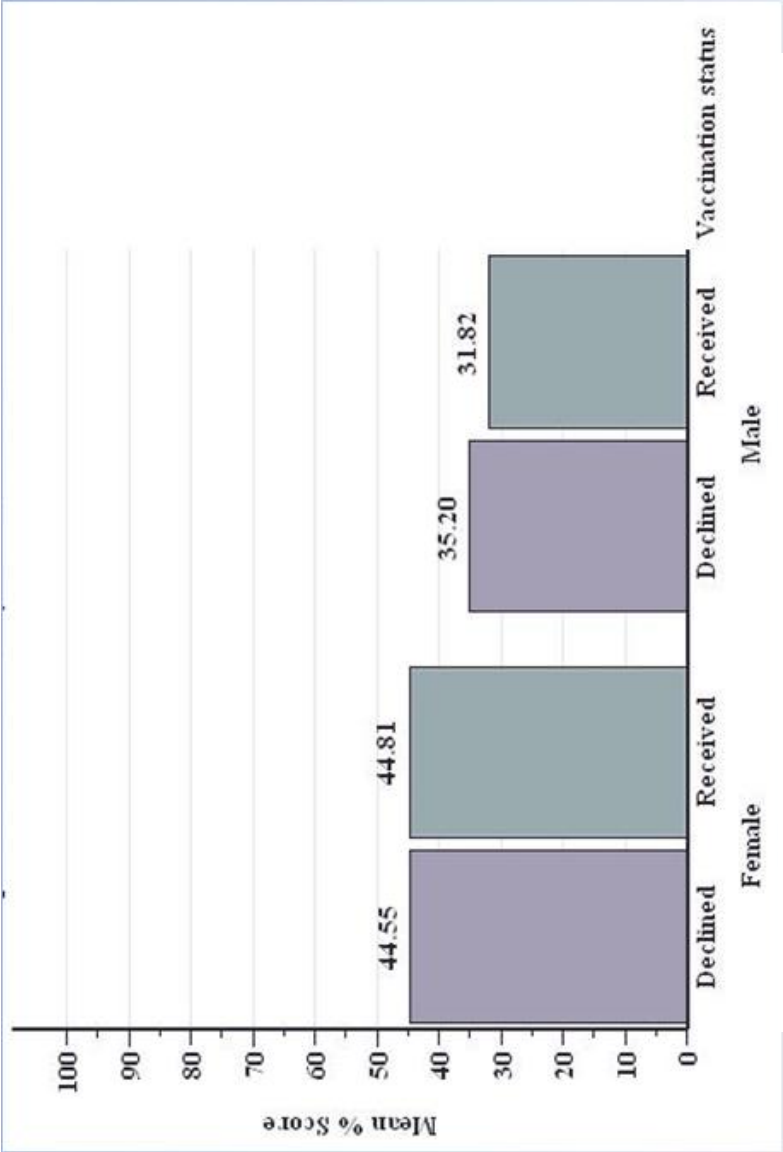


Figure 2: Survey Adolescent's HPV Knowledge: Compares Mean % Correct by Gender across Vaccination Status

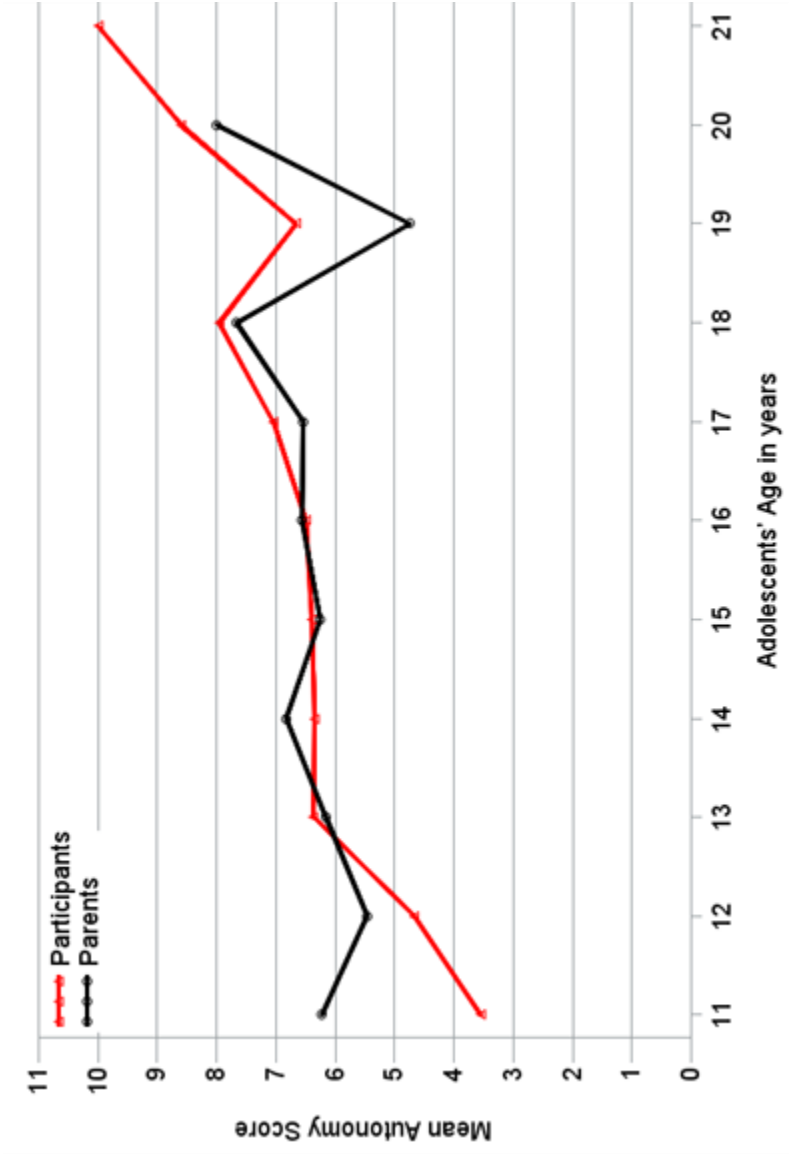


Figure 3: Survey Adolescents' and Parents' Autonomy Scores: Compares Mean Autonomy Score by Adolescents' Age

Appendices

Appendix A1: Adolescent Survey – page 1

Please mark the following statements about HPV as True, False, or Not Sure.

	True	False	Not Sure
There are many types of HPV. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV causes HIV/AIDS. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Antibiotics can cure HPV. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You can always tell when someone else has HPV. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV can cause abnormal Pap smears. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Only women get HPV. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV causes herpes. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV affects your ability to get pregnant. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV is a virus. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Once you get HPV, you always have it. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A vaccine may prevent HPV. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV causes genital warts. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You can have HPV without knowing it. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV can be cured. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV is spread on toilet seats. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV is a sexually transmitted infection. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV causes cervical cancer. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV may go away by itself. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You can get HPV through poor personal hygiene. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Even if you do not see a wart, you can transmit HPV. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You can decrease the chance of transmitting warts during intercourse. --	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using a condom will decrease the chance of transmitting warts. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix A2: Adolescent Survey – page 2

Please mark the following statements as True, False, or Not Sure.

	True	False	Not
Sure			
I trust the doctor with my personal information. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would seek medical help if I found a genital wart. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it difficult to decide. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know someone who has/had cervical cancer. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Making a choice is easy. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will decide if I will get the HPV vaccination. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When asked, I know what I want. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I once had a bad reaction to a vaccination. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find myself not knowing what to think. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know someone who is HPV infected. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often in doubt about what to do. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If I had genital warts I would continue to be sexually active. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is a test to diagnose HPV in males. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If I had genital warts I would tell my partner. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am going to get a vaccination shot for HPV. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix A3: Survey/ Enrollment Questionnaire – Adolescent

Study ID # _____ Date _____

Birth date _____

At which office are you seen?

- ☐ Camden office
- ☐ Voorhees office

What city do you live in? _____

Please describe your gender:

- ☐ Male
- ☐ Female

How would you describe your ethnic or racial background?

- ☐ Asian
- ☐ Black
- ☐ White
- ☐ Other: _____

Are you Hispanic or Latino/Latina?

- ☐ Yes: _____
- ☐ No

Where were you born?

- ☐ U.S.
- ☐ U.S. colony: _____
- ☐ Other: _____

What is the highest grade you have completed? _____

Appendix A4: Parent Survey – page 1

Please mark the following statements about HPV as True, False, or Not Sure.

	True	False	Not Sure
There are many types of HPV. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV causes HIV/AIDS. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Antibiotics can cure HPV. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You can always tell when someone else has HPV. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV can cause abnormal Pap smears. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Only women get HPV. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV causes herpes. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV affects your ability to get pregnant. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV is a virus. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Once you get HPV, you always have it. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A vaccine may prevent HPV. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV causes genital warts. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You can have HPV without knowing it. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV can be cured. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV is spread on toilet seats. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV is a sexually transmitted infection. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV causes cervical cancer. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HPV may go away by itself. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You can get HPV through poor personal hygiene. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Even if you do not see a wart, you can transmit HPV. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You can decrease the chance of transmitting warts during intercourse. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using a condom will decrease the chance of transmitting warts. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix A5: Parent Survey – page 2

Please mark the following statements as True, False, or Not Sure.

	True	False	Not Sure
I trust the doctor with personal information. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child finds it difficult to decide. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child doesn't know anyone who has/had cervical cancer. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child finds making a choice is easy. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will decide if my child gets the HPV vaccination. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When asked, my child knows what he/she wants. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child once had a bad reaction to a vaccination. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child doesn't know what to think. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows someone who is HPV infected. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child is often in doubt about what to do. -----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix A6: Survey Enrollment Questionnaire – Parent

Study ID # _____ Date _____

Birth date _____

At which office are you seen?

- ☐ Camden office
☐ Voorhees office

What city do you live in? _____

Please describe your gender:

- ☐ Male
☐ Female

How would you describe your ethnic or racial background?

- ☐ Asian
☐ Black
☐ White
☐ Other: _____

Are you Hispanic or Latino/Latina?

- ☐ Yes: _____
☐ No

Where were you born?

- ☐ U.S.
☐ U.S. colony: _____
☐ Other: _____

What is the highest grade you have completed in school?

- ☐ No high school
☐ some high school but did not graduate
☐ High school graduate
☐ GED
☐ Some college or trade school
☐ Associate's degree or certificate
☐ Bachelor's degree
☐ Master's degree or higher

What is your health insurance now?

- ☐ Medicaid (MassHealth; Americhoice; SCHIP)
☐ Care Net/ Free Care
☐ Private / HMO
☐ Self pay
☐ N/A

What kind of health insurance does your child have now?

- ☐ Medicaid (MassHealth; Americhoice; SCHIP)
☐ Care Net/ Free Care
☐ Private / HMO
☐ Self pay
☐ N/A

HPV^(HUMAN PAPILLOMAVIRUS)VACCINE

WHAT YOU NEED TO KNOW

1 What is HPV?

Genital human papillomavirus (HPV) is the most common sexually transmitted virus in the United States.

There are about 40 types of HPV. About 20 million people in the U.S. are infected, and about 6.2 million more get infected each year. HPV is spread through sexual contact.

Most HPV infections don't cause any symptoms, and go away on their own. But HPV is important mainly because it can cause cervical cancer in women. Every year in the U.S. about 10,000 women get cervical cancer and 3,700 die from it. It is the 2nd leading cause of cancer deaths among women around the world.

HPV is also associated with several less common types of cancer in both men and women. It can also cause genital warts and warts in the upper respiratory tract.

More than 50% of sexually active men and women are infected with HPV at sometime in their lives.

There is no treatment for HPV infection, but the conditions it causes can be treated.

2 HPV Vaccine - Why get vaccinated?

HPV vaccine is an inactivated (not live) vaccine which protects against 4 major types of HPV.

These include 2 types that cause about 70% of cervical cancer and 2 types that cause about 90% of genital warts. *HPV vaccine can prevent most genital warts and most cases of cervical cancer.*

Protection from HPV vaccine is expected to be long-lasting. But vaccinated women still need cervical cancer screening because the vaccine does not protect against all HPV types that cause cervical cancer.

3 Who should get HPV vaccine and when?

Routine Vaccination

- HPV vaccine is routinely recommended for girls 11-12 years of age. Doctors may give it to girls as young as 9 years.

Why is HPV vaccine given to girls at this age? It is important for girls to get HPV vaccine before their first sexual contact – because they have not been exposed to HPV. For these girls, the vaccine can prevent almost 100% of disease caused by the 4 types of HPV targeted by the vaccine.

However, if a girl or woman is already infected with a type of HPV, the vaccine will not prevent disease from that type.

Catch-Up Vaccination

- The vaccine is also recommended for girls and women 13-26 years of age who did not receive it when they were younger.

HPV vaccine is given as a 3-dose series:

1st Dose:	Now
2nd Dose:	2 months after Dose 1
3rd Dose:	6 months after Dose 1

Additional (booster) doses are not recommended.

HPV vaccine may be given at the same time as other vaccines.

4 Some girls or women should not get HPV vaccine or should wait

- Anyone who has ever had a life-threatening allergic reaction to yeast, to any other component of HPV vaccine, or to a previous dose of HPV vaccine should not get the vaccine. Tell your doctor if the person getting the vaccine has any severe allergies.

HPV Vaccine

2/2/2007

Appendix C: A power calculation to determine the sample size needed to complete the HPV Knowledge survey

Sample Size Calculation:

Though this study involves a convenience sample of adolescents, a power calculation was computed to reduce the probability of a Type II error and determine sample size.¹

Women's correct responses from Daley's study were used to determine sample size in the present adolescent study.²

Confidence Level	Sample Size (N)	Target Width	Actual Width	Proportion (P)	Lower Limit	Upper Limit	Width if P = 0.5
0.800	168	0.100	0.100	0.350	0.301	0.401	0.104
0.900	265	0.100	0.100	0.350	0.301	0.401	0.104
0.950	367	0.100	0.100	0.350	0.301	0.401	0.105

Report Definitions:

1. Confidence level is the proportion of confidence intervals (with the same confidence level.) in repeated samples of the same size that would contain the population proportion.
2. N is the size of the sample drawn from the population.
3. Width is the distance from the lower limit to the upper limit.
4. Target Width is the value of the width that is entered into the procedure.
5. Actual Width is the value of the width that is obtained from the procedure.
6. Proportion (P) is the assumed sample proportion.
7. Lower Limit is the lower limit of the confidence interval.
8. Upper Limit is the upper limit of the confidence interval.
9. Width if P = 0.5 is the maximum width for a confidence interval with sample size N.

Summary Statement: A sample size of 168 produces a two-sided 80% confidence interval with a width equal to $\pm 5\%$ when the sample proportion is 35%

Parents are included in this study to contribute to our knowledge base of understanding human papillomavirus. We have no prior information as to parents' responses on the HPV Knowledge Scale so we cannot calculate a sample size for parents in this study. Power and confidence interval will be reported post hoc.

¹ Fleiss, J. L., Levin, B., Paik, M.C. 2003. *Statistical Methods for Rates and Proportions*. Third Edition. John Wiley & Sons. New York.

Newcombe, R. G. 1998. 'Two-Sided Confidence Intervals for the Single Proportion: Comparison of Seven Methods.' *Statistics in Medicine*, 17, pp. 857-872.

² Daley, E.M.; Perrin, K.M.; Vamos, C.; Webb, C.; Mueller, T.; Packing-Ebuen, J.L.; Rayko, H.L.; McFarlane, M.; McDermott, R.J. (2008) HPV Knowledge Among HPV+ Women. *American Journal of Health Behavior*. 32(5): 477-487.

Appendix D1: Age, Ethnicity, and Gender of Survey Participants Sited
by Pseudonym

Pseudonym		Age	Gender	Ethnicity	Accompanying Adult
Adina	Arce	15	female	Hispanic	mother
Adrienne	Giagunto	14	female	White	mother
Albert	Ercolino	15	male	White	mother
Anastasia	Nikolis	13	female	White	mother
Angelina	Folletta	13	female	White	grandmother
April	Messina	17	female		mother
Barton	Morgan	15	male	Black	mother
Bernard	Steele	11	male	Hispanic	father
Blaire	Smith	16	female		mother
Brad	Garnett	14	male	White	mother
Carol	Reynolds	13	female		mother
Cherokee	Wade	15	female	White	mother
Christopher	Carbone	18	male		
Dallas	Graham	14	male	White	father
Dawn	Myers	15	female		mother
Dolores	Dietch	16	female	White	mother
Donald	Weston	17	male	White	mother
Donna	Donne	17	female	Black	mother
Drake	Zegan	15	male	White	mother
Elena	Donne	16	female	Black	mother
Ellen	Becker	16	female	White	mother
Ellis	Lundy	14	male	White	mother
Fletcher	Little	15	male	White	mother
Gunther	Gunn	20	male	White	
Ida	Pascal	18	female	White	
Josephine	Castillo	19	female	Hispanic	mother
June	Tapper	11	female	White	mother
Katrina	Langston	11	female	Black	mother
Leslie	Kunmr		Female		mother
Lonnie	Horvath	14	female	White	mother
Mary Kay	Castor	11	female		mother
Matthias	Amhera	16	male	Black	mother
Melvin	Vance	16	female	White	mother
Mina	Gilmore	20	female	Black	
Mona	Keebler	15	female		mother

Appendix D1 continued: Age, Ethnicity, and Gender of Survey Participants
Listed by Pseudonym

Pseudonym		Age	Gender	Ethnicity	Accompanying Adult
Morgan	Quinn	12	female	White	mother
Mona	Keebler	15	female		mother
Morgan	Quinn	12	female	White	mother
Noah	Sherlock	17	male	White	aunt
Parker	McManis	18	male	White	
Paulette	Suero	18	female	Black	
Pernell	Roberts	16	male	Hispanic	mother
Phillip	Mott	18	male	White	father
Ray	Elmer	15	male	Black	mother
Renee	Barber	16	female	White	mother
Rhea	Persia	13	female	Hispanic	mother
Stella	Senate	18	female	Black	
Ruth	Trump	18	female	White	mother
Selma	Murray	14	female	White	father
Tabitha	Janis	18	female		mother
Tracey	Stein	15	female	White	mother
Turner	Price	18	male	Hispanic	
Tyos	Alvarez	15	female	Hispanic	mother
Veronica	Bailey	15	female	Black	mother
Wilma	Flint	15	female		mother
	Ms. Dunlop	11	female		mother
	Ms. Fitzer	13	female	Black	mother
	Ms. Kowalski	15	female		mother
	Ms. Meade	9	female		mother
	Ms. McFadden	12	female		mother
	Ms. Sharroitt				mother

Appendix D2: Age, Ethnicity, and Gender of Participants of Participant-physician Encounters Listed by Pseudonym

Pseudonym		Age	Gender	Ethnicity	Accompanying Adult
Adam	Fielder	16	male	White	mother
Asante	Diamond	16	male	Black	step-father
Bella	Burch	12	female	White	mother
Calvin	Cash	11	male	Black	mother
Carlos	Hanson	18	male	Hispanic	
Curtis	Foles	18	male	White	
Cyrus	Briggs	14	male	White	father
Damon	Abbot	14	male	White	mother
Doug	House	18	male	Black	
Drew	Miller	15	male	White	mother
Ga'briel	Chandler	13	female	Black	mother
Horatio	Caruso	15	male	White	mother
J.J.	Haruki	15	male	White	mother
Jasper	Hubbard	15	male	White	mother
Julio	Hanson	16	male	Hispanic	mother
Kenyatta	Carter	16	male	Black	mother
Luther	Celek	17	male	White	father
Marsha	Kennedy	14	female	White	mother
Myranda	Swanson	14	female	Black	mother
Quinton	Rice	14	male	Black	mother
Ruben	Khan	15	male	Hispanic	mother
Sandy	Kennedy	16	female	White	mother
Sydney	Chamberlain	16	female	White	mother
Thatcher	Lee	14	male	White	mother
Trent	Court	18	male	White	
Trindon	Ellerbe	15	male	Black	mother
Wyatt	Anderson	11	male	Black	mother
Zane	Chamberlain	14	male	White	mother

Appendix E: Cronbach Coefficient Alphas for HPV knowledge scale items and autonomy scale items

Group	N participants	Scale	N items	α
All Adolescents	237	Attitudinal Autonomy	5	0.684940
All Parents	190	Attitudinal Autonomy	5	0.734718
All Adolescents	237	HPV Knowledge	22	0.900536
All Parents	190	HPV Knowledge	22	0.922850

Endnotes

Throughout this thesis human papillomavirus is referred to by its acronym *HPV*.

² *Papilloma* is commonly known as a wart.

³ An individual under the age of 18 years is considered *emancipated* if she is in the military, is married, is pregnant, has a child herself, has a court-ordered release from her parents, or is self-supporting.

⁴ The thought is that if their parents were notified adolescents would not otherwise seek the medical care and treatment necessary to remain in or to obtain good health.

⁵ *Habitus*, this manner of an individual acquiring meaning through the business of individuals acting in public spaces are techniques to behave that are limited by conceptions of the social structures which produced the situation (Wacquant, 1992; p9).

⁶ At times participants aged 11 through 17 years are referred to as *young adolescents* as to differentiate them from *older adolescents* aged 18 through 21 years.

⁷ The term *mother* is used interchangeably with the term *parent* throughout this manuscript unless one of these 17 fathers was specifically involved in the situation at hand.

⁸ Critical adolescent issues included for example sexual abuse, incarceration, or self-abusive behaviors.

⁹ This aspect of the typical physician visit is explained later in this chapter.

¹⁰ The Common Sense Model of Self-regulation served as the theoretical framework for this HPV knowledge scale (Leventhal & Mora, 2008).

¹¹ Used by permission through personal communication.

¹² Dr. Noom did not respond to correspondence and attempts to gain permission to use this autonomy scale.

¹³ These authors chose items on the basis of conceptual similarity and write that their “idea of attitudinal autonomy is most closely related to the concepts of beliefs about one’s capabilities (Bandura, 1977); attitudinal independence (Hoffman, 1984); goal setting (Markus and Wurf, 1987); reflection upon preferences, wishes, and desires (Dworkin, 1988); decision making (Frank *et al.*, 1988); and personal goals (Allen *et al.*, 1994)” (p 578).

¹⁴ Throughout this manuscript survey conversations are referred to as *summaries* in order to differentiate them from *transcriptions* of audio-taped participant-physician encounters.

¹⁵ Qualitative analyses were done manually by this investigator without specialized computer programs.

¹⁶ Because this adolescent medical practice was academically affiliated, it was not unusual for multiple health care providers (such as first-year residents, resident physicians, and nurse practitioners) to be present.

¹⁷ The term *vaccination status* is used to differentiate adolescents who received an HPV vaccination (at least one of the recommended three vaccine doses) from those who declined an HPV vaccination (had none of the recommended vaccine doses).

¹⁸ See Chapter 3 above for specifics of the HPV Knowledge scale devised by Daley *et al.*, 2008.

¹⁹ Correlational analyses, involving all adolescents' responses, showed significant response correspondence among the 22 survey item responses so as to conduct all subsequent analyses using the composite score of all 22 survey items (see Appendix 8 for Cronbach alphas). Comparisons between unequally sized groups pose a power problem such that statistical results may accurately describe group differences.

²⁰ As described in Chapter 3 above. In addition, Noom's 1999 article reported Cronbach's $\alpha=0.71$ for attitudinal autonomy.

²¹ As described in Chapter 3.

²² These hypotheses are addressed later in chapter 5.

²³ Adolescent dependency is examined in a later section of this chapter and also in chapter 6.

²⁴ Herd protection or herd immunity is the concept that the more members of the group that are vaccinated render fewer opportunities for transmission and acquisition of infection; thus providing protection for those who are susceptible and unable to be vaccinated.

²⁵ That is, pending overriding critical issues the adolescent faced.

²⁶ Fleiss, J. L., Levin, B., Paik, M.C. (2003). *Statistical Methods for Rates and Proportions*. Third Edition. John Wiley & Sons. New York. Newcombe, R. G. (1998). 'Two-Sided Confidence Intervals for the Single Proportion: Comparison of Seven Methods.' *Statistics in Medicine*, 17, pp. 857-872.

²⁷ Daley, E.M.; Perrin, K.M.; Vamos, C.; Webb, C.; Mueller, T.; Packing-Ebuen, J.L.; Rayko, H.L.; McFarlane, M.; McDermott, R.J. (2008) HPV Knowledge Among HPV+ Women. *American Journal of Health Behavior*. 32(5): 477-487.

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EMPLOYMENT

Camden County College, Blackwood, NJ 1999–present

Adjunct Professor of Psychology; Courses taught: Basic Psychology, Child Psychology, Human Development, Educational Psychology, and Psychology of Personality

Rutgers University Press, New Brunswick, NJ 2010–present

Administrator for Book Series in Childhood Studies

Research Assistant, Dr. Myra Bluebond-Langner, Board of Governors' Professor of Anthropology, Rutgers University and Professor and True Colours Chair in Palliative Care for Children and Young People University College London, Institute of Child Health Summer 2008

Responsibilities included systematical analysis of transcripts and field journals.

William J Lyons Chapter of South Jersey Swimming Officials, 2004–present

Officiate high school swimming and diving meets southern New Jersey.

Cherry Hill Board of Education, Cherry Hill, NJ 1989-1999

Coach of high school girls' field hockey and lacrosse freshman and junior varsity teams.

EDUCATION

PhD in Childhood Studies May 2013. Rutgers University, Camden, NJ

Dissertation: *Adolescents Involved in Decision-making: Clinic Conversations about the Human Papillomavirus and Vaccination*

MA in Educational Psychology, 1985. University of Delaware, Newark, DE

MS in Psychology, 1982. Villanova University, Villanova, PA

BA in Psychology, Honors Program/Psychology, 1974. Arcadia University, Glenside, PA

AWARDS

FCA-Camden Arts & Sciences Academic Excellence Award. Rutgers, the State University of New Jersey 2007, 2008, 2010.

Software Grant. Rutgers University Center for Children and Childhood Studies, 2008.

Graduate Assistantship. Educational Psychology, University of Delaware, 1978–1982.
 Graduate Assistantship. Psychology, Villanova University, Villanova, PA, 1976–1978.
 NSF Student Originated Studies Grant #GY10764 Rat Control: An Interdisciplinary Approach. November 1973.

COMMUNITY SERVICE

Childhood Studies Graduate Student Organization, Rutgers University, Camden, NJ, 2008-present

Co-founder, 2008. Vice President, 2008–2010. Treasurer 2010–2011.

Co-chair, Community Service Committee, 2010–2011.

Established a working partnership with Rutgers' Director of Community Outreach.

Planning committee, *Exploring Childhood Studies: A Graduate Student Conference*, 2009–2010. Served on budget and submission review committees and chaired panel entitled: "Sciences in Childhood Studies." April 2010.

Governance Committee, Congregation M'Kor Shalom, Cherry Hill, NJ 08003, 2011–2012
 Committee member, 2011–2012

RESEARCH EXPERIENCE

February 2010–2012

Ongoing clinical studies with Dr. Lori Feldman-Winter, MD, MPH, Head, Division of Adolescent Medicine and Professor of Pediatrics UMDNJ-RWJMS and CMSRU.

Responsibilities included carrying out all aspects of ongoing investigations including communication in adolescent medicine in the clinical setting and parents' attitudes and responses toward the human papillomavirus and vaccination.

Fall 2007–2010

Research Assistant for Dr. Myra Bluebond-Langner, Board of Governors' Professor of Anthropology at Rutgers University, Camden. Responsibilities include literature reviews, systematical analysis of transcripts and field journals, and writing.

September 1976– May 1978

Research Assistant for Dr. Thomas C. Toppino, Assistant Professor of Psychology, Villanova University. Responsibilities included carrying out all aspects of ongoing experimental studies investigating the fundamental processes by which humans learn and remember verbal information.

PUBLICATIONS AND PRESENTATIONS

Wander, M.D. & Feldman-Winter, L. Relations Among Adolescents' Knowledge about HPV, Parental Knowledge about HPV, and HPV Vaccination. Poster presented at the Association for Psychological Science Annual Convention, Washington, DC, May 2011.

- Wander, M.D., Mukherji, G., Feldman-Winter, L.** Adolescents' and Parents' Understanding of the Human Papillomavirus and Vaccination. Poster presented at 13th Annual Research Week Poster Contest sponsored by Academic Affairs and the Cooper Research Institute, Cooper University Hospital, Camden, NJ, April 2011.
- Wander, M.D.** Analysis of the Process and Outcomes of Institutional Review Board Approval in Research Involving Adolescents. Panel presentation, *IRB-approval challenges for research with children and youth*, at the Anthropology of Children and Childhood Interest Group (ACCIG) meeting, Charleston, SC, February 2011.
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PROFESSIONAL AFFILIATIONS

American Anthropological Association, 2009–present

Association for Psychological Science, 2011–present

Eastern Psychological Association (EPA), 2010–present

Anthropology of Children and Youth Interest Group (ACYIG), 2009–present
