EVERYBODY HAS IT BUT NO ONE KNOWS MUCH ABOUT IT: HOW PATIENT-PROVIDER COMMUNICATION & HPV KNOWLEDGE IMPACT THE LIVED EXPERIENCE OF HAVING HPV

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by

KELSEY SCHWARZ

Under the Direction of Wendy Simonds, PhD

ABSTRACT

Human Papillomavirus (HPV) is the most prevalent sexually transmitted infection in the United States. Many individuals, however, are misinformed about key aspects of the STI, negatively view the disease and those infected with it, and do not use preventive methods to protect themselves and others from transmission. For this study, I used in-person, semi-structured interviews to examine HPV knowledge among those with HPV and how this knowledge impacted individuals’ emotional state upon diagnosis. I also analyzed feelings of stigma among individuals with HPV and how these feelings and HPV knowledge impacted individuals’ motivations to disclose their status to others. I also examined status disclosure and sexual behavior among those with HPV and how HPV transmission knowledge impacted motivations and intentions to participate in prevention behaviors. I found that post-diagnosis many individuals were ill-informed about HPV transmission, dormancy, prevalence, clearance, impact on men, and association with cervical cancer. I also found that post-diagnosis many individuals were anxious and upset about their positive status and felt judged by some individuals in their lives. Confronting and
internalizing this stigma impacted how and why they disclosed and withheld their positive HPV status. I also found that few individuals with HPV disclosed their status to all at-risk sex partners or used barrier methods consistently during sex. These findings suggest that practitioners’ messages and sexual education about HPV are inadequate. More work is needed to facilitate effective and empathetic patient-provider communication and HPV education that includes status disclosure and use of all barrier methods. These findings also suggest that the culture around HPV needs to change so that individuals with a positive status no longer undergo undue stress and can openly educate others about the STI.

INDEX WORDS: HPV, Stigma, Disclosure, Condoms, HPV knowledge, Transmission, STI Prevention
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KELSEY SCHWARZ

A Dissertation Submitted in Partial Fulfilment of the Requirements for the Degree of Doctor of Philosophy in the College of Arts and Sciences
Georgia State University
2018
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April 2018
DEDICATION

I dedicate this dissertation to my family. I thank my husband, Chad, for his support and love during the long research process and my parents, in-laws, and sister for their continued encouragement and belief in my capabilities.
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1 INTRODUCTION

1.1 OVERVIEW OF ISSUE

Human Papillomavirus (HPV), a sexually transmitted infection, is a highly prevalent disease (Brewer and Fazekas 2007; CDC 2017a; McCaffery et al. 2004; McCaffery et al. 2006; Nan 2012; Waller et al. 2007b). It is, in fact, so common that nearly all sexually active individuals will contract at least one type of HPV during their lifetime (Braun and Phoun 2010; CDC 2017a). Approximately 79 million Americans are infected with HPV, with 14 million becoming newly infected annually (CDC 2017a). There are over 100 types of HPV and, although most HPV infections are asymptomatic and transient (usually clearing within two years), other HPV infection types can cause genital warts and/or lead to cervical, vaginal, vulvar, penile, anal, and throat cancer in men and women (CDC 2016; CDC 2017a).

HPV is the primary cause of cervical cancer in the U.S. (Nan 2012). Out of the 100+ infections of HPV, HPV16 and HPV18 are associated with the majority of cervical cancer cases (CDC 2013; Polzer and Knabe 2012). In the United States, 3,700 women die from this type of cancer each year (2.3/100,000 death rate for cervical cancer) (Connell and Hunt 2010; Grantham et al. 2011; USCSWG 2014). In other words, a woman not vaccinated against HPV has a 1 percent lifetime risk of developing cervical cancer (Chapman 2010). The cervical cancer incidence and death rates are higher among Latina and Black women (10.2/100,000 and 9.4/100,000 respectively; 2.8/100,000 and 4.1/100,000 respectively) compared to White women (7.8/100,000 and 2.1/100,000) (CDC 2014) in the United States. Anal, head, neck, penile, vaginal, and vulvar cancers, although rare, are also associated with high-risk HPV (CDC 2017c; ASHA 2018). Over 80% of anal cancers, 70% of head and neck cancers, 60% of penile cancers, and 70% of vaginal and vulvar cancers in the United States are associated with high-risk HPV (CDC 2017c; ASHA 2018).

Individuals tend to be more aware of HPV’s link to cervical cancer than to other cancers; however, 38% of Americans are unsure or do not know that HPV causes cervical cancer (Blake et al
Even individuals who are knowledgeable about HPV’s link to cervical cancer tend to be unaware that it is transient in nature and can resolve on its own within a few years (Gerend and Magloire 2008; Sandfort and Pleasant 2009; Ratanasiripong et al. 2013; Blake et al. 2015). Many Americans are unaware of the highly prevalent and easily transmittable nature of HPV and do not perceive themselves as at risk (Blake et al. 2015; Gerend and Magloire 2008; Sandfort and Pleasant 2009; Ratanasiripog et al. 2013).

Nearly 70% of Americans are aware of the HPV vaccine (Blacke et al. 2015). The HPV vaccine protects against persistent infection of HPV subtypes associated with cancers and anogenital warts (Rothman 2009; Brelsford 2011). According to clinical trials, the vaccine prevents 90-100% of new high risk HPV infections among women (aged 15-26) not infected with HPV at time of vaccination (Herrero et al. 2015). In June of 2006, the HPV vaccine was approved and recommended for girls aged 11-26 (allowing 9 and 10-year-old girls to be eligible for vaccine) (Braun and Phoun 2010; CDC 2011; Connell and Hunt 2010; Shefer et al. 2008; Wailoo et al. 2010). Vaccinations for boys and men aged 9-26 are now recommended due to the role they play in transmitting HPV, as well as their increased risk for cancer (anal, penile, neck), genital warts, and recurrent respiratory papillomatosis (tumors in the air passages) when infected with HPV, specifically types 6, 11, and 16 (Anic et al. 2011; Dunne et al. 2006; Elbasha and Dasbach 2010).

HPV vaccination intention is lower among older adolescents and college age women. The most commonly cited barriers to vaccine intent among college age women were: vaccine safety concerns, side effects, insurance issues, cost, and low perceived risk (Patel et al. 2012). Among older adolescents and young adults, those more likely to receive the HPV vaccine are white, insured, 18 to 20 year old women (Laz et al. 2013). The most commonly cited barriers to vaccine intent and uptake among 18-26 year old women were: vaccine safety concerns, side effects, insurance issues, cost, low perceived risk, and belief they were too old to receive the vaccine (Laz et al. 2013; Patel et al. 2012). According to the CDC, the vaccine is not recommended for women over the age of 26 because it offered limited protection against
HPV-related diseases in clinical trials due to the fact that most women had already been exposed to one or more HPV strains in their late teens or early twenties (CDC 2017d). However, research suggests that the vaccine may be beneficial to older women, even those who are HPV positive. In fact, previously infected individuals may benefit from vaccination by increasing antibodies and thus helping individuals clear HPV more quickly and prevent re-infection (Muderspach et al. 2000; Scherer et al. 2016).

1.2 THEORETICAL BACKGROUND

In my dissertation, I sought to reveal the stories of individuals with HPV, as they discuss their experiences, understandings, and interpretations of living with HPV. Specifically, I aimed to analyze the connections between HPV knowledge and health literacy after diagnosis, patient-provider relationships, perceived stigma, disclosure, and sexual behavior. In order to highlight these issues, I relied on the following theoretical frameworks: stigma, health literacy, patient-provider communication model, and the information, motivation, behavior model.

1.2.1 Health Literacy

Patients are encouraged to be active and informed health care consumers (Parker 2010, Street & Epstein 2008). To do so, they must have a high level of health literacy, defined as the “degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions” (CDC 2016b: n.p.). Patients with high health literacy are capable of finding health information and services, communicating their needs, processing meanings of information, understanding choices and consequences, and deciding what services meet their need (CDC 2016b). To aid in the development of health literacy, providers should help patients find information and services, communicate about health and healthcare, process patient questions and preferences, understand how to provide useful information, and decide what information and services are best for specific situations (CDC 2016b). Level of HPV health literacy is often related to
age, gender, socioeconomic status and race (Kutner 2006). According to research, young, white, educated women are more knowledgeable about HPV compared to men, the elderly, individuals with no college education, and women from racial and ethnic minority groups (Blake et al. 2015; Gerend and Magloire 2008; Gerend and Shepherd 2011; Holcomb et al. 2004; Jain et al. 2009; Reimer et al. 2014; Pruitt et al. 2005; Sandfort and Pleasant 2009; Tiro et al. 2007).

1.2.2 Patient-Provider Communication

Individuals who feel they have a strong relationship with their doctor, compared to those who do not, can have improved health because they are more satisfied, more likely to heed doctors’ recommendations, and are more committed to treatment plans (Fuertes et al. 2007). Patients would prefer to have providers who are informative, emotionally supportive, and with whom they share mutual trust, respect, and engagement (Aelbrecht et al. 2014; Mazzi et al. 2015; Fuertes et al. 2007; Fuertes et al. 2016). By openly communicating with patients, doctors can better understand patients’ health problems, answer patients’ questions, and heighten patients’ sense of control over their diagnoses (Iwamitsu et al 2003; Schofield et al. 2003; Street & Epstein 2008).

Most women diagnosed with HPV tend to have many unanswered questions about their diagnosis because of the impersonal ways in which they were informed of their status (Harvey-Knowles and Kosenko 2012). Research indicates that most women do not fully understand HPV upon initial diagnosis because they are shocked by their diagnosis and lack the mental clarity to ask their doctor for details about HPV (Bertram and Magnussen 2008; Kosenko et al. 2014). Women also report that they receive confusing information from their doctors at time of diagnosis (Daley et al. 2008). Specifically, recently diagnosed individuals are confused about the symptoms, impact on fertility, treatment options, recommended lifestyle changes, impact on male sexual partners, how HPV differs from other STIs, which type of HPV they have, and how low-risk HPV differs from high-risk HPV (Bertram and Magnussen 2008;
Daley et al. 2008; Perrin et al. 2006). This lack of knowledge often occurred when health care providers use excessive medical jargon, allocate insufficient time to explain the diagnosis, seem insensitive to their patients, and lack an established patient-provider relationship (Bertram and Magnussen 2008).

1.2.3 Theories of Stigma

A less desirable attribute than one stereotypically assigned to persons of the same category is known as a “stigma” (Goffman 1963:3). Stigmas can be caused by character flaws, which are personality traits that deviate from those socially accepted or by physical deformities (Goffman 1963). Stigmatized individuals are perceived as dangerous to societal norms (Goffman 1963). Society often views women who stray from the societal norms of female chastity and purity as deviant, morally corrupt, irresponsible, unclean, and promiscuous (East et al. 2012; Nack 2008). Therefore, they possess a character stigma and risk negative judgment from others (Nack 2008). According to symbolic interactionists, individuals incorporate others’ evaluations of them when self-evaluating (Nack 2008:65). Women with HPV often feel embarrassed about their diagnosis and refer to themselves as “unclean, “dirty”, “cheap”, “gross” (Daley et al. 2008; East et al. 2012, 17; Nack 2008).

When an individual’s dissimilarity is not obvious upon first meeting, they have a hidden “discreditable stigma,” and they must determine what to display or who to tell (Goffman 1963:42). According to Goffman, most individuals will intentionally pass if given the opportunity (1963). Women with HPV often choose not to disclose their stigma to others because they fear rejection from their friends, family, and sexual partners (Nack 2008:91). Individuals with a discreditable stigma may choose, however, to disclose their discreditable attribute to others as a form of “stigma management” (Breitkopf 2004; Goffman 1963:100). Often, a discreditable person will reveal their shameful attribute to a few key individuals and then rely on those individuals for support (Goffman 1963). Many women disclose in order to gain the support, sympathy, and acceptance from close friends and family members (Lee and Craft 2002; Nack 2008:98).
More recent research on stigma, among individuals with STIs, draws on the Berger et al.’s HIV Stigma Scale. According to Berger et al., perceived stigma occurs in the context of (1) one’s perception of society’s attitudes toward a person with HIV and (2) one’s personal knowledge of being HIV positive (Berger et al. 2001). This perceived stigma can lead to a mal-adjusted sense of self, attempts to control who knows about one’s status, and even avoidance of potentially stigmatizing social situations (Berger et al. 2001). The HIV Stigma Scale evaluates personalized stigma, which relates to experiences and fears of rejection; disclosure concerns, related to controlling who knows their positive status; negative self-image, related to shame and feeling like a bad person; and concerns with public attitudes, which relates to fear that larger society will judge a person with a positive status (Barnack-Tavlaris et al. 2016; Berger et al. 2001). Using this framework, HPV researchers have found that individuals with HPV most commonly cite feeling negative self-image stigma, whereby they feel dirty and disgusted with themselves for having HPV (Barnack-Tavlaris et al. 2016). Personalized stigma was also commonly felt by individuals with HPV, who worried that others would not understand their situation and reject them (Barnack-Tavlaris et al. 2016). Fewer people were concerned about disclosure, but those who limited their disclosure were worried about sexual rejection (Barnack-Tavlaris et al. 2016). Researchers found that individuals with HPV were less affected by public attitude compared to all other types of stigma (Barnack-Tavlaris et al. 2016).

Attribution theorists posit that public attitude stigma impacts individuals more if they may be blamed for their serious illness (Lebel and Devins 2008; Weiner, Perry and Magnusson 1988). If a person participates in voluntary, avoidable, risky behavior that leads to their illness, larger society may view them negatively (Lebel and Devins 2008; Weiner, Perry and Magnusson 1988). Conversely, if an individual’s illness is deemed to be unavoidable by larger society they are often accepted and even pitied (Lebel and Devins 2008; Weiner, Perry and Magnusson 1988). Researchers found, when comparing the stigma felt by individuals with HIV compared to those with cancer, those with HIV felt
greater stigma which was, in part, due to HIV patients being viewed as responsible for their diagnosis (Fife and Wright 2000). Research specific to cancer-related stigma indicates the level of stigma and blame is associated with type of cancer. They found that blame is more often attributed to women with cervical cancer than to individuals with cancers unrelated to lifestyle choices, such as leukemia, breast, or bowel cancer (Marlow et al. 2010, 1802). Due to the fact that the large majority of cervical cancer cases are linked to high-risk HPV and HPV is acquired through skin-to-skin, oral, vaginal, and anal sexual contact, public opinion of individuals with HPV may be negative, as it is for individuals with HIV. Research indicates that women, specifically, with HPV are often viewed as deviant and irresponsible (East et al. 2012; Nack 2008) and may, therefore, feel more stigma than individuals with cancer whose behavior may not have contributed to their diagnosis (Lebel and Devins 2008).

1.2.4 Information, Motivation, Behavior Model

According to the “information, motivation, behavior” (IMB) theoretical model, STI prevention techniques are used by individuals who are well informed, perceive themselves to be at risk, are motivated to change their risky behavior, and feel capable of using prevention strategies (Bahrami and Zarani 2015; St. Lawrence and Fortenberry 2007). In order to participate in STI prevention behavior, they need to be knowledgeable about STI transmission and prevention methods (Fisher and Fisher 1992; St. Lawrence and Fortenberry 2007). HPV prevention methods include status disclosure to partners and consistent use of barrier methods, such as condoms and dental dams. According to past research, much of the general population is unaware of their risk of acquiring and transmitting HPV (Blake et al. 2015; Gerend and Magloire 2008; Sandfort and Pleasant 2009; Ratanasiripog et al. 2013). Although most of the general public is aware that HPV is an STI, many do not know that it is linked to genital warts and can be transmitted through skin-to-skin contact (Gerend and Magloire 2008; Sandfort and Pleasant 2009). Many individuals are also unaware that STI disclosure is a component of safer sex practices (Luchetti 2009).
Informed individuals must be motivated to act on their knowledge and change their risky behavior to preventive behaviors (Fisher and Fisher 1992; St. Lawrence and Fortenberry 2007). One’s perceived susceptibility to risk and adherence to social norms surrounding prevention techniques are key components to motivation (Fisher and Fisher 1992). Consistent condom use is associated with perceived risk to STIs (Bryan et al. 1997). However, many people often do not perceive themselves at risk for HPV (Gerend and Magloire 2008; Sandfort and Pleasant 2009; Ratanasiripong et al. 2013; Blake et al. 2015). Individuals must also have the skills to perform the recommended preventive behaviors (St. Lawrence and Fortenberry 2007). For prevention of HPV transmission, these skills include: obtaining a vaccine, correct condom use, sexual communication, condom negotiation, and a sense of self-efficacy (Fisher and Fisher 1992). For women, condom use self-efficacy involves agency over sexual communication and negotiation with partners (Artistico et al. 2014; French and Holland 2011). Women who perceive themselves to have less decision-making power in their relationship are less likely to report consistent condom use (Pulerwitz et al. 2002).

1.3 METHODS

For this study, I employed purposive, facility-based sampling and snowball sampling. I utilized key locations to find study participants, such the health clinic at a large public university in the Southeastern United States and multiple privately-operated gynecological clinics around a large metropolitan area in the Southeastern United States. I also posted flyers around two major universities, high-traffic pedestrian areas, and throughout diverse neighborhoods. Additionally, I gained entry into online support groups for individuals with HPV\(^1\) to recruit group members for my study. I displayed and distributed flyers at the recruitment facilities. Multiple versions of the flyer were distributed with

various photos of young girls and women from different racial and ethnic groups on them in order to appeal to a diverse group of potential participants. Each flyer contained tear-off tabs so that interested parties could easily obtain my contact information. Additionally, each flyer included a Quick Response code that linked smartphone users to my online eligibility form. This eligibility form required users to enter their age and HPV status and then, if eligible and interested in participating, their contact information was automatically sent to me.

1.3.1 Sample Demographics

My participants included 23 women of various ages. Six were in their 20s, eleven in their 30s, three in their 40s, two in their 50s, and one over 60 years old. Age at diagnosis varied with three receiving there HPV diagnosis at age 19, seven receiving it in their early 20s, six in their late 20s, three in their early 30s, one at age 45, and one at age 60. My sample was a highly educated group, with 10 of my participants having obtained a graduate degree, four in graduate school at the time of interview, six obtaining a terminal Bachelor’s degree, one currently in undergraduate school at the time of interview, one having had some college education, and one having a GED as highest level of education. The majority of my participants (73.9%) were white, 21.7% were black, and 4.35% were multiracial. Ten of my participants were single at the time of interview, 8 were in a committed relationship, and 5 were legally married. In terms of gender identity, 22 of my participants identified as women and one identified as gender queer. In terms of sexual orientation, 18 classified themselves as heterosexual, one as lesbian, and four as bisexual.

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2 My sample originally included 25 individuals, but after the interview, I determined two no longer qualified to be included in my sample due to their type of HPV. Both of those original participants had HPV that manifested as skin warts on the hands and feet – a condition that is not considered a sexually transmitted infection and is not related to reproductive issues or cancers. Therefore, the numbers next to each quote coincide with the participants’ original interview number (1-25).
1.4 CURRENT STUDY

Past HPV research has mainly focused on knowledge, awareness, and attitudes regarding the illness and vaccine (see: Constantine and Jerman 2007, Dempsey et al. 2006, Gerend and Magloire 2008, Holcomb et al. 2004, Pruitt et al. 2005). Research that has centered on women’s experiences related to STIs is often related to genital herpes (see: Lee and Craft 2002), or a multitude of STIs including HPV, genital herpes, and chlamydia (see East et al. 2012, Nack 2000). Major HPV-specific research studies have been conducted outside of the United States (see: McCaffery et al. 2004, McCaffery et al. 2006, Waller et al. 2007a) and are often survey based (see: McCaffery et al. 2004, Waller et al. 2007a). Due to the fact that the CDC recommendation of the HPV vaccine was fairly recent, past research on HPV (see: Nack 2002, Nack 2008, Perrin et al. 2006) did not analyze women’s lived experience in relation to the vaccine. More recent scholarship related to HPV has instead focused on the influence of social support for Women with HPV (see: Kosenko et al. 2012).

The current study adds to the field of research by exploring the lived experience of individuals who have been diagnosed with HPV through semi-structured interviews. Through detailed accounts of individuals’ experiences with having HPV, I was able to analyze how individuals with HPV felt about themselves, what they knew about their diagnosis, who they told, and how it impacted their sexual behavior. This work contributes to existing research on HPV in the United States and adds to current research on health literacy, patient-provider communication, and STI prevention.

The following chapters highlight the process from diagnosis to post-diagnosis emotional state to disclosure to friends, family, and sexual partners to sexual behavior choices post-diagnosis. A major theme throughout these chapters is HPV knowledge. Many individuals with HPV who were misinformed about HPV prevalence, transmission, consequences for partners, clearance and dormancy experienced undue stress, internalized stigma, put themselves at risk for re-infection and put their sex partners at
risk for contracting HPV. As I posit in the following chapters, informative, emotionally supportive doctors play a vital role in educating individuals at diagnosis and the general public on basic facts related to HPV.
“They Just Railroaded Past It Like It Was Not a Big Deal”: How Providers Impact Patient HPV Knowledge and Experience

2.1 ABSTRACT

Human Papillomavirus (HPV) is the most prevalent sexually transmitted infection in the United States, however, health literacy around HPV is relatively low. Many individuals are misinformed about key aspects of HPV. This study uses in-person, semi-structured interviews to examine HPV knowledge among those with HPV. It also analyzes how this knowledge impacted individuals’ emotional state upon diagnosis. The study found that post-diagnosis many individuals were ill-informed about HPV transmission, dormancy, prevalence, clearance, and association with cervical cancer. These findings suggest that practitioners’ messages about HPV are inadequate and more work is needed to facilitate effective and empathetic patient-provider communication.

2.2 INTRODUCTION

Human Papillomavirus (HPV) is transmitted most commonly through sexual contact, such as vaginal, anal, oral sex, and intimate skin-to-skin contact (Moscicki 2005). It is the most prevalent sexually transmitted infection in the U.S. (CDC 2017a). According to 2016 data, nearly 79 million Americans are infected with HPV, with 14 million becoming newly infected annually (CDC 2017a). Although increased incidence of HPV has long been associated with greater number of sexual partners and “risky” sexual behavior (e.g., multiple partners, unprotected sex), according to recent data, many women acquire HPV within the first few months (2.6 month median) of their first sexual relationship (Collins et al. 2002). In fact, Collins et al. suggest that “perhaps cervical human papillomavirus infection should now be considered an inevitable consequence of sexual activity” (2002:98). Despite heightened vaccine messaging (Abdelmutti and Hoffman-Goetz 2009; Mamo et al. 2010), 32% of Americans have never heard of HPV; 31% have never heard of the HPV vaccine; nearly 38% are unsure or do not know that
HPV causes cervical cancer; 43% do not know that HPV was a sexually transmitted infection; and 95% do not know that HPV often clears\(^3\) from the body without treatment (Blake et al. 2015).

Over the past few decades, the United States health care system has transitioned. Previously, patients were passive participants, now they are encouraged to be active and informed health care consumers (Parker 2010, Street & Epstein 2008). Despite the health care industry’s promotion of patient empowerment, misinformation and misunderstanding are common, therefore researchers and health practitioners “must pay attention to how patients access, understand, and use health information provided to them to promote, protect, and manage their health” (Parker 2010:29). Health literacy is the “degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions” (CDC 2016b: n.p.). Patient health literacy skills include: finding health information and services, communicating their needs, processing meanings of information, understanding choices and consequences, and deciding what services meet their need (CDC 2016b). Provider health literacy skills include: helping patients find information and services, communicating about health and healthcare, process patient questions and preferences, understanding how to provide useful information, and deciding what information and services are best for specific situations (CDC 2016b). Health literacy is a basic tenet of public health promotion and a critical effort of the United States Department of Health and Human Services (U.S. Dept. of Health and Human Services 2010).

Level of HPV health literacy is often related to age, gender, socioeconomic status and race (Kutner 2006). Americans, aged under 65 are more likely to have heard of HPV, the vaccine, and to know that HPV can cause cervical cancer, compared to Americans over the age of 65 (Blake et al. 2015). White women are more likely to be aware of HPV and the vaccine, have greater knowledge of HPV, and to have been diagnosed with HPV, compared to women of other racial and ethnic groups (Blake et al. 2015;  

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\(^3\) According to research, HPV often clears from the body because of the host’s immune response (Moscicki et al. 2006). Most HPV infections clear within 2 years (CDC 2013).
Gerend and Shepherd 2011; Jain et al. 2009; Reimer et al. 2014; Tiro et al. 2007). HPV health literacy, specifically awareness of and knowledge about HPV, is positively associated with level of education (Blake et al. 2015; Holcomb et al. 2004; Jain et al. 2009; Pruitt et al. 2005; Tiro et al. 2007). Americans with a college education are more likely than those with a high school degree to have heard of HPV and the HPV vaccine, to know the link between HPV and cervical cancer, and to know that HPV is a sexually transmitted infection (Blake et al. 2015). While many college students are knowledgeable about HPV’s link to cervical cancer, they tend to be unaware of the link to genital warts; that HPV can be transmitted skin-to-skin; that HPV is transient in nature and can resolve on its own; that HPV is highly prevalent; and that most women with HPV will never develop cervical cancer (Gerend and Magloire 2008; Sandfort and Pleasant 2009). College students also often do not perceive themselves as at risk for HPV (Gerend and Magloire 2008). A more recent study on a racially and ethnically diverse group of women college students found both vaccinated and non-vaccinated women are unaware of the disease’s prevalence, risks of transmitting HPV, and that HPV can cause genital warts (Ratanasiripong et al. 2013).

2.3 THEORY

2.3.1 Doctor Communication Regarding HPV

Researchers have analyzed patient-provider interactions since the 1950s. These interactions range from the paternalistic model of the 1950s, where the patient was a passive actor and the doctor maintained control, to the 1970s’ consumerist model, where patients exercised greater control than their doctors (Street & Epstein 2008). Recent research indicates that patients prefer their relationship with their doctor to be one with mutual trust, respect, and engagement (Fuertes et al 2007; Fuertes et al. 2016). They prefer to have providers who are informative, emotionally supportive, empathetic, respectful, competent, and pleasant (Aelbrecht et al. 2014; Mazzi et al. 2015). Individuals who feel they have a strong relationship with their doctor, compared to those who do not, can have improved health
because they are more satisfied, more likely to heed doctors’ recommendations, and are more committed to treatment plans (Fuertes et al. 2007).

Squier developed the model of “empathetic understanding,” in which he posited that doctors could better understand health problems through open communication and labeling of feelings and sensations (Street & Epstein 2008). However, doctors are not often comfortable discussing patients’ distress because emotional detachment to patients is favored in the Western medical field (Kerasidou and Horn 2016). Additionally, some patients refrain from expressing emotion upon diagnosis of a potentially life-threatening disease, which can lead to heightened anxiety and depression (Iwamitsu et al. 2003). According to researchers, encouraging patients’ emotional expression at diagnosis, being reassuring, clearly communicating disease-specific information, and answering patients’ questions the same day can give patients a better sense of control and diminish their distress (Iwamitsu et al. 2003; Schofield et al. 2003).

In-depth interview analysis demonstrates that general practitioners and nurse practitioners do not widely discuss HPV with their women patients (McSherry et al. 2012). Research suggests that among women receiving routine Papanicolaou (Pap) tests, rarely do doctors discuss the topic of HPV (Cermak, et al. 2010). In fact, women often report that their doctors neglected to mention HPV associated risks, HPV prevention, and the HPV vaccine during their Pap test appointments (Cermak, et al. 2010). Women undergoing routine Pap tests rarely demonstrate an understanding of why the test is being performed and what normal and abnormal results indicate (Mays et al. 2000).

Most women diagnosed with HPV are informed by their clinical staff by phone, letter, or email (Harvey-Knowles and Kosenko 2012; McCree et al. 2010). They tend to have many unanswered questions about their diagnosis, because of the impersonal ways in which they news is delivered (Harvey-Knowles and Kosenko 2012). Researchers posit that most women do not fully understand HPV upon initial diagnosis (Bertram and Magnussen 2008; Kosenko et al. 2014). Upon initial diagnosis,
women are often shocked and lack the mental clarity to ask their doctor details about HPV (Kosenko et al. 2014). Patients may express embarrassment, fear, confusion, anger, and concern about cancer and fertility (Daley et al. 2008; Diaz 2013; Nack 2008). Upon diagnosis, women with HPV may feel “dirty,” “gross,” or “unclean” (East et al. 2012:17; Nack 2008:66). They are often confused about the symptoms, impact on fertility, treatment options, recommended lifestyle changes, impact on male sexual partners, and how HPV differs from other STIs (Bertram and Magnussen 2008; Perrin et al. 2006).

Post-diagnosis surveys conducted across four states indicate that women are incorrect or unsure about: how many types of HPV exist; that it is not a sex-specific infection; that a vaccine can prevent it; and that it is transient in nature and can clear (McCree et al. 2010). Research also indicates that women with HPV often lack knowledge about the sexual transmission and high prevalence of HPV (Barnack-Tavlaris et al. 2016; Bertram and Magnussen 2008; Sharpe et al. 2006). Other misconceptions about HPV, among women with HPV, are that it is a bacterial infection similar to a yeast infection or that it is a permanent illness (Barnack-Tavlaris et al. 2016; Bertram and Magnussen 2008; Daley et al. 2008). Women with HPV often understand that there is an association between abnormal Pap test results and cancer (Tiro et al. 2007; Sharpe et al. 2006), although few specify cervical cancer (Sharpe et al. 2006). They are less likely to associate abnormal Pap tests with HPV (Sharpe et al. 2006). Prior to HPV+ diagnosis, many women with abnormal Pap tests report little concern about their health at the time of their first abnormal Pap test (Sharpe et al. 2006). These women often are unsure or incorrect about which type of HPV they have, and often confuse low-risk HPV with high-risk HPV (Bertram and Magnussen 2008; Daley et al. 2008).

Women often report that they receive confusing information from their doctors at time of diagnosis, formulate new questions after leaving the doctor’s office, and are too upset at time of diagnosis to understand their doctor (Daley et al. 2008). Women often seek out HPV information online post-diagnosis (Harvey-Knowles and Kosenko 2012). Women who are diagnosed with HPV and are then
scheduled to have a colposcopy\textsuperscript{4} also lack knowledge about the infection’s transmission, treatment, symptoms, and association with cervical cancer (Pruitt et al. 2005). Women with HPV have recommended, in a research study, that doctors discuss the prevalence of HPV and do not solely focus on discussing their condition as potentially cancerous (Bertram and Magnussen 2008).

When given educational materials on HPV, women are less likely to feel anxious about testing and be less concerned if they test positive, compared to before reviewing the educational materials (Papa et al. 2009). Despite some reports of helpful and communicative doctors, women recently diagnosed with HPV often lack information about the infection (Bertram and Magnussen 2008; Kosenko et al. 2014; Perrin et al. 2006; Sharpe et al. 2006). This lack of knowledge often occurred when health care providers used excessive medical jargon, allocated insufficient time to explain the diagnosis, seemed insensitive to their patients, and lacked an established patient-provider relationship (Bertram and Magnussen 2008).

2.4 CURRENT STUDY

Due to the fact that many individuals are still unaware of HPV, its link to cervical cancer, and the HPV vaccine, researchers highlight the need for effective patient-provider communication about this topic (Blake et al. 2015; Smith et al. 2015). Through my research, I sought to discover whether individuals with HPV were knowledgeable about the infection prior to and after their own diagnosis and how their knowledge of HPV influenced their feelings upon diagnosis.

Due to health practitioners’ noted poor communication about the STI, I sought to discover whether individuals diagnosed with HPV were knowledgeable about the infection prior to and after

\textsuperscript{4} A colposcopy is often recommended after an abnormal pap result. During this procedure, a health care provider examines the cervix through a colposcope and, if need be, performs a biopsy of the cervix for laboratory testing (Johns Hopkins n.d.).
diagnosis. Through my research, I also sought to understand how those diagnosed with HPV felt about themselves after diagnosis and how their knowledge of HPV influenced these feelings.

2.5 METHODS

I recruited my participants via advertisements (flyers) displayed and distributed at the recruitment facilities. This discreet recruitment method is commonly used among STI researchers in order to avoid embarrassment of participants (see: Kosenko et al. 2012; East et al. 2012). Multiple versions of the flyer were disseminated with various photos of young girls and women from different racial and ethnic groups on them in order to appeal to a diverse group of potential participants. Each flyer contained tear-off tabs so that interested parties could easily obtain my contact information. Additionally, each flyer included a Quick Response code. Quick Response codes are an increasingly popular advertisement tool that can be scanned and read by smartphones (Shin, Jung, and Chang 2012). The flyers contained a unique Quick Response code that linked smartphone users to my online eligibility form. This eligibility form required users to enter their age and HPV status and then, if eligible and interested in participating, their contact information was automatically sent to me.

Due to the fact that individuals with STIs qualify as a hard-to-reach population and recruitment can be difficult (Dixon-Woods et al. 2001; Nack 2008), I employed purposive, facility-based sampling and snowball sampling. I utilized key locations to find study participants (Magnani et al. 2005), such the health clinic at a large public university in the Southeastern United States and multiple privately-operated gynecological clinics around a large metropolitan area in the Southeastern United States. Commonly cited barriers to STI screenings include cost, privacy, language barriers, and perceived discrimination at the clinical site (Tilson et al. 2004). Therefore, I chose to include clinics that offer free or low-cost STI screening services to English and non-English speakers and that abide by anti—discrimination laws specific to patient admission and treatment. I also posted flyers around two major
universities, high-traffic pedestrian areas, and throughout diverse neighborhoods. Additionally, I gained entry into online support groups for individuals with HPV⁵ to recruit group members for my study. In order to allow for fully informed consent on the part of my subjects, I included accurate and straightforward information about my research and its purposes.

2.5.1 Sample Demographics

I gave all of my participants pseudonyms to protect their identity. My participants included 23 women of various ages⁶. Six were in their 20s, eleven in their 30s, three in their 40s, two in their 50s, and one over 60 years old. Age at diagnosis varied with three receiving there HPV diagnosis at age 19, seven receiving it in their early 20s, six in their late 20s, three in their early 30s, one at age 45, and one at age 60. Sixteen of the 23 participants grew up in a two-parent family, three had a single parent, three had divorced parents and stepparents in the home, and one had divorced parents that never remarried. Twelve of my participants grew up in the Southeastern United States. Six of my participants grew up in the Northeast, three grew up in the Midwest, and two grew up outside of the United States. My sample was a highly educated group, with 10 of my participants having obtained a graduate degree, four in graduate school at the time of interview, six obtaining a terminal Bachelor’s degree, one currently in undergraduate school at the time of interview, one having had some college education, and one having a GED as highest level of education. Regarding occupation, eight worked in health and medicine, four in education, three in law, three in the arts, one in business administration, one in marketing, one in plumbing/engineering, and two as current students. The majority of my participants (73.9%) were white,⁷

⁶ My sample originally included 25 individuals, but after the interview, I determined two no longer qualified to be included in my sample due to their type of HPV. Both of those original participants had HPV that manifested as skin warts on the hands and feet—a condition that is not considered a sexually transmitted infection and is not related to reproductive issues or cancers. Therefore, the numbers next to each quote coincide with the participants’ original interview number (1-25).
21.7% were black, and 4.35% were multiracial. Ten of my participants were single at the time of interview, 8 were in a committed relationship, and 5 were legally married. In terms of gender identity, 22 of my participants identified as women and one identified as gender queer. In terms of sexual orientation, 18 classified themselves as heterosexual, one as lesbian, and four as bisexual. Fifteen of the participants resided in the Southeastern U.S. at the time of their interviews, and three lived in the Northeast, one in the Southwest, two in the West, and two outside of the United States.

2.5.2 Interview Method

Although many past researchers have used surveys to analyze knowledge, awareness, and attitudes regarding HPV and the vaccine, other researchers find that semi-structured interviews allow participants to demonstrate meanings attached to their STI diagnosis and personal experiences of dealing with this new diagnosis (see: Gerend and Magloire 2008; Lee and Craft 2002). Interviews of HPV+ participants, compared to survey research, are more likely to foster discussion of actual lived experiences related to diagnosis and living with HPV.

As a feminist interviewer, I was cognizant of my role as a researcher and my potential source of authority during the interview process (Hesse-Biber 2007). In order to diminish the hierarchical relationship between researcher and participants, after each interview, I shared relevant aspects of my own biography (Hesse-Biber 2007) and experience with HPV. I strove to be reflexive and to consider how my biography, values, and attitudes influenced the research process (DeVault and Gross 2012; Hesse-Biber 2007). As a woman with HPV, throughout the interview and analysis stages, I reflected on how my attitudes regarding the disease impacted my choice of interview questions and my
interpretation of participants’ responses (DeVault and Gross 2012). For example, my experience with a non-empathetic, uninformative doctor motivated me to ask about doctor-patient interactions and helped me understand the participants’ frustrations with similar experiences.

Interview topics included: how participants felt upon initial diagnosis of HPV, what information they knew about HPV and the vaccine prior to diagnosis, what information they were given or sought out about HPV after diagnosis, how their diagnosis impacted them, and how they felt about themselves post-diagnosis.

2.5.3 Analysis

I conducted, recorded, and transcribed all of the interviews. I imported all transcribed materials into NVivo and analyzed using a grounded theory approach. I chose this analytic method because it is well suited for understanding social processes not yet commonly researched (Milliken 2010). And, as noted above, there have been very few qualitative studies on the lived experiences of individuals with HPV. From my transcription and pre-analysis coding, I identified a few themes that I wanted to further investigate related to patient-provider relationships: “patient-provider communication,” “HPV,” and “HPV vaccine.” I analyzed the transcripts using the triadic coding scheme of open, axial, and selective coding (LaRossa 2005). During open coding, I identified major themes related to patient-provider relationships, emotional response to diagnosis, and HPV knowledge, and deciphered what each concept represented (Lofland et al. 2005; LaRossa 2005). Most participants discussed how they received their diagnosis and what information their doctor did or did not provide them with at diagnosis. In the context of their diagnosis, each participant mentioned what they knew about HPV and how they felt upon initial diagnosis. I then reviewed the concepts for similarities and variations, assigned them to categories, and identified the most salient categories (Corbin and Strauss 1990). I analyzed patient-provider communication to determine whether or not the doctors were generally informative,
supportive, and accessible to their patients. I then examined possible relationships between having an empathetic doctor and one’s experience with the diagnosis of a sexually transmitted infection. I also analyzed participant HPV knowledge pre- and post-diagnosis to determine what information each one learned after they were diagnosed with the STI. Finally, I analyzed the participants’ emotional responses to diagnosis (to determine if they were upset, unsuspecting, or seemingly unaffected by their positive status) and feelings about themselves post-diagnosis. In the axial coding stage, I analyzed the categories to determine how and why they differed among the participants, by focusing on the context, strategies, and consequences associated with each category (Corbin and Strauss 1990; LaRossa 2005). I analyzed relationships between HPV knowledge post-diagnosis and patient-provider communication. I also analyzed the relationship between HPV knowledge post-diagnosis and participants’ emotional response to the diagnosis and how they learned about diagnosis. Finally, I moved on to the selective coding stage of my analysis, where I decided which categories were most representative of the central argument of my analysis (Corbin and Strauss 1990; LaRossa 2005). I found the relationships of post-diagnosis knowledge, how participant was diagnosed, and their emotional response to diagnosis to be most informative and related to patient-provider communication.

2.6 FINDINGS

2.6.1 Pre-Diagnosis Knowledge

I looked at the impact informative doctors made on their patients’ knowledge of HPV. In order to access what knowledge each participant gained from their interactions with their doctor, I had to evaluate what information they knew about HPV prior to their diagnosis. Thirteen of the participants
already knew basic facts\(^7\) about the STI. Six of these individuals knew HPV was medically related to cancer. One of those participants felt that she would avoid the “really really scary stuff” (Amber) like cervical cancer because she had been vaccinated against HPV, while another noted that her knowledge of the link between cancer and HPV also came from vaccine messaging, stating: “I think I knew of it mostly through the vaccine advertisements. It was something that could cause cancer -- but maybe not necessarily -- and that there was a vaccine for it, but I had never considered getting it” (Erica). Seven of the individuals already knew that HPV was highly prevalent before their diagnosis. Most of those recalled not being scared or upset about their diagnosis because they knew how common HPV was in the United States. One participant learned about the prevalence because she had a friend diagnosed earlier and had researched the topic. She said: “I … found out that 90% of women have it at one point in their life whether or not they are aware of it” (Amber). Six participants explicitly stated that they were aware that HPV was a sexually transmitted infection before discussing their status with their doctor. Only two of the participants knew all of these basic HPV facts, four more knew two out of three of these facts.

Eleven participants were unaware of HPV prevalence, sexual transmission, and cancer consequences before their diagnosis. Five participants recalled having no knowledge of HPV pre-diagnosis, revealing: “I didn’t know anything about it when I was diagnosed (Emily)” and “I hadn’t even heard of HPV at that time” (Andrea). Two of these participants researched the STI after visiting their doctor and learning they were HPV positive. One maintained that she “did not feel like she [the nurse] knew much … so I looked it up myself when I got to the car… right away.” (Janelle) Researching HPV, however, sometimes caused more anxiety about their diagnosis. For example, one woman, who already knew HPV basics before diagnosis said: “I looked up stuff on the internet which is always terrifying. I

\(^7\) Basic HPV facts, based on past research (Gerend and Shepherd 2011; Sandfort and Pleasant 2009), include (1) genital HPV infection can cause cancer (2) most genital infections clear up on their own (3) most individuals with HPV are asymptomatic (4) HPV is very prevalent (5) HPV can be transmitted by skin-to-skin contact.
think I tried to skip WebMD and went to the Mayo clinic... something a little more reliable, but it was still, like, this causes cancer and you will die.... That is not what I want to hear” (Erica).

2.6.2 Post-Diagnosis Knowledge

Post-diagnosis, nineteen participants knew about prevalence, transmission, dormancy, clearing, or risk associated with HPV post-diagnosis. The most frequently cited HPV facts were related to prevalence of the STI. Fifteen participants discussed the high prevalence of HPV. Three of them received this information upon initial diagnosis (e.g.: “My gynecologist said it was really not that big of a deal so really don’t worry about it... ‘cause 1 in 5 people has it.” [Emily, diagnosed at age 19]), while others attributed their knowledge to the Garadasil commercials: “I knew more about what was going on... the prevalence... at that point there were already commercials and stuff for the vaccine which was out by then (Ashley, diagnosed at age 19).” Two individuals acquired their knowledge of HPV prevalence from studying the subject: “I have worked in sexual health since, like, 1989 so you know.... I understand that 98% of the world has it (Colleen, diagnosed at age 38)” and “I know a lot about it because I formally studied reproductive health ... at a conference I went to a presenter said that HPV was biomarker of sexual activity for our generation (Phoebe, diagnosed at age 20).” Most of these individuals simply conveyed that they knew it was common or that a “fairly significant proportion of the population has HPV (Leah, diagnosed at age 22)” and this oftentimes made them feel like their diagnosis was less worrisome: “Everybody has it. I am just one of everybody (Colleen, diagnosed at age 38).” However, knowledge about prevalence did not alleviate everyone’s worry about the diagnosis, as one participant stated: “you know, I judge myself.... I should have been more assertive about using condoms....I know it [HPV] is really common but I just have a different standard for myself I guess (Whitney, diagnosed at age 45).” One individual felt that her doctor’s message about prevalence was both beneficial and detrimental: “I think it makes people feel less stigmatized. I think it matters how it is said. Talking about
the prevalence is different than saying, ‘oh, everyone has it and it is not a problem.’ Just because something is prevalent does not mean it is not a problem or that it does not have negative consequences (Candace, diagnosed at age 19).

As stated above, participants also demonstrated knowledge of HPV related to transmission, dormancy, and clearing. Four individuals explicitly stated that HPV could be transmitted from skin-to-skin contact, did not require penetrative sex, and that condoms would not completely protect a person from contracting it. According to two of these participants: “There is no 100% and I think it is a false sense of security people do get from using condoms (Riley, diagnosed at age 20)” and “People probably don’t know that HPV is transmitted by skin-to-skin contact, and you can use condoms but it is not just about covering an orifice. You would have to have sex with a rubber suit on (Colleen, diagnosed at age 38).” One participant explained that this information came from her doctor upon diagnosis: “She mentioned that the protection of a condom does not always work (Ava, diagnosed at age 22).” Another individual may have been misinformed by her doctor who told her that “it was sexually transmitted and I could pass it from cervical to penile contact … that was it (Tiffany, diagnosed at age 31).” Four participants mentioned that HPV can lie dormant in your body for a period of time. Specifically, they mentioned: “HPV can come up years after you've had a relationship with someone (Amber, diagnosed at age 25)” A different participant actually felt misinformed by her doctor when she found “things [that] conflicted with what my doctor said…. She was very sure I had gotten it from my current partner and ... research I did online said it could be dormant (Ava, diagnosed at age 22).” Only two participants stated that their doctor told them that HPV could clear from a person’s body: “I had HPV and then I had normal Paps since, and my doctor said that my body must have cleared it - that was the language that he used (Candace, diagnosed at age 19)” and the doctor “said it is really common; your body will probably clear it in a couple of years (Carla, diagnosed at age 32).” Two other participants learned about clearance on their own; one knew about it only after no longer having HPV: “everything after that was fine. They
never needed to do anything else after…. I think it was just that I am fine... because I had HPV... it cleared out of my system I want to say within 2 years.... Then I was tested for my yearly the next year. I was clear of everything and I thought that was weird, but I came to find out that it can come and go out of your system [clear]. (Ashley, diagnosed at age 19).”

Eight participants mentioned their knowledge about developing cancer from HPV. Some of these individuals learned that HPV was related to cancer directly from their doctors: “the second diagnosis, when it was pre-cancerous... I believe they said ‘cervical’... the second time.... My only concern was if I was going to develop cancer (Leslie, diagnosed at age 22)” and “I just wanted to know if it [biopsy] would come back as anything..., like, anything important that was going to be leading to cancer.... That was my biggest concern (Ashley, diagnosed at age 19).” Two participants actually referred to their diagnosis as “pre-cancer (Leah, diagnosed at age 22).” Three learned this information from the Gardasil marketing campaign: “Now that I have it I think about cervical cancer ... only because the commercials are, like, if you have HPV you are more likely to get cervical cancer (Emily, diagnosed at age 19)” and “I think I knew of it mostly through the vaccine advertisements. It was something that could cause cancer but maybe not necessarily and that there was a vaccine for it (Erica, diagnosed at age 26)”.

Another individual said: “I read a statistic that, like, 90% of cervical cancer is caused by HPV even though most HPV is perfectly harmless. And reading that for the first time was like, oh I have this thing that basically you don't get cervical cancer if you don't have [it] (Phoebe, diagnosed at age 20).” One participant knew about the link between HPV and cancer, but stated that she was more concerned with infertility as a consequence of the STI: “from what I read the odds of developing cancer are relatively small, but after having the Loop Electrosurgical Excision Procedure (LEEP)⁸, the odds of having a complication from that are small, but something about that was scary to me. Anything that impacts

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⁸ With LEEP, an electric current heated wire loop removes abnormal cells and tissues in the cervix and vagina. The tissue is then sent to a lab for testing. LEEP is often performed in order to detect cancer of the cervix or vagina (Johns Hopkins n.d.).
fertility to me is, like, oh.... I don't know why that is scarier than cancer... but something about it made it really serious to me (Candace, diagnosed at age 19).”

2.6.3 Comparing Pre- and Post-Diagnosis Knowledge

Although almost all of the participants were informed about at least one aspect of HPV after their diagnosis, many were not fully informed. Nineteen of the 23 participants remained unaware of the fact that HPV can lie dormant in a human body for many years and 19 did not know that the body can clear HPV within a few years of contracting it. Among the individuals who knew about the body’s ability to clear HPV, only two learned this information from their doctor. Another participant who was aware of clearance learned this information by reading literature on HPV. Nineteen of the participants also did not know that HPV could be contracted through skin-to-skin contact and did not require penile-vaginal or penile-anal penetration. One of the 4 participants who knew about skin-to-skin transmission of HPV learned this information by working in the STI field, not from her doctor. One participant who knew about skin-to-skin transmission learned this directly from her doctor and the others were unsure where this information originally came from stating, “honestly my education may have come from commercials which is probably bad... but ... yeah it could have been a thing where my doctor mentioned it first... I don't really remember. I don't think I knew much about it until the time I was about to get the vaccine” (Carla, diagnosed at age 32). Seven interviewees did not understand that HPV was linked to cancer in women. Among those who knew about the association between HPV and cancer, four learned this from their doctor, two learned this through online research, three learned this through the Gardasil campaign, and the rest were unsure about where they obtained this knowledge. Eight participants remained unaware of the high prevalence of HPV after their diagnosis. Among those who learned about the high prevalence of HPV post-diagnosis, three attributed this knowledge to their own research or the vaccine commercials, rather than their doctor.
2.6.4 Emotional Impact of Diagnosis

Participants’ emotional responses upon initial HPV diagnosis demonstrate a range of responses, framed largely in terms of anxiety and worry or lack thereof. Five participants were ambivalent about their positive diagnosis. One stated: “I wasn't upset because, you know, what can I do about it?” (Carla). Another related her lack of anxiety surrounding diagnosis to her pre-diagnosis knowledge stating, “I must have known how common it was because I never got freaked out, really” (Phoebe).” One participant differentiated between cancer and HPV: “HPV's not really the problem - the problem is the cancer cells, so while I didn't worry about what was going on with that... I don't know, it didn't seem like something worth worrying about. Everybody has it, we will just have to deal with it” (Andrea). Another participant related her reaction to the diagnosis to her personality: “I just thought, it is what it is.... I am just the type of person.... I don't mope and groan about one thing because there is just so much more for me to have to worry about” (Tiffany).

Nineteen participants, however, had negative feelings toward their diagnosis. Many of them felt anxious and scared upon diagnosis. One said: “I was stressed out. It was more confusing... everything else was fine on the day of my checkup... everything else was fine, I was good ... I NEVER expected to have an STI just because I play it safe and I haven't had many partners AT ALL. So I was upset. I felt that I was tainted unfairly” (Kendra). Another stated: “I felt scared ... yeah and nervous about it. There was a point when I was 20 or something when I had bumps, like, in my vulva and they really looked white and I got freaked out - I don't remember if that was before or after I found out I had the abnormal cells - but I remember being terrified by that ... terrified that I had something” (Candace). Other participants stated:

I was concerned. There was nothing they could do... (Katherine),

I was really upset... I cried... I was really afraid... (McKenzie),

I mean I was initially scared and you know (Summer),
I was mortified... absolutely mortified (Ashley),

I kind of just felt like I was broken (Kaylee),

[I]s it that serious... how quickly can it become serious (Erica).

[I]s it something that is going to kill me (Janelle).

Some were caught off guard by their diagnosis. One participant stated: “I was really surprised to be honest” (Jessie). Another stated that she “had a shockingly late, surprising diagnosis... I don't understand how I have HPV now and I haven't for the majority of my life” (Colleen). Others were ashamed by their diagnosis; saying things like: “I felt dirty and I felt gross ... I felt ugly and I did not feel sexually viable” (Emily), and “I feel ashamed I guess... you know, you are just dirty, kind of” (Whitney).

Some participants felt that their positive HPV status was deserved because they had been “irresponsible with [my] body” (Amber) in the past or upon diagnosis they thought, “‘Holy Shit! what Bastard had it?’... I thought, in my own Roman Catholic upbringing as a child..., ‘oh, now I guess you paid for that piece of ass’” (Theresa).

2.6.5 Emotional Impact of Diagnosis by Type of Diagnosis

Five of the participants received word of their positive status from a nurse or clinic staff member, not their doctor. The participants who were informed by a nurse commonly felt their conversations were awkward. All of these participants had negative emotional reactions to their diagnosis. One participant, who felt ashamed and dirty upon diagnosis, stated: “It was weird because somebody called me on the phone that was not my regular gynecologist - she was on vacation- so this stranger called me up and told me about it” (Whitney). One participant who was shocked by her diagnosis recalled receiving this information over the phone stating: “So the nurse called and said, ‘We got your test results back and everything looks good, HPV came back positive,’ and she just RAN through it and I was, like, ‘what?’ and she was ‘your HPV is positive’ and I said ‘how is that possible, I am always
negative’…. So I said to the nurse, ‘no my doctor needs to call me back immediately and explain these test results’” (Colleen). Another participant who was very concerned about the seriousness of her diagnosis was told she was HPV+ as an afterthought by her clinic, “they were, like, ‘oh and by the way you have HPV sorry we did not call you, we forgot’…. I remember them botching the situation… they forgot to call me, if I had not called them I don’t think they ever would have told me… unless I would have pursued getting whatever test redo and been, like, ‘hey what’s going on’…. so I was really really unimpressed with how the whole thing was handled. I was, like, you know what I am going somewhere else” (Erica). Another participant who was mortified upon diagnosis, found out her status from a nurse in an abrupt manner: “the nurse or whoever was working was very abrupt and she was, like, ‘you have warts’ and I did not understand what was happening... so I then went and got tested for everything and she said I had HPV... so that was when I was technically diagnosed the first time” (Ashley). Another participant who was worried that HPV could lead to death stated: “I found out [that I had HPV] from my Pap test from my annual gynecological visit that I hate... the worst day of the year every year... she just.. it was kind of casual when she called me and told me ‘oh yeah you tested positive for that and everything else is good.’ I was, like, ‘whoa whoa lets back up to the tested positive for that’... it wasn’t the doctor who told me, it was a nurse in the office and she just kind of railroaded past it like it is not a big deal, she acted like it was nothing” (Janelle).

Four participants recalled finding out they had HPV and their doctors or clinical staff assumed they already knew because it was in their medical records. All of these participants experienced negative emotions upon HPV diagnosis. One participant felt ashamed about her diagnosis, but did not feel offended by this assumption stating: “Given my age [late 40’s], I think my doctor assumed I knew, so she called me up and was, like, ‘your pap was abnormal so we have to do this LEEP procedure.’ I was focusing on that and then she said and ‘you have HPV’” (Whitney). However, others recall being shocked by their doctor or nurse’s bluntness. One participant who described herself as “broken” when
diagnosed, recounts the negative exchange she had with her doctor: “He was, like, ‘well you do carry the Human Papillomavirus (HPV)’ and I was, like, ‘what? I did not know that I had that’ and he was, like, ‘yea you have had to have had it for a while’ .... I was, like, ‘I have been with the same person for 6 years ... no one told me this’...I wish my doctor told me ... it feels, like, they are definitely keeping it a secret. Like, the doctors are not telling us” (Kaylee). Another participant experienced a similar late diagnosis: “I did not find out that HPV was the cause of my dysplasia until many years later when I was digging through my medical records with my doctor after they told me my dysplasia was back... there is actually a 3 year long story of that... so the dysplasia at 20 which they did a LEEP for was definitely HPV but I did not know that until years later which I was kind of pissed about ...so I sat there with the nurse practitioner and my medical records and we went through it and I was, like, ‘tell me what the fuck is going on here’.... so they saw the old HPV results so there it was clear as day and piece of paper from when I was 20 years old saying HPV positive... so I am 33 now... so 13 years ago around they thought it was not important to tell you, you had HPV.. they knew it” (Riley). This particular participant felt so ill-informed by her earlier clinicians about HPV that she felt extreme anxiety from her condition stating: “I was, like, I am going to die of cancer... because I did not know it was a communicable virus that caused it I thought my body had manifested cancer at 20 years old” (Riley).

Another who said she was “scared” upon diagnosis found out she had HPV only after asking questions about her last abnormal Pap test, “No they CALLED me and said, ‘you have another abnormal pap smear’ and .... I was worried about getting the biopsy again because the first one was painful.... so I was, like, ‘is there any way we can do something else?’ And I was asking them all these questions and the woman was like... she said very bluntly something, like, ‘how long have you known you've had this disease?’ and I was just ‘what disease are you talking about’ and she told me and then I was at home and I did a bunch of research that day” (Summer).
Only three out of 23 participants felt supported by their doctors at diagnosis in such a way that they felt less emotional upheaval after discussing their diagnosis with their doctor. One participant reasoned that having confidence in her informative doctor possibly prevented her from having an emotional response to the diagnosis stating: “I don't really remember having a strong emotional response to it. I mean I was worried about it but I tended to have a good bit of faith in the medical profession. It’s kind of, like, ok this is cool this guy knows what's going on and what to do next and he’s going to take care of it. It's not cancer yet so I think we are ok” (Leah).

Two of the 23 participants who were upset upon initial diagnosis had their worries assuaged by the doctors. One of these participants stated that upon initial diagnosis: “I started crying. I was really upset because I was not really educated and did not know what it meant and then he [doctor] kind of calmed me down and explained. He gave me an education on it and I feel like that was pre-Google everything” (Leslie). Another stated: “I was, like, panicking and crying and the doctor was, like, ‘oh no it is going to be ok’ .... She said it really is so common and a lot of people are affected by this and it is not going to harm you” (Ava).

Some participants, however, could not be assuaged by their doctors’ attempts to emotionally support them. One participant stated, “when I found out about it I kind of just felt like I was broken... even though he told me that there are tons of women that have it and its nothing to be scared of. He told me I am not going to die from it or anything. It still made me feel like I wasn’t a complete woman. Especially considering what he said [that]... the hysterectomy thing is next... it diminished my value... that's what it felt like” (Kaylee).” Another stated, “at the time I was kind of freaking out.... I was, like, oh my god I have an STD... that was an emotional crisis for me even though she told me it was very common ... it is not gonna hurt me at all in my future?.. I asked” (Ava).
2.7 LIMITATIONS

Past qualitative research on HPV has relied on non-diverse samples of primarily white, college-education women (see: Kosenko et al. 2012, Nack 2008). Although I sought to reveal the stories of a diverse sample based on ethnicity, race, and educational attainment level, my sample was more homogeneous than initially intended. My sample included cis-gender and gender non-conforming biological females from different racial and ethnic groups ranging in age. However, I was unable to include participants of varying levels of educational attainment. This may have been a result of my sampling method, however, I also believe it is due to the fact that women with lower socioeconomic status and less education are less likely to have regular gynecological appointments and routine Pap tests compared to their more educated peers (Behbakht et al. 2004; Katz and Hofer 1994). Without regular visits to the gynecologist and routine Papanicolaou tests, women are much less likely to know they are HPV positive. Therefore, individuals who saw my flyers may have thought they did not qualify because they did not know their positive status.

Despite this limitation, my research adds knowledge to the field because of the rich detail my participants provided during their interviews. Many past researchers used surveys to analyze knowledge, awareness, and attitudes regarding HPV, but qualitative researchers have found that semi-structured interviews allow participants to demonstrate meanings attached to their STI diagnosis and personal experiences of dealing with this new diagnosis (see: Gerend and Magloire 2008; Lee and Craft 2002). My work differs from existing studies where researchers ask undiagnosed women how they would feel if they were diagnosed with HPV (see: Waller et al. 2007a). My interviews of HPV+ participants, however, fostered detailed discussion of actual lived experiences related to HPV diagnosis, HPV knowledge, emotional impact of diagnosis, and patient-provider communication.
2.8 DISCUSSION

Numerous studies highlight the correlation between health literacy and health behaviors. Researchers have found that many cervical cancer prevention brochures are written at reading levels too difficult for most consumers (Helitzer 2012). Women under 40 years old with below-basic health literacy have a lower probability of having a Pap test than women in the same age group with proficient health literacy (Hanchate 2008). Individuals with higher health literacy levels have been found to have a greater understanding of cervical cancer and pap smears (Tiraki and Yilmaz 2017). They are also more likely to participate in prevention measures, such as Pap smears (Tiraki and Yilmaz 2017).

Two decades ago, researchers found that individuals with HPV were dissatisfied with their health care providers’ handling of their diagnoses because their providers did not offer emotional support, provide written information on HPV, or refer them to a specialist (Clarke and Ebel 1996). Common barriers to discussing HPV for surgeons, clinical oncologists, and nurse specialists alike included lack of knowledge about the virus and not feeling well informed about HPV (Dodd et al. 2016). Researchers have discovered that practitioners’ non-discussion of HPV is influenced by a general lack of knowledge, a difficulty in keeping up-to-date on ever evolving HPV facts, and concern that information on HPV from pharmaceutical companies is biased (McSherry et al. 2012). They also cite patient-provider issues as barriers to this communication, including: concern that they will embarrass their patient and themselves; lack of a clear opening to facilitate discussion of HPV; difficulty explaining HPV to patient in terms they can understand; fear that their discussion of HPV would be viewed as judgmental; uncertainty of necessity to discuss potential transient infection with patient; and lack of time and discussion aids for consultations with patients (McSherry et al. 2012). Other communication barriers to HPV discussion include patient lack of knowledge or interest in the STI, and fear that women would not follow through with Pap tests once they knew more about HPV (McSherry et al. 2012). Many head and neck practitioners (who diagnosis individuals with high-risk HPV types linked to oropharyngeal
squamous cell carcinoma) say they worry about patients blaming themselves after diagnosis (Dodd et al. 2016). Therefore, the practitioners try to assure their patients that they could not have done anything to prevent their diagnosis (Dodd et al. 2016).

Researchers have suggested that practitioners’ messages about HPV are inadequate because there is a dearth of HPV knowledge among the general public; it is not often included in sexual education curriculum and those who are aware of HPV overestimate their risk of cancer (Warren and Ebel 2005). Effectively communicating about HPV without causing undue psychosocial stress requires skill and sensitivity on the part of the provider (Harper 2004). In fact, breaking bad news is cited as one of the most difficult aspects of being a medical service provider, yet doctors often lack adequate training in this area (Sparks et al. 2007). Therefore, practitioners must stay informed of the most current scientific data on HPV and be able to educate their patients on the subject in an empathetic manner (Diaz 2013).

Many of my participants received their HPV diagnosis over the phone which supports the findings of past research (see Harvey-Knowles and Kosenko 2012; McCree et al. 2010). Doctors, however, are best able to offer emotional support and correctly answer patient questions when they diagnosis face-to-face (Harvey-Knowles and Kosenko 2012). Unsurprisingly, this method of diagnosis communication is most preferred among patients (Harvey-Knowles and Kosenko 2012). When receiving a diagnosis over the phone, patients often have many unanswered questions about HPV and how it will impact them (Harvey-Knowles and Kosenko 2012).

According to past research, at diagnosis, some women recall experiencing supportive healthcare providers who gave information on HPV while providing reassurance (Bertram and Magnussen 2008). In my study, however, few participants cited having an empathetic, supportive, and informative doctor who diagnosed them. To minimize the psychological distress associated with a positive diagnosis, doctors should discuss abnormal results with their patients in a clear, concise, supportive manner (Diaz
Doctors should also be mindful of the timing of their discussion and their patients’ health literacy level (Diaz 2013).

Doctors should consider key messages that may minimize the negative consequences of HPV diagnosis such as: normalizing HPV by focusing on how it is easily transmitted through sexual activity, highlighting the high prevalence of HPV and perhaps even stating that it is as common as the flu, and reassuring patients that they do not need to modify their behavior because they did not cause their status (Dodd 2016). In my study, participants who were knowledgeable about the high prevalence of HPV were less worried when diagnosed. Only 15 of my 23 participants were aware of how common it was after diagnosis, however, and only 3 of those were informed of this fact when receiving their diagnosis.

Post-diagnosis, many individuals are ill-informed about other important aspects of the disease. Only 8 participants in my study were aware of HPV’s link to cervical cancer after their own diagnosis. Over half of the participants who knew this information learned it from a source other than their doctor (Gardasil commercial or online). This is problematic because, without being informed by a doctor if their particular strain of HPV was linked to cancer, these participants could assume the worst and suffer from unnecessary stress. I found that women were also rarely told about HPV’s tendencies to lay dormant in the body and clear after a few years. Some of my participants found out about clearance a while after being diagnosed with HPV (through their own research, from a new doctor) and felt relief at the prospect that they would not have HPV for a lifetime. Those who knew about HPV dormancy were less likely try to link their diagnosis to past sexual experiences or partners. Doctors should, therefore, inform their patients, at time of diagnosis, about HPV dormancy and clearance in order to mitigate any feelings of blame on partners, self-blame, or pessimism. Very few participants were correctly informed about HPV transmission. Only four individuals stated that HPV could be transmitted from skin-to-skin contact and only one of these participants remembers that information coming from their doctor. It is a public
health issue that post-diagnosis, individuals are still misinformed about how this STI is transmitted. Without correct information on this topic, HPV positive individuals can do nothing to stop the spread of the disease.

I found, in support of past research (see Bertram and Magnussen 2008; Kosenko et al. 2014; Perrin et al. 2006; Sharpe et al. 2006), that many individuals with HPV are misinformed about HPV. Based on my research, I recommend that healthcare practitioners strongly consider taking the time to have a face-to-face conversation with their patient when providing a positive HPV diagnosis. This may alleviate some patient confusion and any undue worry. Providers should also discuss with their patient the high prevalence of HPV at time of diagnosis. According to my research, which supports the findings of Bertram and Magnussen (2008), this discussion of prevalence is much appreciated by patients and can ease their minds upon initial diagnosis. Based on my findings, I also recommend that doctors make sure their patients are fully informed about key aspects of the disease: transmission, dormancy, clearance, and how, specifically, it is linked to cancer.
3 “She’s a Slut, She Has HPV”: HPV Stigma and Disclosure

3.1 ABSTRACT

Human Papillomavirus (HPV) is the most prevalent sexually transmitted infection in the United States, however, many Americans negatively view the disease and those infected with it. This study uses in-person, semi-structured interviews to examine feelings of stigma among individuals with HPV. It also analyzes how these feelings and HPV knowledge impacted individuals’ motivations to disclose their status to others. The study found that post-diagnosis many individuals were anxious and upset about their positive status and felt judged by some individuals in their lives. Confronting and internalizing this stigma, impacted how and why they disclosed and withheld their positive HPV status. These findings suggest that the culture around HPV needs to change so that individuals with a positive status no longer undergo undue stress and can openly educate others about the STI.

3.2 INTRODUCTION

Human Papillomavirus (HPV) is transmitted most commonly through sexual contact, such as intimate skin-to-skin contact, and vaginal, anal, and oral sex (Moscicki 2005). It is the most prevalent sexually transmitted infection in the U.S. (CDC 2017a). According to 2016 data, nearly 79 million Americans are infected with HPV, with 14 million becoming newly infected annually (CDC 2017a). Increased incidence of HPV has long been associated with greater number of sexual partners and “risky” sexual behavior (e.g., multiple partners, unprotected sex). However, according to recent longitudinal research, HPV detection, on average, occurs within 2.6 months of first intercourse (Collins et al. 2002). In fact, Collins et al. suggest that “perhaps cervical human papillomavirus infection should now be considered an inevitable consequence of sexual activity” (2002:98).

Despite the high prevalence and easy transmission of this STI, many Americans negatively view the disease and those infected with it. Individuals with an STI often report disclosing their diagnosis
because keeping it secret interferes with their relationships with others (Lee and Craft 2002). By disclosing their condition, individuals with STIs can be reassured that they have not changed post-diagnosis (Lee and Craft 2002). According to Lee and Craft, “through telling, the respondents get verification that they are still the same persons they were before genital herpes” (Lee and Craft 2002, 286).

Past research indicates that women feel more stigmatized and rejected socially when diagnosed with an STI, compared to men (Smith et al. 2007). Past research indicates that women are more likely than men to hide their STI diagnosis due to embarrassment (Smith et al. 2007). Additionally, women with STIs report internalizing their stigma and believing the stereotypes are true for them (East et al. 2012). Women’s disproportionate stigmatization stems from historic blame of women as the vectors of sexually transmitted infections (East et al. 2012; Nack 2008).

3.3 THEORY

3.3.1 Stigma

The symbolic interactionist approach, specifically Goffman’s theory on stigma is an appropriate framework through which to investigate the experience of living with HPV. According to Goffman, stigma is a less desirable attribute than one stereotypically assigned to persons of the same category (Goffman 1963:3). Stigmas can be related to character flaws, which are personality traits that deviate from those socially accepted or by physical deformities (Goffman 1963). Society views women who stray from the societal norms of female chastity and purity as deviant, morally corrupt, irresponsible, unclean, and promiscuous (East et al. 2012; Nack 2008). Therefore, they possess a character stigma (Nack 2008).

When an individual’s dissimilarity is not obvious upon first meeting, they have a “discreditable stigma,” which can be hidden (Goffman 1963:42). They must determine what to tell or not tell and to
whom and when (Goffman 1963). According to symbolic interactionists, individuals incorporate others’ evaluations of them when self-evaluating (Nack 2008:65). Therefore, they may choose not to disclose their discreditable stigma, and instead, to hide it from others. Other discreditable persons, however, may reveal their shameful attribute to a few key individuals and then rely on those individuals for support (Goffman 1963). Alternatively, an individual can self-disclose and admit to having the stigma if they no longer feel the need to conceal it (Goffman 1963).

Recent research on stigma also lends itself to this analysis. HPV stigma researchers that used the HIV Stigma Scale found that feelings of uncleanliness and disgust with oneself, categorized as negative self-image stigma, and fear of rejection, categorized as personalized stigma, were often felt by individuals with HPV (Barnack-Tavlaris et al. 2016). Attribution theorists suggest that individuals with illness that may be attributed to their behavior will face more judgement and stigma from others (Lebel and Devins 2008; Weiner, Perry and Magnusson 1988). As noted above, individuals with HPV are often seen as promiscuous and thus to blame for their sexually transmitted HPV (Nack 2008).

### 3.4 CURRENT STUDY

Research centered on individuals’ experiences of STI stigma is often related to genital herpes (see: Lee and Craft 2002), or a multitude of STIs including HPV, genital herpes, and chlamydia (see East et al. 2012, Nack 2000). Stigma related HPV research is often conducted outside of the United States (see: McCaffery et al. 2004, McCaffery et al. 2006, Waller et al. 2007a) and is survey based (see: McCaffery et al. 2004, Waller et al. 2007a). Through my research, I sought to discover how an HPV + status, a character stigma, influenced my participants’ feelings about themselves, and why they decided whether or not to disclose their status to family and friends.
3.5 METHODS

Due to the fact that individuals with STIs qualify as a hard-to-reach population and recruitment can be difficult (Dixon-Woods et al. 2001; Nack 2008), I employed purposive, facility-based sampling and snowball sampling. I utilized key locations to find study participants (Magnani et al. 2005), such the health clinic at a large public university in the Southeastern United States and multiple privately-operated gynecological clinics around a large metropolitan area in the Southeastern United States. Commonly cited barriers to STI screenings include cost, privacy, language barriers, and perceived discrimination at the clinical site (Tilson et al. 2004). Therefore, I chose to include clinics that offer free or low-cost STI screening services to English and non-English speakers and that abide by anti-discrimination laws specific to patient admission and treatment. I also posted flyers around two major universities, high-traffic pedestrian areas, and throughout diverse neighborhoods. Additionally, I gained entry into online support groups for individuals with HPV\(^9\) to recruit group members for my study.

I recruited my participants via advertisements (flyers) displayed and distributed at the recruitment facilities. This discreet recruitment method is commonly used among STI researchers (see: Kosenko et al. 2012; East et al. 2012) so that interested parties can contact the researcher anonymously with any questions. Multiple versions of the flyer were distributed with various photos of young girls and women from different racial and ethnic groups on them in order to appeal to a diverse group of potential participants. Each flyer contained tear-off tabs so that interested parties could easily obtain my contact information. Additionally, each flyer included a Quick Response code. Quick Response codes are an increasingly popular advertisement tool that can be scanned and read by smartphones (Shin, Jung, and Chang 2012). The flyers contained a unique Quick Response code that linked smartphone users to my online eligibility form. This eligibility form required users to enter their age and HPV status and then, if eligible and interested in participating, their contact information was automatically sent to me.

3.5.1 Sample Demographics

I gave all of my participants pseudonyms to protect their identity. My participants included 23 women of various ages\(^{10}\). Six were in their 20s, eleven in their 30s, three in their 40s, two in their 50s, and one over 60 years old. Sixteen of the 23 participants grew up in a two-parent family; three had a single parent; three had divorced parents and stepparents in the home; and one had divorced parents that never remarried. Twelve of my participants grew up in the Southeastern United States. Six of my participants grew up in the Northeast; three grew up in the Midwest; and two grew up outside of the United States. Fifteen of the participants resided in the Southeastern U.S. at the time of their interviews with three living in the Northeast; one in the Southwest; two in the West; and two outside of the United States. My sample was a highly educated group, with 10 of my participants having obtained a graduate degree, four in graduate school at the time of interview, six obtaining a terminal Bachelor’s degree, one currently in undergraduate school at the time of interview, one having had some college education, and one having a GED as highest level of education. Regarding occupation, eight worked in health and medicine, four in education, three in law, three in the arts, one in business administration, one in marketing, one in plumbing/engineering, and two as current students. The majority of my participants were white (n=17, 73.9%), five (21.7%) were black, and one (4.35%) was multiracial. Ten of my participants were single at the time of interview, 8 were in a committed relationship, and 5 were legally married. In terms of gender identity, 22 of my participants identified as women and one identified as gender queer. In terms of sexual orientation, 18 classified themselves as heterosexual, one as lesbian, and four as bisexual.

\(^{10}\) My sample originally included 25 individuals, but after the interview, I determined that two no longer qualified to be included, due to their type of HPV. Both of those original participants had HPV that manifested as skin warts on the hands and feet – a condition that is not considered a sexually transmitted infection and is not related to reproductive issues or cancers.
3.5.2 Interview Method

Although many past researchers have used surveys to analyze knowledge, awareness, and attitudes regarding HPV and the vaccine, other researchers find that semi-structured interviews allow participants to explain their personal experiences of dealing with STI diagnosis and what this diagnosis meant to them (see: Gerend and Magloire 2008; Lee and Craft 2002). Interviews of HPV+ participants, compared to survey research, are more likely to foster discussion of actual lived experiences related to living with HPV and disclosure to others, and stigma.

As a feminist interviewer, I was cognizant of my role as a researcher and my potential source of authority during the interview process (Hesse-Biber 2007). In order to diminish the hierarchical relationship between researcher and participants, after each interview, I shared relevant aspects of my own biography (Hesse-Biber 2007) and experience with HPV. I strove to be reflexive and to consider how my biography, values, and attitudes influenced the research process (DeVault and Gross 2012; Hesse-Biber 2007). As a woman with HPV, throughout the interview and analysis stages, I reflected on how my attitudes regarding the disease impacted my choice of interview questions and my interpretation of participants’ responses (DeVault and Gross 2012). For example, I was motivated to ask about disclosure to friends and family because of my own decision-making about disclosure. My personal experience also helped me understand the participants’ willingness or hesitation to tell others about their status.

Interview topics included: how participants felt about themselves post-diagnosis, to whom they disclosed their status, and reasons for their disclosure and non-disclosure of status.
3.5.3 Analysis

I conducted, recorded, and transcribed all of the interviews. I imported all transcribed materials into NVivo and analyzed them using a grounded theory approach. I chose this analytic method because it is well suited for understanding social processes not yet commonly researched (Milliken 2010). And, as noted above, there have been very few qualitative studies on the lived experiences of individuals with HPV. From my transcription and pre-analysis coding, I identified a few themes that I wanted to further investigate related to consequences of HPV: “stigma,” “disclosure,” and “initial impact of diagnosis”. I analyzed the transcripts using the triadic coding scheme of open, axial, and selective coding (LaRossa 2005). During open coding, I identified major themes related to stigma, emotional response to diagnosis, and disclosure to friends and family, and deciphered what each concept represented (Lofland et al. 2005; LaRossa 2005). In the context of their diagnosis, each participant mentioned how they felt about their diagnosis and who they told about it. I then reviewed the concepts for similarities and variations, assigned them to categories, and identified the most salient categories (Corbin and Strauss 1990). I analyzed consequences of HPV to determine how participants felt when first diagnosed, whether or not participants felt stigma due to their status, to whom and when they disclosed their status, and why they decided not to disclose their status to some individuals, if applicable.

In the axial coding stage, I analyzed the categories to determine how and why they differed among the participants, by focusing on the context, strategies, and consequences associated with each category (Corbin and Strauss 1990; LaRossa 2005). I analyzed relationships between participants’ experience with the diagnosis, stigma, and disclosure. Finally, I moved on to the selective coding stage of my analysis, where I decided which categories were most representative of the central argument of my analysis (Corbin and Strauss 1990; LaRossa 2005). I found the relationship between stigma and disclosure to friends and family to be most informative in this study.
3.6 FINDINGS

3.6.1 Stigma

3.6.1.1 Participants Who Felt Little to No Stigma

Nine participants felt little to no stigma associated with their HPV status. One stated, “since everybody has it, I feel like it is a bacteria that lives in everyone. I don’t think it has any stigma the way HIV has stigma” (Andrea). A few individuals mentioned not feeling stigma because of the types of people they acquaint themselves with, “I think it depends on the type of people that you date and I tend to date people that are educated so I could see where someone who was dating uneducated men or women, that they could feel more stigmatized” (Leslie). Another similarly articulated, “no [I do not feel stigma] but I guess on top of that, the part of society I interact with aligns very closely with what I believe and how I live my life” (Erica). Those that were aware of the high prevalence of HPV and/or associated with individuals who were more knowledgeable about HPV felt less HPV stigma.

Three of these participants recognized the stigma attached to HPV even when they did not experience it themselves. One individual recalled a friend’s reaction to her own HPV diagnosis, “you would have thought she was the whore of Babylon. She thought she was a horrible person, ‘how could this happen, who could have given this to me? I have not had that much sex’” (McKenzie). Another participant explained how others with HPV often feel by saying, “I think that most people end up thinking they are punished or they are dirty or because that boy or that person or that bad decision... I think that everybody has that because sex has a terrible stigma attached to it” (Riley). This individual recalled how societal pressures on women translated into women with HPV feeling at blame, “I feel like since you can’t test men, then it becomes the women’s problem and the dirty slutty women, we are the ones carrying it around. It has that feel to it. And the women that I have known that are diagnosed have been devastated” (Riley). Another recalled men friends saying “she had HPV, she’s gross” but equates this stigmatizing behavior to people being ignorant about HPV, “they are uneducated about it... I just tell
them they are wrong and explain. It's just miseducation” (Leslie). These participants, even if experiencing no stigma personally, understood how many individuals with HPV could feel judged by others and internalize that judgement.

3.6.1.2 Participants Who Felt Stigma

Fourteen participants explicitly mentioned feeling stigma due to their HPV status. Ten of these participants felt judged by others. One did not tell her mother about her HPV “because there is a level of shame that comes with stuff like this that is not acceptable” (Ashley). Another worried what her family would think, saying: “I believe that they would [be judgmental]. My family on my mother's side ...oh yes, they are very... a different breed. They would probably blame it on me.... ‘That's what you get’ type of thing” (Kaylee). Another told a friend for support and was shamed for it, “I told a friend of mine about what happened at the clinic [my diagnosis] and she told everybody that I had a venereal disease” (Ashley). One participant vocalized what she assumes others think about HPV, “most people who haven’t done the research themselves, despite what I would have to say, would be very quick to just hear STD, and judgment, and all the stigma that comes along with that” (Amber). One individual worried about potential stigma from a friend, “I had a close friend at work and we were on a departmental team together and one of the girls was in and out a lot and she was having reproductive problems. So, my friend was like ‘she's a slut.... She has HPV'” (Summer). Another felt her status reflected poorly on her in the eyes of others, “if you say that you have HPV that is like saying I have had unprotected sex” (Whitney). She worried about being judged for her status and sexual behavior.

Two of the participants who felt judged by others believed this was related to the form of cancer they had from HPV. One felt judged by the diagnosing doctor, recalling “it comes back [as] HPV and my doctor down here tells me I need to change my lifestyle.... He is supposed to be learned about these things and be accepting. Whether I was partaking in anal intercourse or not was not his call” (Theresa).
Another explained, “I was first diagnosed [with anal cancer] and I had to tell my boss and all of a sudden it was just like they did not want to hear about it. I think people are just very put off by cancer that is caused by something that could be sexually related.... Of course, nobody wants to say anal and when they do it is in a negative context” (Katherine). Both of these participants had HPV which led to anal cancer. They believed they were being judged for their status and cancer because of how they are acquired.

Seven of these fourteen participants internalized the stigma and judged themselves. One individual explained, “she [mom] was kind of pissed at me for getting HPV and having to have this colposcopy\(^{11}\).... I remember not wanting to deal with that and maybe feeling a little ashamed and shitty like she was making me feel shitty” (Phoebe). Another stated, “I was really fascinated with how I was identifying with my body...the physical part of my body that nobody could see but me...and how much I internalized that. I felt dirty and I felt gross. I felt ugly and I did not feel sexually viable, but nobody knew that but me. Thinking about it...it grosses me out. It takes me back to that feeling of shame...really shameful. I did not do anything that shameful; it just kind of happened. But it made me feel shameful. I felt this internalized sense of dirty” (Emily). Another said, “there was a little bit of like...the dirty feeling.... I have a sexual.... No one wants to say that about themselves....[It] left a sour feeling in my stomach” (Summer). Another voiced similar feelings, stating, “it is just embarrassing and you know you feel dirty and feel that there is something wrong with me. After that [diagnosis], I feel ashamed” (Whitney). She continued, “I am kind of upset with myself. I know who exactly I got it from and I should have been more assertive about using.... You know, I judge myself. I should have been more assertive about using condoms.... I just feel like at my age, I should have known better” (Whitney). Another felt shame at her diagnosis, “after the diagnosis, I was like, that sucks. I really had pride about the fact that I

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\(^{11}\) A colposcopy is often recommended after an abnormal pap result. During this procedure, a health care provider examines the cervix through a colposcope and, if need be, performs a biopsy of the cervix for laboratory testing (Johns Hopkins n.d.).
had never been diagnosed with an STD.... After this diagnosis, I thought, you can't say that anymore, you are like everybody else and you now have HPV which is considered an STI” (Colleen). A few of these participants blamed themselves for their diagnosis: “I guess you paid for that piece of ass” (Theresa), and “I think that I got genital warts, not because of the strain, but because I was treating my body very unhealthy” (Emily). All of these participants viewed themselves negatively at some point since their diagnosis because of their status, sexual behavior, or how others judged them.

Three of these participants felt stigmatized when first diagnosed, but felt less so over time. One participant demonstrated that she was upset at diagnosis, but no longer internalizes that stigma, “growing up things I heard like STDs have a stigma ... this connotation that she must sleep around or that he sleeps around or that I don't use protection or that I am not responsible.... I am dirty...damaged goods.... It was a rough moment... in that first day or two that I learned I had it.... That is why I was so upset because STDs have a very.... It is like...oh, I am that statistic now. I am part of that group.... So it was hard, but now it is no big deal to me now. I know more about it. I don't think that way anymore” (Ava). One participant explained, “[I felt stigma] just in the very beginning when my friend told people I had a venereal disease” (Ashley). Another stated, “it did feel like a little bit of a stigma. I had done a bunch of reading and it was like...it is ridiculously common and very easily transmitted and people often don't know if they have it. But it still, it did feel a little bit like...you know I had this disease now.... I don't think it was a very lasting kind of impact but I definitely was aware of it” (Jessie). These participants’ sense of self-blame and internalized stigma dissipated over time when they gained more knowledge about HPV.
3.6.2 Disclosure

Twenty-two participants mentioned disclosing their HPV+ status to at least one person in their life. These participants disclosed to friends, family members, sexual partners (see Article 3), and/or other people with HPV. Two of these individuals revealed their status to only one person in their life.

Disclosure was often related to a feeling of stigma related to HPV, or a lack thereof.

3.6.2.1 Stigma and Disclosure

Twelve participants who felt stigma from their HPV status decided to disclose to individuals close to them for a variety of reasons. Two only told their sexual partner; one disclosed to only one person, a close friend; nine participants mentioned their HPV status to friends and/or family members. Some participants disclosed because it merely came up in conversation with their family or friends. Others tended to offer this information when giving advice to others. One explained, “whenever any of my friends mention their gynecologist doing any overt testing... I felt like they were treating me really aggressively and did a lot of stuff that didn’t need to happen.... So recently I feel like I have been a lot more open about it to my friends” (Summer). Many of the participants disclosed to friends who had previously been diagnosed with HPV or who were more knowledgeable about the STI. One individual stated, “[I told] one of the girls I worked with because she had gone through it. I just asked her about it one day. She is my older friend. I just asked if she had ever had the same issue and she had. She was like yeah it is super uncomfortable but lots of women have had to deal with it [HPV and colposcopy]. She was the only person I really talked to about it because it was just this thing I had to do” (Ashley). One recalled that she mentioned having it after her friend revealed her own status, however, she refrained from disclosing all aspects of her diagnosis, “the only thing I don’t talk about is the genital warts” (Emily). Others told friends who may have been more knowledgeable about HPV. One recalled, “I talked to my roommate who is a nurse because I had told her before I got diagnosed. I was like there is this
thing that I got - what do I do?” (Ava). These participants decided to tell their status to others in order to gain knowledge about their own diagnosis or to inform others about HPV.

The participant who disclosed to only one friend recalled telling her right after diagnosis, “I’m like, ‘guess what just happened? I got a call about my pap smear.’ I called her like, ‘do you believe this?’ I made a special call with that in mind” (Janelle). Although this friend was supportive, she knew very little about HPV; “she did not know anything more than I did so she wanted to know what I found out about HPV” (Janelle). Most participants who disclosed to their friends felt supported. Friends often pointed out that HPV was “really common and they were sure I would be fine,” (Jessie) and, “it’s no big deal, this happens all the time” (Summer).

3.6.2.2 Stigma and Non-Disclosure

One individual made the conscious decision to tell no one. This participant stated that her motivation for non-disclosure was related to the judgment she would receive due to people’s lack of HPV knowledge: “I just feel like it would be awkward you know telling someone that you have an STI. Especially the people that I talk to that are not really educated about it - I don’t want an ignorant response” (Kendra). This individual also felt that friends would pass judgment, therefore she did not disclose her status to them: “they are virgins so our conversations about sex are very limited. It would be awkward to tell them because they just want to dis it” (Kendra). This participants assumed that individuals in her life lacked the necessary sexual experience and HPV knowledge to understand her status.

Fourteen of the participants who felt stigma at some point in their life related to their HPV status refrained from disclosing their status to some individuals close to them. Eight did not tell their status to their most recent sexual partners, and one did not mention it to any of their sexual partners.
(Disclosure to sexual partners is the topic of another article.) Six participants chose to not disclose their status to others close to them.

A few participants withheld their status from specific individuals in their life while telling others. One withheld this information from her mother’s side of the family, also due to fear of stigma, stating, “it’s not like they aren't going to be judgmental or anything. I just wanted to keep it to myself” (Kaylee). However, this participant also did not tell the rest of her family about her status because she felt disclosure was not important due to HPV’s prevalence: “I haven't mentioned it. I don't know.... It seems like it has been normalized. It is not so much of a big deal to me for me to tell anyone else because there are lots of people that are going through it too” (Kaylee). Another individual voiced similar motivations for non-disclosure to most friends and family stating, “I guess if it had been something I was more worried about especially with my medical health, I would have talked to my parents about it” (Jessie). These participants felt they had nothing to gain from disclosure because it was not a cause for concern. Another withheld her status from friends, not due to stigma, but due to there being no benefit in disclosing, “because it is none of their [friends’] business. They can't help me. There is absolutely nothing they can do to help me” (Janelle). She felt that telling others about her status would not help her handle the aftermath of her diagnosis.

3.6.2.3 No Stigma and Disclosure

Nine participants who felt little to no stigma related to their HPV status disclosed their status. Many of these participants discussed HPV with friends who had been previously diagnosed or had undergone HPV-related procedures. One felt relieved after discussing HPV with friends who had it, saying, “that they essentially had the same diagnosis that I did and like a year later they didn't have it anymore and it didn't affect their sex life or their life in general” (Leslie). This participant reached out to friends she
knew who had HPV to ask about their experiences, “I was having to get those procedures done. I was asking if anyone had it before and one of them had and we talked about it” (Leslie). Another recalled, “One of my good friends was diagnosed with the genital warts type. So, I talked to her about it” (Carla). These participants felt supported by their friends and gained valuable knowledge about HPV, both of which may have led to less feelings of stigmatization.

Three participants were very open about having HPV. One noted how she tells most people, but educates them while doing so, “I am very open with my friends... if I am around a conversation where people are talking about STDs... I will disclose ... to educate people” (McKenzie). Another mentioned, “I would tell anybody. If it was a topic of conversation and relevant, I would happily speak about it” (Riley). These participants were very candid about their status and disclosed to most people in their lives.

Others felt open about their status, yet did not tell everyone in their life. One participant revealed her status to her partner and family, yet did not reveal it to most friends. This was not a purposeful non-disclosure, as she states, “we are a fairly open group so I don't think that it was something that I tried to hide. If it had come up in conversation I don't think I would have been worried to disclose.... Just to the best of my recollection I don't think it came up” (Leah). Many participants said that they would disclose if it came up in conversation with friends or family. One individual, who was diagnosed a year prior to the interview, mentioned how the passage of time since diagnosis has made disclosure easier: “I think the farther away it has gotten from the diagnosis, it is not something I feel like I need to hide if it ever came up in a conversation” (Erica). Although this participant felt little to no HPV stigma and openly disclosed to friends, she is now more candid about her status with others in her life if it is relevant to the conversation.
Two participants disclosed their status to a few family members and friends only in the context of HPV-related treatment and lab results (LEEP\textsuperscript{12}, abnormal pap smear, colposcopy) while rarely drawing a connection to HPV. One participant decided to not disclose her HPV to most of the people in her life, but discussed treatments with friends and family members recalling, “when I was going to be out for a few days [for LEEP] and that was it...I think I probably glossed over the fact that you need LEEP if you have HPV - the connection” (Candace). She did, however, draw the connection, and thus disclosed her status, to close friends, “I think the only time I disclosed was when I was about to have the LEEP and people wanted to know why...I think I said it was because of HPV” (Candace). Another participant disclosed her HPV to her sexual partner but only discussed treatments with family while withholding her HPV status from them, “I talked to my parents and sister about the treatments. No one has ever mentioned HPV. I haven't mentioned it to them. I don't want to have that conversation with my mother” (Andrea). She assumed her parents and sister did not understand that the treatments were associated with HPV because they did not draw the connection on their own and discuss it with her.

3.7 LIMITATIONS

Past qualitative research on HPV has relied on non-diverse samples of primarily white, college-educated women (see: Kosenko et al. 2012, Nack 2008). Although I sought to reveal the stories of a diverse sample in terms of ethnicity, race, and educational attainment level, my sample was more homogeneous than initially intended. My sample included cis-gender and gender non-conforming women from different racial and ethnic groups ranging in age. However, I was unable to include participants of varying levels of educational attainment. This may have been a result of my sampling method. However, I also believe it is due to the fact that women with lower socioeconomic status and

\textsuperscript{12} With LEEP, an electric current heated wire loop removes abnormal cells and tissues in the cervix and vagina. The tissue is then sent to a lab for testing. LEEP is often performed in order to detect cancer of the cervix or vagina (Johns Hopkins n.d.).
less education are less likely to have regular gynecological appointments and routine Pap tests, compared to their more educated peers (Behbakht et al. 2004; Katz and Hofer 1994). Without regular visits to the gynecologist and routine Pap tests, women are much less likely to know they are HPV positive. Therefore, individuals who saw my flyers may have thought they did not qualify because they did not know their positive status.

Despite this limitation, my research adds knowledge to the field because of the rich detail my participants provided during their interviews. Many past researchers used surveys to analyze knowledge, awareness, and attitudes regarding HPV, but qualitative researchers have found that semi-structured interviews allow participants to explain personal experiences related to this diagnosis (see: Gerend and Magloire 2008; Lee and Craft 2002). My work differs from existing studies where researchers ask undiagnosed women how they would feel if they were diagnosed with HPV (see, e.g., Waller et al. 2007a). My interviews of HPV+ participants fostered detailed discussion of actual lived experiences related to HPV diagnosis, disclosure, and stigma.

3.8 DISCUSSION

According to past research, some HPV + individuals do not feel stigma associated with their diagnosis and instead view it as an inevitable consequence of being sexually active (McCaffery 2006). While nine of the participants in this study felt little to no stigma associated with their status, fourteen did feel stigma associated with having HPV.

Individuals’ embarrassment and shame surrounding diagnosis often stems from the connotations of promiscuity associated with STIs (McCaffery et al. 2006). My findings support this past research, with many of my participants voicing worry about being judged for having a sexually transmitted infection. They thought others would associate their diagnosis with having unprotected sex and sleeping around. Individuals with STIs may face increased prejudice because they potentially caused
their own stigma (Breitkopf 2004; Nack 2008). Attribution theorists posit that those who are seen as contributors to their own illness are often more harshly judged by others (Lebel and Devins 2008; Weiner, Perry and Magnusson 1988). It is socially acceptable to blame individuals for contracting infectious illnesses (Breitkopf 2004; Nack 2008). Research indicates that blame is more often attributed to women with cervical cancer than to individuals with cancers unrelated to lifestyle choices, such as leukemia, breast, or bowel cancer (Marlow et al. 2010, 1802). While many of my participants worried about judgment from friends or family due to their status being linked to sexual behaviors, only one felt this judgment from their diagnosing doctor. This participant felt that her doctor was blaming her for having HPV because of assumed sexual behavior.

Women with STIs often internalize this stigma (East et al. 2012). In fact, the most commonly reported type of stigma among individuals with HPV is negative self-image stigma (Barnack-Tavlaris et al. 2016). Women with HPV often refer to themselves as “unclean, “dirty”, “cheap”, “gross” (East et al. 2012, 17; McCaffery et al. 2006; Nack 2008, 66). Some of my participants echoed these sentiments and mentioned feeling “ashamed”, “dirty”, “gross”, “ugly”, “damaged”, and “no longer sexually viable”. Women sometimes stated that their diagnosis signified them paying for past behaviors (Daley et al. 2008). A few of my participants recalled feeling disappointed in themselves for not using condoms or having safer sex. Others recalled feeling that their diagnosis was retribution for having sex with a particular person or for treating their body poorly. Researchers have found this type of self-blame is more common among individuals with STIs, such as HIV, compared to unavoidable illnesses, such as some forms of cancer (Fife and Wright 2000).

When an individual’s “differentness is not immediately apparent, and is not known beforehand,” she has a discreditable stigma, according to Goffman (1963, p. 42). My participants’ HPV status was not known to others unless disclosed, making them discreditable. Discreditable individuals engage in strategies of stigma management to control the information that others know about their
discreditable attribute (Goffman 1963). Many individuals with HPV feel personalized stigma, where they worry that others will not understand their diagnosis and reject them (Barnack-Tavlaris et al. 2016). According to previous research, women with HPV feel anxiety about disclosing their status to family and friends (East et al. 2012; Kosenko et al. 2012). Women with HPV often chose not to disclose their stigma to others because they fear rejection from their friends, family, and sexual partners (Barnack-Tavlaris et al. 2016; Nack 2008:91). Therefore, some individuals do not disclose their positive status in order to avoid making a stressful situation more anxiety provoking (McCaffery et al. 2006). Over half of my participants withheld this information from many individuals close to them due to fear of rejection and judgment. One individual had not disclosed to anyone for the same reasons.

Individuals with a discreditable stigma may choose, however, to disclose their discreditable attribute to others as a form of “stigma management” (Breitkopf 2004; Goffman 1963:100). Many women with HPV eventually disclose their stigma because they feel increasing guilt about concealing it from friends and family (Nack 2008:91). Selective disclosure, another strategy for managing stigma, is when an individual conceals their stigma to most and discloses it to a few people, usually their intimates, family members, and doctors (Goffman, 1963). The majority of my participants decided to disclose their status to at least one person in their life, their sexual partner(s), close friend(s), or family member(s), but very few disclosed to everyone.

As a form of stigma management, individuals may pose as having a similar, yet less stigmatizing condition in order to avoid judgement (Goffman 1963). Past research demonstrates that some individuals chose to disclose their abnormal pap smear results rather than their HPV status (McCaffery et al. 2006). A few of my participants mentioned their abnormal results or their HPV-related procedures rather than disclosing their status as a way of avoiding full disclosure. By mentioning their lab results, LEEP, or colposcopy these individuals made their friends and family aware that they were undergoing
some type of cervical condition, but they did not disclose that this was related to a sexually transmitted infection.

According to Goffman, close relationships cause a discreditable person to disclose their secret or feel guilty for not doing so (1963). Many women disclose in order to gain the support of loved ones (Lee and Craft 2002). All but one of my participants disclosed to close friends, family, or partners who were supportive. One individual faced a single judgmental friend, but later found support in others. Seven participants disclosed to friends who had previously been diagnosed or who had undergone an HPV-related procedure. These participants found support and reassurance by disclosing their status. In-depth HPV research reveals that after diagnosis, women face the harsh reality that many of their close friends and family now see them as diseased (Nack 2008). Fortunately, this was not the case for my 22 participants who felt loved and supported once disclosing their status to select friends and/or family.

Another stigma management strategy for those with discreditable stigmas is self-disclosure (Goffman, 1963, p. 100). An individual can self-disclose by openly admitting to having the stigma (Goffman, 1963, p. 101). Many of my participants disclosed their status although they felt no stigma associated with it. Many recalled that they disclosed because it merely came up in conversation. Others told their HPV experience to individuals who had since been diagnosed as a way of offering advice and support. Seven participants stated that their disclosure to others was a means for them to help educated people about HPV. Goffman asserted that if an individual “accepts himself and respects himself he will feel no need to conceal his failing” (Goffman, 1963, p. 101), three of my participants had reached this point of self-acceptance and shared their HPV experience with most everyone in their lives.

Individuals with HPV often feel embarrassed about their diagnosis (Daley et al. 2008; Nack 2008). This embarrassment can lead to self-blame and non-disclosure of status. Although thirteen of my participants felt HPV stigma at some point since diagnosis, almost all of them (12 of 13) told someone in their life about their status. This disclosure is often beneficial to those with HPV. It can be cathartic and
allow them to seek sympathy and acceptance from close friends and family members (Nack 2008: 98).

My participants gained support and knowledge from their disclosure. Both of which were valuable resources while trying to navigate what being HPV positive meant to them.
4 “They Probably Already Had It Anyway”: Status Disclosure and Sexual Behavior

4.1 ABSTRACT

Human Papillomavirus (HPV) is the most prevalent sexually transmitted infection in the United States, however, many Americans do not use preventive methods to protect themselves and others from transmission. This study uses in-person, semi-structured interviews to examine status disclosure and sexual behavior among those with HPV. It also analyzes how HPV transmission knowledge impacts motivations and intentions to participate in prevention behaviors. The study found that post-diagnosis many individuals were ill-informed about HPV transmission and how HPV impacts men. This study also found that few individuals with HPV disclosed their status to all at-risk sex partners or used barrier methods consistently during sex. These findings suggest that more work is needed to facilitate effective HPV education which includes status disclosure and use of all barrier methods.

4.2 INTRODUCTION

Human Papillomavirus (HPV) is the most prevalent sexually transmitted infection in the U.S. (CDC 2017a). Nearly 79 million Americans are infected with HPV, with 14 million becoming newly infected annually (CDC 2017a). Over 40 types of HPV are transmitted through vaginal, anal, and oral sex, or intimate skin-to-skin contact (CDC 2013; Moscicki 2005). Men are not currently tested for HPV and screening tests are not available for HPV-related cancers or genital warts in men (CDC 2017b). The vast majority of women diagnosed with HPV have strains that present low-risk for cancer (CDC 2013). At least two of these low-risk strains are associated with genital warts, which are also transmitted through sexual contact, highly infectious, and very common (WHO 2016).

HPV is the primary cause of cervical cancer in the U.S., with over 90% of cases caused by HPV (CDC 2017c; Nan 2012). There are over 100 subtypes of HPV; however, only a few are associated with cervical cancer (CDC 2013; Polzer and Knabe 2012). These high-risk types of HPV are also associated with
other cancers. Anal cancer is strongly associated with high-risk HPV, although its occurrence is rare (ASHA 2018). Over 80% of anal cancers in the United States are caused by high-risk HPV (CDC 2017c). Men and women, especially those with a history of severe cervical dysplasia, can be affected by HPV-related anal cancer (ASHA 2018). Head and neck cancers are also rare, but 70% of cases are associated with high-risk HPV transmitted through oral sex (CDC 2017c; ASHA 2018). Penile cancer is extremely rare, but has been linked to high-risk HPV in over 60% of cases (CDC 2017c; ASHA 2018). HPV is also associated the rare vaginal and vulvar cancers, making up over 70% of those cases (CDC 2017c; ASHA 2018).

4.2.1 HPV Knowledge

Many Americans are unaware of HPV’s prevalence and risk of transmission (Blake et al. 2015; Gerend and Magloire 2008; Sandfort and Pleasant 2009; Ratanasiripog et al. 2013). This knowledge varies based on level of health literacy, education, age, and race (Blake et al. 2015; Kutner 2006). However, even college educated individuals who are aware of HPV’s link to cervical cancer, tend to be less knowledgeable about its prevalence and often do not perceive themselves at risk (Gerend and Magloire 2008; Sandfort and Pleasant 2009; Ratanasiripong et al. 2013; Blake et al. 2015). These individuals are also often unaware of HPV-related health threats to men and the risk of developing genital or cervical warts (Sandfort and Pleasant 2009).

Prior to HPV+ diagnosis, many women report little concern about their health at the time of their first abnormal Pap (Sharpe et al. 2006). Even women recently diagnosed with HPV lack information about the infection (Perrin et al. 2006; Sharpe et al. 2006). They are confused about the symptoms, treatment options, and recommended lifestyle changes (Perrin et al. 2006). Research indicates that
women with HPV often lack knowledge about the sexual transmission and high prevalence of HPV (Sharpe et al. 2006).

The HPV vaccine protects against persistent infection of HPV subtypes associated with most cancers and genital and cervical warts (Rothman 2009; Brelsford 2011). In June of 2006 the HPV vaccine was approved and recommended for girls aged 11-26 (allowing 9 and 10-year-old girls to be eligible for the vaccine) (Braun and Phoun 2010; CDC 2011; Connell and Hunt 2010; Shefer et al. 2008; Wailoo et al. 2010). Although young girls (11 and 12-year-olds) are the targeted demographic for vaccination, routinely the vaccination requires surrogate decision making, whereby parents decide if their child gets vaccinated (Chapman 2010; Connell and Hunt 2010). Research demonstrates that parents of girls often intend to vaccinate them against HPV before the age of 13 (Constantine and Jerman 2007). Vaccine uptake among male adolescents is lower than females because most parents report a lack of awareness of the health consequences for men and the possibility of administering the vaccine to boys (Reiter et al. 2011; Voss and Wofford 2016). In general, parents of girls and boys view the vaccine as safe and effective in preventing cancer (Alexander et al. 2012; Brewer and Fazekas 2007; Rosenthal et al. 2008).

HPV vaccination intention is lower among older adolescents and college age women, compared to younger girls. The most commonly cited barriers to vaccine intent among college age women were: vaccine safety concerns, side effects, insurance issues, cost, and low perceived risk (Patel et al. 2012). Past research demonstrates that younger (18 to 21-year-olds), white, insured women were more likely to receive a doctor’s recommendation for the vaccine compared to older (22 to 26-year-olds), uninsured, minority women (Gerend et al. 2015). Not surprisingly, the same demographic group is more likely to receive the HPV vaccine: white, insured, 18 to 20-year-old women (Laz et al. 2013). The most commonly cited barriers to vaccine intent and uptake among 18 to 26-year-old women were: vaccine safety concerns, side effects, insurance issues, cost, low perceived risk, and the belief they were too old to receive the vaccine (Laz et al. 2013; Patel et al. 2012). According to the CDC, the vaccine is not
recommended for women over the age of 26 because it offered limited protection against HPV-related diseases in clinical trials due to the fact that most women had already been exposed to one or more HPV strains in their late teens or early twenties (CDC 2017d). However, research suggests that the vaccine may be beneficial to older women, even those who are HPV positive. In fact, previously infected individuals may benefit from vaccination by increasing antibodies and thus helping individuals clear HPV more quickly and prevent re-infection (Muderspach et al. 2000; Scherer et al. 2016).

### 4.2.2 Non-Disclosure

A key element of safer sex is understanding one’s risk of acquiring an STI from your one’s partner/s. To understand this, partners must be honest about their own sexual health and disclose any positive STI statuses (Emmers-Sommer et al. 2010; Luchetti 2009). Past research indicates a large portion of college students are unaware that disclosure is a component of safer sex practices (Luchetti 2009). However, most college students believe it is appropriate to disclose a positive STI status to one’s casual or serious partner prior to having sex for the first time with this partner (Emmers-Sommer et al. 2010). However, these individuals cited many barriers to disclosure, including embarrassment and fear of rejection by partners (Emmers-Sommer et al. 2010). Research also demonstrates that some individuals knowingly misrepresent their STI status to their partners (Luchetti 2009).

Many women with HPV believe that their diagnosis will affect their sexual relationships, and thus feel anxiety about disclosing their status to sexual partners (East et al. 2012; McCaffery et al. 2006). Some women with HPV do not disclose their status to sexual partners because of shame and lack of knowledge (McCaffery et al. 2006). Many women delay disclosure until just before having sex with their
partner (Nack 2008). Individuals may decide to continue to have sexual relationships without disclosing their STI status with their partner. Some women do not disclose their status until after having sex with their partner, for fear of rejection (Nack 2008).

4.2.3 Inconsistent Condom Use

Researchers have long posited that consistent condom use is related to condom use self-efficacy, or an individual’s belief that they have the capabilities to control sexual situations (Artistico et al. 2014; Bandura 1990; Bryan et al. 1997). Gendered condom use self-efficacy findings are mixed. According to some research, women report lower condom use self-efficacy scores compared to men (Farmer and Meston 2006; Roberts and Kennedy 2006; Wildsmith et al. 2010). This is because, for women, condom use self-efficacy involves agency over sexual communication and negotiation with partners (Artistico et al. 2014; French and Holland 2011). Other researchers posit that women have greater condom use self-efficacy than men, are more likely to engage in safer sex communication, and have a more active role in condom negotiation while men have a more reactive role (Allen et al. 2002; Carter et al. 1999). Women claim that they feel capable of convincing their partner to use a condom even if the partner does not want to and men are more likely to report being convinced to use a condom if their partner wants to (Carter et al. 1999). However, women who perceive themselves to have less decision-making power in their relationship are less likely to report consistent condom use (Pulerwitz et al. 2002). Women’s intent to use condoms is also often derailed by their partner’s negative attitude towards condoms (Farmer and Meston 2006; Roberts and Kennedy 2006). Men claim that they can convince their female partners to have condomless sex even if she wanted to use a condom (Carter et al. 1999). Women often report condom non-use because they believe condoms will decrease their
partners pleasure during sex and they do not perceive themselves at risk for STIs (Roberts and Kennedy 2006).

Consistent condom use is also associated with perceived risk of STIs and intent to use condoms (Bryan et al. 1997). However, most individuals’ perceived risk is lower than their actual risk for acquiring an STI (Farmer and Meston 2006; Roberts and Kennedy 2006; Wildsmith et al. 2010). Individuals with past STI diagnosis also do not perceive themselves at risk (DiClemente et al. 2002). They are not any more likely to report condom use and are thus at risk for subsequent infection of STIs (DiClemente et al. 2002).

According to nationally representative research, only 23% of young adults aged 18 to 26 in dating relationships used dual methods (condoms and hormonal birth control) and 26% used only condoms (Manlove et al. 2011). Condom use decreased and hormonal contraception use increased in these relationships as the duration and level of intimacy increased (Manlove et al. 2011). Individuals in serious relationships are less likely to use condoms compared to single individuals (Emmers-Sommer et al. 2010; Roberts and Kennedy 2006). Individuals in long-term relationships no longer view their partner as an STI risk and as trust and a sense of security increases in a relationship, condoms are no longer viewed as a necessary precaution (Emmers-Sommer et al. 2010; Manlove et al. 2011; Roberts and Kennedy 2006).

Findings on the effectiveness of condoms in HPV transmission prevention are mixed. Some studies show that condom use is related to a decreased risk for positive HPV status and development of dysplasia (Manhart and Koutsky 2002; Winer et al. 2006). Research demonstrates that male-to-female genital HPV transmission, specifically, is reduced by condom use (Winer et al. 2006). Other research indicates an elevated risk for positive HPV status and development of dysplasia among women who use condoms (Kjaer et al. 1997; Manhart and Koutsky 2002). This increased risk may be related to timing of condom use (used after HPV was acquired) or to ineffectiveness of condoms on initial HPV infection
(Manhart and Koutsky 2002). More recent research, however, posits that women whose partners use condoms over 50 percent of the time are at reduced risk for acquiring a new HPV infection, both low-risk and high-risk types (Winer et al. 2006). Studies also show that condoms and dental dams provide protection against cervical cancer in women, HPV-related genital warts in both men and women, and oral HPV infection in men (Edelstein et al. 2012; Manhart and Koutsky 2002).

4.3 THEORY

4.3.1 Information, Motivation, Behavior Model

The information, motivation, behavior (IMB) model is an appropriate theoretical framework through which to investigate disclosure and sexual practice among the HPV positive. This model was established to predict HIV prevention based on the concept that information, motivation, and behavioral skills determine preventive behavior (Bahrami and Zarani 2015). The key elements of this model applied to primary and secondary STI prevention include: STI knowledge related to transmission and prevention techniques; motivation to change risky behavior and practice preventive behavior related to one’s beliefs and attitudes; perception of personal risk of contracting and transmitting the STI; perceived self-efficacy to perform STI prevention behaviors, such as condom and dental dam use, condom negotiation, and disclosure of status (Bahrami and Zarani 2015; St. Lawrence and Fortenberry 2007).
4.4 CURRENT STUDY

Disclosure and sexual behavior related to HPV diagnosis is a relatively new direction in research. Most researchers have focused on the impact of condom use on HPV transmission (see: Manhart and Koutsky 2002; Winer et al. 2006) or disclosure among individuals with a multitude of STIs including HPV, genital herpes, and chlamydia (see East et al. 2012, Nack 2000). Through my research, I sought to discover how an HPV + status influenced my participants’ sex lives, feelings about disclosure, and reasons for not disclosing to sexual partners.

4.5 METHODS

Due to the fact that individuals with STIs qualify as a hard-to-reach population and recruitment can be difficult (Dixon-Woods et al. 2001; Nack 2008), I employed purposive, facility-based sampling and snowball sampling. I utilized key locations to find study participants (Magnani et al. 2005), such the health clinic at a large public university in the Southeastern United States and multiple privately-operated gynecological clinics around a large metropolitan area in the Southeastern United States. Commonly cited barriers to STI screenings include cost, privacy, language barriers, and perceived discrimination at the clinical site (Tilson et al. 2004). Therefore, I chose to include clinics that offer free or low-cost STI screening services to English and non-English speakers and that abide by anti-discrimination laws specific to patient admission and treatment. I also posted flyers around two major universities, high-traffic pedestrian areas, and throughout diverse neighborhoods. Additionally, I gained entry into online support groups for individuals with HPV13 to recruit group members for my study. In order to allow for fully informed consent on the part of my subjects, I included accurate and straightforward information about my research and its purposes.

I recruited my participants via advertisements (flyers) displayed and distributed at the recruitment facilities. This discreet recruitment method is commonly used among STI researchers (see: Kosenko et al. 2012; East et al. 2012) so that interested parties can contact the researcher anonymously with any questions. Multiple versions of the flyer were distributed with various photos of young girls and women from different racial and ethnic groups on them in order to appeal to a diverse group of potential participants. Each flyer contained tear-off tabs so that interested parties could easily obtain my contact information. Additionally, each flyer included a Quick Response code. Quick Response codes are an increasingly popular advertisement tool that can be scanned and read by smartphones (Shin, Jung, and Chang 2012). The flyers contained a unique Quick Response code that linked smartphone users to my online eligibility form. This eligibility form required users to enter their age and HPV status and then, if eligible and interested in participating, their contact information was automatically sent to me.

4.5.1 Sample Demographics

I gave all of my participants pseudonyms to protect their identity. My participants included 23 women of various ages\textsuperscript{14}. Six were in their 20s, eleven in their 30s, three in their 40s, two in their 50s, and one over 60 years old. Sixteen of the 23 participants grew up in a two-parent family; three had a single parent; three had divorced parents and stepparents in the home; and one had divorced parents that never remarried. Twelve of my participants grew up in the Southeastern United States; six grew up in the Northeast; three grew up in the Midwest; and two grew up outside of the United States. Fifteen of the participants resided in the Southeastern U.S. at the time of their interviews with three living in the Northeast; one in the Southwest; two in the West; and two outside of the United States. My sample was a highly educated group, with 10 of my participants having obtained a graduate degree, four in

\textsuperscript{14} My sample originally included 25 individuals, but after the interview, I determined that two no longer qualified to be included, due to their type of HPV. Both of those original participants had HPV that manifested as skin warts on the hands and feet – a condition that is not considered a sexually transmitted infection and is not related to reproductive issues or cancers.
graduate school at the time of interview, six obtaining a terminal Bachelor’s degree, one currently in undergraduate school at the time of interview, one having had some college education, and one having a GED as highest level of education. Regarding occupation, eight worked in health and medicine, four in education, three in law, three in the arts, one in business administration, one in marketing, one in plumbing/engineering, and two as current students. The majority of my participants were white (n=17, 73.9%), five (21.7%) were black, and one (4.35%) was multiracial. Ten of my participants were single at the time of interview, 8 were in a committed relationship, and 5 were legally married. In terms of gender identity, 22 of my participants identified as women and one identified as gender queer. In terms of sexual orientation, 18 classified themselves as heterosexual, one as lesbian, and four as bisexual.

4.5.2 Interview Method

Although many past researchers have used surveys to analyze knowledge, awareness, and attitudes regarding HPV and the vaccine, other researchers find that semi-structured interviews allow participants to explain their personal experiences of dealing with STI diagnosis and what this diagnosis meant to them (see: Gerend and Magloire 2008; Lee and Craft 2002). Interviews of HPV+ participants, compared to survey research, are more likely to foster discussion of actual lived experiences related to living with HPV and disclosure to others, and stigma.

As a feminist interviewer, I was cognizant of my role as a researcher and my potential source of authority during the interview process (Hesse-Biber 2007). In order to diminish the hierarchical relationship between researcher and participants, after each interview, I shared relevant aspects of my own biography (Hesse-Biber 2007) and experience with HPV. I strove to be reflexive and
to consider how my biography, values, and attitudes influenced the research process (DeVault and Gross 2012; Hesse-Biber 2007). As a woman with HPV, throughout the interview and analysis stages, I reflected on how my attitudes regarding the disease impacted my choice of interview questions and my interpretation of participants’ responses (DeVault and Gross 2012). For example, I was motivated to ask about disclosure to sexual partners because of my own decision-making about disclosure. My personal experience also helped me understand the participants’ motivations to disclose or withhold this information from sexual partners.

Interview topics included: what participants knew about HPV post-diagnosis, to whom they disclosed their status, reasons for their disclosure and non-disclosure of status, and how their diagnosis impacted their sex life, if at all.

4.5.3 Analysis

I conducted, recorded, and transcribed all of the interviews. I imported all transcribed materials into NVivo and analyzed them using a grounded theory approach. I chose this analytic method because it is well suited for understanding social processes not yet commonly researched (Hutchison et al. 2010). And, as noted above, there have been very few qualitative studies on the lived experiences of individuals with HPV. From my transcription and pre-analysis coding, I identified a few themes that I wanted to further investigate related to consequences of HPV: “feelings about HPV,” “impact on sex life” and “disclosure to sexual partners.” I analyzed the transcripts using the triadic coding scheme of open, axial, and selective coding (LaRossa 2005). During open coding, I identified major themes related to consequences of HPV, impact on sex life and disclosure to sexual partners, and deciphered what each concept represented (Lofland et al. 2005; LaRossa 2005). In the context of their diagnosis, each participant mentioned how their diagnosis impacted their sexual relationships. I then reviewed the concepts for similarities and variations, assigned them to categories, and identified the most salient
categories (Corbin and Strauss 1990). I analyzed participant feelings and knowledge post diagnosis, whether or not participants disclosed their status to past and present partners, why they did or did not disclose, and how their diagnosis impacted their sex life.

In the axial coding stage, I analyzed the categories to determine how and why they differed among the participants, by focusing on the context, strategies, and consequences associated with each category (Corbin and Strauss 1990; LaRossa 2005). I analyzed relationships between participants’ experience with the diagnosis, disclosure and sexual behavior. Finally, I moved on to the selective coding stage of my analysis, where I decided which categories were most representative of the central argument of my analysis (Corbin and Strauss 1990; LaRossa 2005). I found the relationships of (1) feelings and knowledge about HPV impacting sexual behavior and (2) feelings and knowledge about HPV impacting disclosure of status to sexual partners to be most informative in this study.

4.6 FINDINGS

4.6.1 HPV & Prevention Knowledge

My participants had a variety of HPV types and stages of cervical dysplasia. Cervical dysplasia indicates abnormal cells on the cervix surface that may clear or develop into cancer depending on the severity of the dysplasia (Mayo 2017). Six did not know whether their type was high-risk or low-risk or what level of cervical dysplasia they had at the time of interview. Without this knowledge, these individuals were unaware of the potential risk they may have been causing their partners or their partners’ future partners. Three individuals had an HPV strain that led to the development of anogenital warts at their vaginal opening, inside their vagina, or inside their cervix. Anogenital warts are easily transmitted through sexual contact and thus, potentially consequential for sexual partners. Five participants stated that they had low-risk HPV, which is asymptomatic, does not lead to cancer, and usually clears from the body within a few years. This type of HPV poses little risk to one’s sexual
partners. One participant knew she had a high-risk strain of HPV that was more commonly linked to cervical cancer. Two individuals had mild dysplasia (level 2) and four participants knew they had moderate to severe dysplasia (level 3 or 4). The higher the level of dysplasia, the more likely it will lead to cancer if left untreated. Two of my participants had developed anal cancer by the time of our interview. This type of cancer is rare in women, but can develop from severe cervical dysplasia. Although most high-risk strains of HPV that lead to higher levels of dysplasia do not lead to cancer in males, male partners can acquire a high-risk strain and then transmit it to future female sex partners or re-infect their current partner once it has cleared from her body.

In another article, I analyzed my participants’ HPV knowledge pre and post-diagnosis. Eight participants remained unaware of the high prevalence of HPV after their diagnosis. Nineteen of the participants did not know that HPV could be contracted through skin-to-skin contact and did not require penile-vaginal or penile-anal penetration. Only two individuals explicitly stated that condoms would not completely protect a person from contracting HPV. They stated: “there is no 100% and I think it is a false sense of security people do get from using condoms” (Riley), and “people probably don't know that HPV is transmitted by skin-to-skin contact, and you can use condoms but it is not just about covering an orifice. You would have to have sex with a rubber suit on” (Colleen). Only two more participants knew that HPV could be transmitted from skin-to-skin contact and did not require penetrative sex. Many of my participants lacked this knowledge of HPV transmission and thus, did not use recommended protection, such as condoms and dental dams.

Despite most participants not having a complete understanding of how HPV is transmitted, nine of my 23 participants voiced concern about transmitting HPV. Seven participants worried about infecting their current partner at time of diagnosis. One participant was afraid of transmitting HPV through oral sex when her boyfriend had a toothache, “he got a horrible toothache...he was really worried. He was like I don't know what it is, what if it is oral cancer? I was like, ‘you don't have oral cancer’... and he was
like, ‘HPV brings oral cancer.’ So I was concerned about oral sex because we did not use any protection with that” (Summer). Another worried about transmitting to a serious partner, “I felt a little guilt around that ... exposing him. I really loved him” (Phoebe). One participant expressed guilt about possibly having transmitted HPV to past sexual partners. She said that she may have unknowingly infected past partners due to the dormant nature of HPV, “who knows how long I have been carrying it and not showing anything -- and, second of all, who I may have affected along the way. I just kind of feel like a jerk. But I don't know there is really anything I can do about it now, just be more careful and not let it happen again” (Amber). Due to a lack of HPV transmission knowledge, the dormant nature of HPV, and the inability to have male sex partners tested for HPV, many of my participants were concerned about transmitting HPV to their partners, but felt unable to control the situation.

Although the HPV vaccine reduces one’s risk for infection and thus prevents the spread of disease, sixteen of my participants were not vaccinated. Among those not vaccinated, the most cited reason was that the vaccine was not available to them pre-diagnosis. Seven participants stated that they would have gotten the vaccine if that had been an option for them. These participants were either diagnosed before the HPV vaccine was manufactured or they were diagnosed when they were past the recommended vaccination age cut off of 26. One complained about the vaccine age cut off stating: “this really sucks because I would have taken the HPV vaccine. I get that they want to target people before they become sexually active and by 40, most people have had it, but clearly I am the outlier” (Colleen). Another reflected on the availability of the vaccine for younger aged women stating, “when they [HPV vaccines] came out I was already past 26, I was like, damn it, they [younger women] get it so much easier now” (Riley). Although the vaccine is recommended for younger men and women and not covered by insurance past the age of 26, many of my participants could have opted to pay out-of-pocket for it. This was information that most of my participants were unaware of at the time of interview. Without this information, they were unable to utilize this method to prevent their own infection and
transmission to their sex partners. Three of my participants opted to receive the vaccine after testing positive for HPV. They used it as a method to prevent against “flare-ups”, developing cancer, or acquiring another strain of HPV that caused warts. Two received the vaccine at the recommendation of her doctor, while another had to insist on getting the vaccine. She recalled that many people in her life said, “you already have HPV; this [the vaccine] is not going to help you” (Theresa). She, however, decided to get vaccinated anyway.

4.6.2 **Impact on Sexual Behavior**

4.6.2.1 **Risky Sex**

Twelve participants, were in a monogamous relationship at the time of interview. All of these individuals disclosed their HPV status to their monogamous partners. Nine of these individuals did not use barrier methods (condoms, dental dams) with their monogamous partner. Two of these participants did not use barrier methods because they did not have sexual intercourse with their partner. One of these abstained due to pain associated with intercourse from chemotherapy and scar tissue. The other participant who did not have intercourse, chose to abstain as a protective measure until she and her partner were treated for HPV. One participant did not use barrier methods because HPV had cleared from her body before beginning her current monogamous relationship.

Six participants did not use a barrier method with their monogamous partner, were still HPV+, and continued to have sexual intercourse. Although some of the participants used a condom during their first sexual encounter with this partner, none continued to use condoms due to testing negative for other STIs, being on birth control, or trusting that their partner did not have any other STI. One stated that her reason for not using condoms was because she “assumed he probably already had it” (Carla). This individual was not concerned about passing HPV on to her partner because she knew how common it was and did not understand the potential health consequences for men. Another cited her trust in her
partner as a reason to not use condoms: “you can never know 100% but we have been together 12 years and I trust him so ... as far as I know, we have only ever been sexually active with one another since we were like 17. Because of that we knew fairly early on in our relationship that this was a long-term thing and, um, so we weren't super concerned about safer sex practices. I was always on some form of birth control but we did not worry a lot about STIs because I think we felt comfortable in each other’s commitment” (Leah). This individual worried about transmitting to her partner and asked him to see a doctor. Once the doctor told them that her male partner had no external physical abnormalities, so they assumed he was HPV free. Another participant stated that she only used condoms with her current partner during their first sexual encounter and did not consider using condoms post diagnosis, “because I knew I already had it and even if I got it from someone else, I had been sexually active for about 6 months with my current partner so either I had it and for sure now he has it or I just got it from him anyway” (Ava). Another stated, “I was sure we both already had it from years and years of unprotected sex…. Theoretically if [my husband] had gotten it too, we could just keep giving it to one another” (Andrea). These participants’ experience highlight that an inability to test men and assumed positive status based on high prevalence can lead to transmission and even reinfection between partners.

Eleven participants were single or in non-monogamous relationships at the time of interview. Three of these participants did not use condoms, but did disclose their HPV status to some of their partners. One of these participants told a few of her recent sexual partners about having HPV, but did not practice safer sex with them because they did not ask to use condoms once they knew about her status. When telling one partner her status she told him “how common it was. That men are the carriers. That he probably already had it anyways” (Leslie). One participant told her primary partner right after diagnosis, but they did not start practicing safer sex: “I went home and told my partner. We did not start using
condoms” (McKenzie). She did, however, mention practicing safer sex with her other sexual partner, although she did not disclose her status to them.

Three of the participants who did not use condoms also did not disclose their HPV status to their at-risk partners. One participant disclosed her status to her husband, but has not disclosed to any new partners since their divorce. She did not use condoms with her husband or the more recent partners. She demonstrated that this was related to a lack of knowledge, “there was not a lot of information about that [HPV in men] and by the time there was information we were divorced” (Katherine). Another individual did not disclose her status or start using condoms with a casual sex partner because, “we had already been having sex and already not using a condom at that point so I was like... he's screwed already.... It was only after both of us tested for STDs that we started not using condoms, but again, I didn't tell him about the HPV” (Whitney). One participant, who did not tell some of her recent sexual partners, cited disliking condoms as her reason for not using protection against transmitting HPV: “condoms suck. Nobody wears condoms and if you do you are not having very good sex because condoms are lame. Having HPV has not changed anything. Like I really don't use condoms and I don't think HPV merits that” (Emily). She asserted that she was having casual sex with people whom she trusted, “like if I was having random stranger sex I would of course wear a condom and probably not even have sex with them. But condoms just suck. That is it. I don't like them. And just because I have HPV, I won't use them” (Emily). The lack of barrier method use among these participants at least in part resulted from misinformation about how HPV is transmitted, how men are impacted by HPV, and the inability to test men for HPV.

**4.6.2.2 Safer sex**

Fourteen participants used barrier methods with some of their sex partners who were at risk for contracting HPV. One participant recalled using dental dams and gloves with her current female partner:
“I did start a relationship many months later. I have only had sex with women and I have a female body so I had never had to use a dental dam or gloves, and I was like ‘are you freaking kidding me’... it was not as much fun. And my girlfriend was great at the time, she was like ‘we will figure it out, it will be fine’. I was like ‘seriously? Gloves?’...but she was understanding. And until we were sure of it - that the HPV had been cleared up and I was ok... yeah it changed things drastically” (Jessie). Thirteen participants specifically mentioned using male condoms. Eleven of these participants continued using condoms after diagnosis, a practice they started before knowing they were HPV positive. Two participants who used condoms stated that their diagnosis motivated them to practice safer sex than they had previously. One said, “I was having it [safer sex] more often after the diagnosis” (Tiffany).

Four of the participants who continued or began to use condoms post diagnosis, disclosed their status to all of their at-risk partners, one disclosed to some of her casual partners, and another disclosed only to her primary partner. One stated, “up until we got married we always used condoms. I went on birth control and it did not suit me so we always used condoms not to have children. So using them protected us I guess from passing it [HPV] back and forth” (Summer). One participant vaguely alluded to having safer sex, “[I am] more careful, but that was something that kind of happened naturally with growing up and having more respect for myself. It’s [HPV diagnosis] just kind of reinforced that... in terms of being promiscuous or sleeping around, those days are over. Not just because of that [diagnosis], emotionally I have grown beyond it” (Amber). This individual did not explicitly state that her safer sex practices included using condoms or other barrier methods.

Four of the participants who did not disclose their status to sexual partners stated that they practiced safer sex post diagnosis. Two of these participants used condoms with every sexual partner while HPV positive. One stated that since her first boyfriend, every other encounter has been “100% condoms every single time, non-negotiable” (Collen). Another stated that she, “used condoms with those sex partners.... It was a standard for me at the time. I wasn’t on birth control so I would not have
not used condoms. It wasn’t about HPV... just general safe sex” (Phoebe). One participant noted that she
did not use condoms every time she had sex after diagnosis, just more often. This participant felt that
her more frequent condom use warranted not disclosing her status, “I was being more cautious though,
and using more condoms too. I was like, ‘ok, if we are using condoms I don't need to tell you’” (Tiffany).

Although fourteen of my participants used barrier methods with some or all of their sex
partners at risk for contracting HPV, thirteen of these only used condoms. Condoms alone do not
prevent transmission of HIV because it can be contracted through skin-to-skin contact and does not
require penile-vaginal or penile-anal penetration. A more effective way of preventing HPV transmission
would have been to use multiple barrier methods, such as condoms during vaginal, anal and oral sex and
dental dams during oral sex. Only one participant used dental dams, however, and she stated a common
barrier to using this method: “I mean this is so clinical. It was really not fun” (Jessie).

4.6.2.3 Less Sexual Activity

Ten participants, in total, recalled having less frequent sexual encounters after their diagnosis. Five
of these had disclosed their status to their current sexual partner. Those who had disclosed cited both
the diagnosis and the related treatments as sources for their decreased sexual activity with their
partners. One participant mentioned thinking negatively about sex because of the diagnosis: “I
remember right around the time feeling a little less horny, like I had less desire to have sex because I
was like, this is what happens when you have sex, this kind of fucked up shit” (Summer). Another cited
fear of transmitting HPV to her female partner and acquiring it again as a reason to avoid sexual
intercourse. To protect each other, they “primarily just [do] not having sex...We make out sometimes
and feel each other but we don't get anywhere close that things could be exchanged” (Amber). One
participant that linked her related treatments to decreased sexual activity stated that her partner was
supportive of her during this difficult time, “because of the scar tissue from the surgeries [multiple cold
knife conizations\textsuperscript{15}, my cervix is closed the same way a woman in menopause cervix is closed... It has affected me because most of the time sex is painful. My fiancé, he loves me to death so he works with me and doesn’t pressure me about it or get upset about it. He understands. But it is definitely something that impacts me sexually in being confident as well during sex” (Kaylee). Another said that being no longer sexually active was a consequence of HPV-related cancer radiation, “because of all of this and the after effects of radiation, we are no longer intimate with intercourse. So I am not able to partake that way” (Theresa). However, she mentioned that she would also have stopped being intimate with her partner because of her positive status alone: “It [sex life] would probably change because I would not have been comfortable having unprotected sex. I couldn't sit there and be in a relationship being a detriment to somebody's health, basically” (Theresa). Another individual whose sexual activity lessened at time of diagnosis and during treatment stated “Our sex life did start to change - I think... we started having sex less frequently... We would start to have sex and I would just not want to keep going and I would stop feeling it... for whatever reason would be turned off...I remember especially after getting the colposcopy I was not feeling well and was not interested in having sex” (Erica). All of these participants disclosed their status to their sex partners and felt supported in their decision to have less frequent sex or abstain due to their status and/or consequences of treatment.

Five participants who did not disclose their status to their current partner, recalled participating in less sexual activity since their diagnosis. Two of these participants mentioned that their sexual activity decreased or stopped completely after diagnosis because of their status. One explained how her diagnosis impacted her sex life, stating: “the desire [to have sex] was there but the will definitely decreased.... We don’t do it very often at all and I avoid it a lot.... I am just going to hold out as much as I can until next year when I get my next pap smear. Yeah try to space it out [sex] as much as possible”

\textsuperscript{15} Cold knife conization surgery removes a portion of abnormal cervical tissue with a scalpel for examination. This method causes significantly more bleeding than LEEP and often requires general, epidural, or spinal anesthesia. The use of this method of conization has decreased since LEEP became widely accepted (Nyirjesy 2015).
(Kendra). One participant who was single at the time of the interview also felt her sex life was impacted by diagnosis, “Yes, right afterwards yes. I was tested in November and I don't think I was sexual at all for a couple of months. It was just a bummer.... It makes you not interested” (Whitney). Three of the non-disclosing participants did not feel their diagnosis impacted the frequency of their sexual activity at time of diagnosis, but recalled how HPV-related procedures and recovery caused them to be less sexually active. One recalled, “the fact that I needed to take 6 weeks after the procedure and not be available... it made me feel upset because it made me feel like my body was not cooperating with me” (Candace). Another stated, “it took a really long time to heal. For the longest time I had - they weren't scars but you could see - and the skin was really thin so for a really long time sex hurt. I could not have sex for long periods of time after that but now I am back to normal but it too a really long time to heal because it is such vulnerable skin down there. That was very difficult and uncomfortable” (Emily). One participant’s sex life was not impacted at diagnosis, but has since become sexually inactive due to the HPV and anal cancer-related procedures stating that future sexual partners are “highly unlikely. I don't have much to work with - that makes it somewhat difficult” (Katherine).

Ten of my 23 participants’ sex lives were impacted by having HPV. Many reported painful sex, long recovery from HPV treatment, and long-term consequences of treatment as the main reasons why their sexual activity lessened or stopped completely. Those who disclosed their status to partners felt supported in their choice to have less sex. Some of my participants avoided sex with their committed or casual partners who were unaware of their status. This avoidance was often rooted in their reasoning to non-disclose, as discussed below.

4.6.3 Non-Disclosure

Sixteen of my 23 participants did not disclose their HPV status to one or more of their sexual partners. Most of the sexual partners they did not inform were at risk for acquiring HPV because they
were recent or current sexual partners. Reasons for non-disclosure varied from merely never discussing STIs, to avoiding embarrassing and hard conversations, to believing their partners were at little risk for contracting HPV from them.

4.6.3.1 Difficult Conversation

One individual explained that they did not disclose to their current sexual partner merely because they never spoke about STIs. She came to that realization when stating, “wow, 16 years and we have not had that kind of conversation” (Tiffany). Six participants, however, purposefully withheld their positive HPV status from current or past sexual partners because they believed it would be a difficult conversation to initiate. Two individuals decided not to mention their status because they feared sexual rejection from their partners, “I did not want to risk them having a bad reaction and not want to have sex with me. I did not want to deal with it or disclose so I did not disclose at that time” (Phoebe). Another stated, “it's an embarrassing thing to have.... What is telling him going to do, except probably have him not see me anymore?” (Whitney). One participant, in a non-monogamous relationship, was too embarrassed to disclose to any secondary or tertiary sexual partners, “I think it [reason for non-disclosure] is embarrassment and shame. It has less to do with rejection. I don't really care about that from those folks. I just don't think it is necessary. I think that is not a rational response. This part of me just doesn't want to tell anybody” (McKenzie). One individual disclosed to their current sex partner, but not to past partners at risk because it would be a “difficult” conversation with these past sexual partners (Summer). One did not disclose her status because she believed it was a result of infidelity, “it [disclosure] would have been me telling him I got HPV from cheating on him” (Phoebe). Another participant does not plan on telling future sex partners, explaining that conversation was too intimate: “do I feel like I need to talk about it with someone that I am just having sex with? No, because I don't feel like it is important. It is more deep than I want that relationship to be. I just want someone to come
hang out, we have sex, you can go” (Emily). All of these participants actively avoided having a conversation with some of their at-risk sex partners about their positive status, but some of them did so because they assumed their partner was also HPV positive.

4.6.3.2 Little Risk to Male Partners

Over half (14 of 23) of my participants did not disclose their HPV status to at least one of their male sexual partners because they believed there to be little risk of new transmission or few negative physical consequences for their male partners. Four individuals chose not to tell their sexual partners about their HPV because they assumed the partner had already contracted it, “I never talked to sexual partners before we have sex like ‘I have HPV, just want to let you know’ because they probably have it too” (Emily). Another recalled, “I remember offhandedly being like ‘well obviously I have HPV so obviously you do too’” (Phoebe). One stated, “the people that I have had sex with are around my age so I am sure that everyone has HPV and there is literally nothing that you can do about it” (Colleen). Another said she would not tell her sex partner “because he is already a carrier there is nothing I can do about it” (Ava). One participant thought it was too late to prevent transmission and therefore did not mention it to her partner, “we had already been having sex and already not using a condom at that point so I was like... he’s screwed already.... It was only after both of us tested for STDs that we started not using condoms, but again, I didn’t tell him about the HPV.... I’m a jerk” (Whitney). All of these participants decided to not disclose their status to sex partners because they assumed their partner had it previously or had already contracted it from them. They felt there was little to gain for either partner by disclosing their status.

Three participants did not think to tell their male partners because they knew it was something men could not get tested for, “there is no way to easily test on a man. I just don’t think it is that big of a deal” (Emily). One individual stated, “I think it was a matter of just did not think to. I know that sounds odd but yeah. I guess probably because male partners really can’t get tested for it” (Katherine). Another
stated that disclosure is unnecessary for this reason, “If I called someone now and told them that [I had HPV] they would laugh at me... I really do feel like that because really what are you supposed to do? He can't... he won't ever know if he has it” (Ashley). Four individuals thought HPV would not impact male partners and thus did not disclose, “it is not going to affect them in any real way except give them this random information that they can do nothing with... what is the point” (Ashley). Another did not feel the need to mention it to her past male partners, “I don't really see the point in doing so [disclosing] because the two people I am thinking of are both men and they wouldn't have any symptoms if they have what I have” (Amber). One said she did not disclose to her partner “because it is not going to affect him” (Ava). One of these participants did not consider telling their partner, “I did not even think about it. This is the first time I have thought about it... because it is transmittable, right?” (Janelle). All of these participants did not feel compelled to disclose their positive status because they knew their male partners would not be able to find out their own status. One participant, who disclosed only to her current sex partner, asked the diagnosing doctor for advice about disclosing to sexual partners and recalled, “I did ask him [doctor] questions about if it would impact my partner because my boyfriend was worried about it as well. The gynecologist wasn't as concerned about how it would affect partners unless they were female partners. He was like, ‘well, you can't test on guys so there is nothing I can do or advise on that’” (Erica). This patient-provider exchange supports my participants’ motivations to not disclose to male sex partners.

Three participants did not tell their past sexual partner because they were having safer sex. One felt no need to tell her partner because they were using condoms and she wanted, “just not to have to deal with the whole process of explaining the diagnosis and whether the person may have been familiar with it or understood it or anything... just to not have to deal with that... not necessarily the proper thing to do” (Tiffany). Another stated, “that [disclosing] is an awkward conversation starter and I knew that we were practicing safe sex and it wasn't a huge risk” (Kendra). One individual similarly explained,
“Unless they asked if I had an STD before I didn’t really say. I didn’t really think it was a big deal. Maybe I was wrong in that thinking but since we were using condoms and it was the cervical cancerous kind, I was not really concerned about my male counterpart” (Leslie). As mentioned above, these participants, while aware of the protective effect of condoms, were not aware that using additional barrier methods would decrease the likelihood of transmitting HPV.

Six individuals mentioned that they would disclose other STIs that were more serious in their eyes. One participant compared it to other STIs when rationalizing non-disclosure stating, “HPV is very different. If you have any other kind of STD... a disease is different than an infection. A disease is really fucked up. When you have unprotected sex with someone you are taking a risk of faith on them and they on you” (Emily). Another explained, “I think you know with the herpes HSV the fact that you can give it to someone else and it is a lifelong thing and doesn’t clear up.... it is also cosmetically not pretty. I would definitely disclose that or my sexual behaviors would change. If it was HPV with genital warts - yeah I would have said something” (Leslie). Another said, “it still did not occur to me to tell about HPV, but I will disclose about HSV” (Candace). One individual stated, “I was thinking in my mind that if the results were positive [for HSV] that I would call and tell him [sex partner] because he was the only one I had been with since then but this [HPV] did not seem that serious, like I did not need to make a phone call. This one [HPV] does not seem so scary because she [nurse] told me it would go away” (Janelle).

Another participant, who had not disclosed to their most recent partner, mentioned how other STI diagnoses would impact disclosure and sexual behavior. They stated, “if I was diagnosed with HSV2 I would feel shitty about that even though I know how prevalent that is too... I would feel a responsibility to disclose and I don't want to do that. If I were diagnosed with gonorrhea or chlamydia I would think that sucked, but it would not be a big deal because I would take the antibiotics and be done with it. I would probably not have sex until it cleared. I would probably tell my current sexual partner and hold off until it cleared. I would not have sex with a new partner while under treatment for chlamydia”
(Phoebe). Another said, “if it was something that would affect my health and if it happened to other women and would affect their health severely - like if it was something like I don't know much about other STDs but definitely like AIDS or like - things that cause long symptoms I would have gone back and informed” (Ava). All of these participants felt that HPV was not serious enough to warrant diagnosis disclosure. Again, all 14 of the above participants did not disclose because of a lack of knowledge regarding HPV’s impact on men. They did not believe they were putting their male sexual partners at risk for HPV or HPV-related consequences, such as genital warts, penial, or throat cancer.

4.6.3.3 Clearance and Prevalence

Two participants did not disclose their HPV status because they knew it was highly prevalent, “I think I was like well it is so common it does not matter. It wasn't something I thought of... like a thing I need to disclose” (Phoebe). Another stated, “I never thought to disclose that I had it to partners. It didn't even occur to me. It was just abnormal cells and basically everyone has it is” (Candace). Two no longer disclosed because HPV has cleared from their bodies, “in the last year it has been clear so I stopped telling partners” (McKenzie). Another who no longer tests positive for HPV stated, “I think it is irrelevant if it is not a current thing” (Riley). These two participants disclosed their status to most of their sex partners when they still tested positive for HPV, but felt that they no longer had it to transmit and thus, no longer needed to disclose.

4.6.3.4 Guilt

Three participants expressed some guilt due to their non-disclosure. One stated, “if I feel bad about anything it is not disclosing [to the secondary and tertiary partners]” (McKenzie). Another recalled, “I didn’t tell him about the HPV... I'm a jerk (Whitney). Another who believed she acquired HPV from sex
outside of her relationship stated, “I am sure I felt a little guilt around that - exposing him[boyfriend]. I really loved him” (Phoebe). Despite feeling guilt for non-disclosure, these participants chose not to disclose for multiple reasons: it was a difficult conversation to have, believed there was little HPV risk to men, and knew HPV was extremely common. Two of these participants did not use condoms with their at-risk partners.

4.7 LIMITATIONS

Past qualitative research on HPV has relied on non-diverse samples of primarily white, college-educated women (see: Kosenko et al. 2012, Nack 2008). Although I sought to reveal the stories of a diverse sample in terms of ethnicity, race, and educational attainment level, my sample was more homogeneous than initially intended. My sample included cis-gender and gender non-conforming women from different racial and ethnic groups ranging in age. However, I was unable to include participants of varying levels of educational attainment. This may have been a result of my sampling method. However, I also believe it is due to the fact that women with lower socioeconomic status and less education are less likely to have regular gynecological appointments and routine Pap tests, compared to their more educated peers (Behbakht et al. 2004; Katz and Hofer 1994). Without regular visits to the gynecologist and routine Pap tests, women are much less likely to know they are HPV positive. Therefore, individuals who saw my flyers may have thought they did not qualify because they did not know their positive status.

4.8 DISCUSSION

According to past research, individuals with HPV are often unaware of symptoms, risk of transmission, and recommended lifestyle changes (Perrin et al. 2006; Sharpe et al. 2006). Use of barrier methods (condoms, dental dams) and disclosure of HPV status are two prevention strategies that can be
used by individuals who are HPV positive. These behaviors, while not 100% effective at preventing the transmission of HPV, can prevent initial acquisition, transmission to partner, and re-infection among partners. Although many Americans are unaware of the potential of HPV re-infection after clearance, re-infection with the same HPV type is a common occurrence (Trottier et al. 2010). Many women with HPV do not disclose their status to partners because of this lack of knowledge and feelings of shame for having an STI (East et al. 2012; McCaffery et al. 2006; Nack 2008). Some individuals with HPV, according to past research, do not use barrier methods to protect against transmission to their partners (Nack 2008).

According to the information, motivation, behavior (IMB) theoretical model, STI prevention techniques are used by individuals who are well informed, perceive themselves to be at risk, are motivated to change their risky behavior, and feel capable of using prevention strategies (Bahrami and Zarani 2015; St. Lawrence and Fortenberry 2007). In order to participate in STI risk-reducing behavior, according to the IMB model, individuals must be informed about STI risk-reduction (St. Lawrence and Fortenberry 2007). Specifically, people need to be knowledgeable about STI transmission and prevention methods (Fisher and Fisher 1992; St. Lawrence and Fortenberry 2007). Many individuals are unaware that STI disclosure is a component of safer sex practices (Luchetti 2009). The majority of my participants did not disclose their HPV status to one or more of their sexual partners. According to past research, much of the general population is unaware of their risk of acquiring and transmitting HPV (Blake et al. 2015; Gerend and Magloire 2008; Sandfort and Pleasant 2009; Ratanasiripog et al. 2013). Although some of my participants were concerned about transmitting HPV to their partners, the majority of them did not know that HPV could be transmitted from skin-to-skin contact. Past research indicates that people are also misinformed about how HPV impacts men and believe there are no HPV-related health threats for men (Sandfort and Pleasant 2009). Fourteen of my participants who did not disclose to a male sex partner were unaware of the HPV-related health consequences for men.
Individuals who participate in oral sex often do not understand STI transmission through oral sex, and are unaware of prevention methods (dental dams) to use during oral sex (Chambers 2007). Only one of my participants used dental dams to protect against transmission. None of my heterosexual participants used this barrier method to prevent transmission through oral sex.

Knowledge alone is not sufficient enough to change behavior, according to the IMB model (Fisher and Fisher 1992). Informed individuals must be motivated to act on their knowledge and change their risky behavior (Fisher and Fisher 1992; St. Lawrence and Fortenberry 2007). They must have the strong desire to initiate and maintain prevention strategies, such as condom use, dental dam use, and status disclosure. This motivation is, in part, related to one’s perceived susceptibility to risk and adherence to social norms surrounding prevention techniques (Fisher and Fisher 1992). Consistent condom use is associated with perceived risk to STIs (Bryan et al. 1997). However, many people often do not perceive themselves at risk for HPV (Gerend and Magloire 2008; Sandfort and Pleasant 2009; Ratanasiripong et al. 2013; Blake et al. 2015). Many of my participants were unaware of the high prevalence of HPV, even after their own diagnosis. Normative behavior related to condom use differs for individuals in committed relationships compared to those in casual sexual relationships. Individuals in serious relationships are less likely to use condoms, compared to single individuals, because as trust and a sense of security increases in the relationship, condoms are no longer viewed as a necessary precaution (Emmers-Sommer et al. 2010; Roberts and Kennedy 2006). The majority of my participants in monogamous relationships did not use condoms or other barrier methods to prevent HPV transmission and reinfection. Many of these individuals used condoms at the beginning of their relationship, but discontinued use once they trusted their partner, had been tested for other STIs, or went on hormonal birth control. Motivation to disclose status, among those with HPV, is often thwarted by fear of rejection, embarrassment, and feelings of shame (East et al. 2012; McCaffery et al. 2006; Nack 2008).
Some of my participants withheld their status from partners because they were embarrassed or worried that their partner would reject them.

In order for a knowledgeable, motivated individual to actually change their risky behavior, they must have the skills to perform the recommended preventive behaviors (St. Lawrence and Fortenberry 2007). These skills include obtaining a vaccine, correct condom use, sexual communication, condom negotiation, and a sense of condom use and condom negotiation self-efficacy (Fisher and Fisher 1992). Individuals must feel that they are skilled enough to act on their knowledge and motivations in order to change their risky behavior or initiate and maintain preventive behavior (Fisher and Fisher 1992). HPV vaccination intention and uptake is lower among older adolescents and college age women due to vaccine safety concerns, side effects, insurance issues, cost, low perceived risk, and belief they are too old to receive the vaccine (Laz et al. 2013; Patel et al. 2012). Most of my participants never received the HPV vaccine because they did not qualify for insurance coverage based on age, were diagnosed before the vaccine was readily available, or were unaware of the vaccine before diagnosis. In support of previous research (see: East et al. 2012; McCaffery et al. 2006), some of my participants were unable to disclose because they were embarrassed, feared sexual rejection, and did not feel confident in having the difficult conversation about their status. Actual condom use is related to condom use and negotiation self-efficacy (Bryan et al. 1997). In some studies, women report lower condom use self-efficacy scores than men and often report not using condoms because their male partner does not want to (Farmer and Meston 2006; Roberts and Kennedy 2006; Wildsmith et al. 2010). Other researchers, however, posit that women have greater condom use and condom negotiation self-efficacy (Allen et al. 2002; Carter et al. 1999). Some research demonstrates that women with HPV become more assertive about condom use with their partner post diagnosis to avoid transmission and re-infection (Nack 2008). Some of my participants practiced safer sex post diagnosis because they feared transmitting it to their partners. Many, however, felt incapable of preventing HPV transmission through the use of condoms.
because they assumed their partner already had HPV or they knew that condoms would not completely protect their partner.

I found, in support of past research (see Bertram and Magnussen 2008; Kosenko et al. 2014; Perrin et al. 2006; Sharpe et al. 2006), that many individuals with HPV are misinformed about the transmission of HPV and HPV-related health consequences for men. My participants’ lack of perceived risk for transmitting HPV; inaccurate knowledge about HPV transmission, prevention, and consequences for male partners; and low self-efficacy for preventing the spread of HPV all impacted their decisions about disclosure and sex behavior post diagnosis. Based on my research, I recommend that practitioners discuss transmission, prevention methods, and the potential consequences of putting their partners at risk. Individuals with HPV will not be able to prevent the continued spread of this highly prevalent STI unless they are well informed about transmission and prevention, perceive themselves to be at risk for re-infection or for infecting others, are motivated to use prevention methods, and feel capable of sexual communication and condom negotiation with their partners.
5 CONCLUSION

In this study, I used semi-structured interviews to uncover the lived experiences of individuals with HPV. This method, compared to past HPV scholarship which heavily relied on survey research, fostered discussion of actual experiences related to living with HPV, specifically knowledge, stigma, disclosure, and sexual behavior. I sought to discover (1) whether individuals diagnosed with HPV were knowledgeable about the infection prior to and after diagnosis, (2) how those diagnosed with HPV felt about themselves after diagnosis and how their knowledge of HPV influenced these feelings, (3) why they decided whether or not to disclose their status to family, friends, and sexual partners, and (4) how HPV status influenced my participants’ sex life and use of STI prevention methods.

As a whole, my dissertation highlights how patient-provider interaction surrounding HPV diagnosis greatly impacts individuals’ emotions, disclosure, and sexual behavior post diagnosis, in addition to their general knowledge of the STI. Unsympathetic, impersonal, uninformative patient-provider interactions often led my participants to negatively view their status, feel shame, internalize stigma, be misinformed on HPV transmission, withhold their status, and participate in unprotected sex with their at-risk partners.

Despite the high prevalence of HPV, health literacy and basic knowledge about it remain relatively low. Health literacy is positively associated with level of education, however, even among my participants, who represented a highly educated portion of the population, HPV knowledge pre-diagnosis was low. Pre-diagnosis, many of my participants were uninformed about HPV prevalence, transmission, and cancer facts. After diagnosis, participants often remained unaware of HPV’s skin-to-skin transmission, clearance, and dormancy, thus demonstrating a continued low HPV health literacy.

An HPV diagnosis, similar to other STI diagnoses, often causes concern and anxiety. The majority of my participants experienced feeling anxious, scared, or stressed when they were first diagnosed with HPV. Many also expressed surprise and shame over their positive status. All participants who received
word about their diagnosis from a nurse rather than their primary doctor, or who had an experience where their clinical staff assumed their status was already known, recalled these negative emotions. Very few of my participants mentioned feeling supported and having their worries assuaged by their doctors.

Women with HPV possess a character stigma because they deviate from societal norms of female chastity and purity. They can be viewed as promiscuous, irresponsible, and unclean. A majority of my participants felt stigma related to their positive status. Many assumed that others judged them based on the fact that HPV is an STI and thus, indicated they were not sexually responsible. Others believed they were facing stigma because of the type of cancer they developed from HPV – anal cancer, which they knew others were quick to pass judgement on. Many participants internalized this stigma and felt shameful about their diagnosis and blamed themselves for their status. Some of my participants, however, did not experience stigma related to their status, but realized that others with HPV may face judgment from larger society.

Individuals with a hidden, discreditable stigma must decide who to tell or not tell about their condition. Some may choose to disclose their character stigma to friends, family, or partners for support. Others may decide to hide their status because of internalized shame and embarrassment. Almost all of my participants disclosed their HPV status to someone in their life. Some participants who felt stigma sought support or advice from friends who had previously experienced HPV themselves. Even individuals who felt little to no stigma often disclosed to gather the same information. Many of these individuals (both those that felt stigma and those that did not), in turn, were open about disclosing to others who were newly diagnosed and wanting information or advice. Some of my participants withheld their status from specific individuals in their life. They used this form of stigma management, selective disclosure, because they knew they would face judgement from those people. Even some participants
who felt little to no stigma attached to their status chose to selectively disclose by only mentioning their treatments and not the fact that they were HPV related.

My participants had a variety of HPV types and stages of cervical dysplasia. Some individuals had low-risk, asymptomatic HPV strains that posed little to no risk to their sexual partners. Many others, however, had high-risk strains or mild to severe dysplasia caused by HPV. Transmitting these types of HPV to sexual partners posed risks to them, depending on the specific strain of HPV - which most participants did not know. These high-risk HPV strains could also be consequential for male partners’ future female partners. Although a high-risk strain may have cleared from my participants’ bodies, they could become re-infected after treatment if they have already transmitted it to their current partner. A few individuals had anogenital warts caused by HPV, which were easy to transmit to one’s partner through sexual intercourse or skin-to-skin contact. Others did not know what type of HPV or cervical dysplasia they had at the time of interview and without this knowledge, these individuals were unaware of the potential risk they may have been causing their partners or their partners’ future partners.

Secondary STI prevention methods, which prevent transmission from a positive individual to their partner, are more likely to be used if individuals are informed about transmission and prevention techniques, motivated to practice preventive behaviors, perceive themselves and others to be at risk, and are confident in their ability to perform prevention behaviors. The majority of my participants did not disclose their HPV status to one or more of their at-risk sexual partners. Some did not disclose because they felt it was a difficult conversation they did not want to initiate because of fear their partner would reject them, embarrassment about their status, or a disinterest in admitting to their infidelity. The majority of my participants, however, did not disclose their status to sexual partners because they did not believe they were putting their male partners at risk. Many assumed their partners already had HPV or saw no point in disclosing to male partners that could not get tested. Others
assumed they were not putting their partners at risk because they were using condoms most of the time or admitted that they would disclose if it were an STI they considered to be more serious.

None of my participants, however, used all barrier methods during male-female sexual activities. Many used condoms on occasion, but none used dental dams with their male partners to prevent transmission through oral sex. Some participants felt that their diagnosis was a catalyst for participating in safer sex. Others, however, did not use condoms consistently and this was more often true for those in monogamous relationships. A few participants reasoned that they were abstaining or having sex less frequently as a means of protecting their partner. Most who were having less frequent sex post-diagnosis, however, were doing so because sex had become painful after their HPV treatments.

The HPV vaccine reduces one’s risk for infection and thus prevents the spread of disease, however, it is recommended for younger men and women and not covered by insurance past the age of 26. Most of my participants were not vaccinated because the vaccine was not available to them pre-diagnoses or they were unaware of the vaccine before being diagnosed with HPV or reaching the insurance cut-off age. Many of my participants could have opted to pay out-of-pocket for the vaccine past the age of 26 or post-diagnosis. Research suggests that previously infected individuals may benefit from vaccination by increasing antibodies and thus helping individuals clear HPV more quickly and by preventing re-infection. This was information that most of my participants were unaware of at the time of interview. Without this information, they were unable to utilize this method to prevent their own infection, transmission to their sex partners, or potential re-infection.

Many of my participants felt incapable of preventing the spread of HPV. This low self-efficacy existed even if they knew how easily it was transmitted and sometimes was rooted in this knowledge. Few understood that the most effective way to prevent transmission was through multiple barrier methods, and even fewer were motivated to start using these prevention methods after diagnosis.
Many of my participants saw HPV as an inescapable consequence of being sexually active, despite being shocked and ashamed when they were diagnosed with it.

Participants’ low HPV health literacy, high levels of anxiety at time of diagnosis, continued stigma, non-disclosure, and risky sexual behavior are related to sexual education, practitioner messaging, and social norms around HPV. A substantial portion of the American population that is at risk for acquiring and transmitting HPV is unaware of many aspects of the infection. Sexual education programs should include curriculum on HPV related to the vaccine, transmission, dormancy, clearance, cancer, and prevention methods. Decades of research demonstrate that people are dissatisfied with how their doctors handle HPV diagnosing. Medical practitioners should strongly consider having a face-to-face conversation with their patients when providing a positive HPV diagnosis and make sure their patients are fully informed about key aspects of the disease, such as prevalence, transmission, dormancy, clearance, and how, specifically, it is linked to cancer. To prevent the continued spread of high-risk HPV, normative behaviors around sex must change. Prevention programs should focus on heightening the knowledge about and acceptance of alternative barrier methods to STIs. In addition to increasing consistent condom use before penetrative sex in order to decrease transmission through skin-to-skin contact, prevention efforts should aim at increasing the use of dental dams to prevent the high-risk HPV through oral transmission.

My small exploratory study brought to light many unknowns that still surround HPV among those infected. Past HPV research often relied on survey methods that did not provide rich detail about experiences of those who lived with HPV. Few qualitative studies before this one were conducted since the HPV vaccine was routinely recommended in the United States. I analyzed how routine vaccination and subsequent increased awareness of HPV in the general public impacted by participants. Although I sought to reveal the stories of a diverse sample based on ethnicity, race, and educational attainment level, my sample was more homogeneous than initially intended. Future research should focus on how
HPV knowledge varies among racial and ethnically diverse populations and how that knowledge impacts stigma, disclosure, and sexual behavior among those groups. A few of my participants were vaccinated before testing positive for HPV. Future research should focus on this small, but interesting group of individuals living with HPV to better understand their lived experience and attitudes toward the vaccine. My research shed light on how HPV impacted individual’s status disclosure and sexual behavior with their partners. Future, large-scale, quantitative research can analyze how these aspects of safe and risky sex differed among those who had low-risk HPV compared to high-risk HPV. Findings from such research could pave the way for new prevention efforts that aim at stopping the spread of high-risk HPV strains that are associated with most cervical, vaginal, vulvar, penile, anal, and throat cancer cases in American men and women.
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