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The vaccine and the virus: An autoethnographic account of HPV, sex education, and the psychosocial effects of STI's

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The Vaccine and the Virus: An Autoethnographic Account of HPV, Sex Education, and the
Psychosocial Effects of STIs

by

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Thesis

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Abstract

In 2006 the Food and Drug Administration (FDA) approved the Gardasil vaccine to assist in the protection from the Human Papillomavirus (HPV): The leading contributor to cervical cancer. After stressing the importance of the vaccine, but disregarding its inadequacies, young women were subjected to invasive and excessive protocols. This study utilizes autoethnographic methods to understand the psychological and social effects of the individuals who were diagnosed with HPV before the release of the Gardasil 9 vaccine in 2014 and forced to go through these unnecessary procedures before the medical field began adopting imperative changes to treatment.

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Introduction

According to the Centers for Disease Control and Prevention, the “Human Papillomavirus (HPV) is the most common sexually transmitted infection,” with two specific strands being responsible for “70% of cervical cancers worldwide” (CDC, 2014). In 2006 the U.S. Food and Drug Administration (FDA) approved the first Gardasil vaccine for women between age 16 and 26 (Gross et al., 2015) protecting them from two strands of HPV that led to cervical cancers: 6 and 11. This began a conversation about the virus that was imperative in developing procedures to combat HPV within the medical field. However, as the virus continued to spread it was obvious that more action needed to be taken. Eight years later, the FDA approved the Gardasil 9 vaccine offering protection against five more strands of the HPV virus including 31, 33, 45, 52, and 58. This would protect women from about 20 percent of cervical cancers that the previous vaccination did not, according to the Food and Drug Administration (2015). This was a monumental step in the medical field.

Between 2006, the release of Gardasil, and 2014, the release of Gardasil 9, there has been a plethora of changes in how the medical field tackles HPV. These changes were necessary because as of 2010 “approximately 20 million Americans [were] infected with HPV and an additional 6.2 million become infected with HPV each year. It is estimated that 80 percent of males and females will become infected with HPV at some point in their lives...most individuals will clear the infection on their own; however, some individuals will remain infected and...at risk” (Daley et al, 2010, p.282). Unfortunately, the conversation circling HPV, sexual health, and patient-doctor communication has not been addressed. Because the first HPV vaccination came out in 2006, school-based sexual

education programs were unable to provide adequate information regarding the virus for anyone in high school between 2002 and 2007. Moreover, anyone who was diagnosed before 2015 will experience a drastic shift in the way doctors approach the virus.

For people in their late 20s, this could create two results: An uninformed environment and the instilment fear. However, when considering the ways in which individuals handle uncertainty, it is important to understand that many individuals of this age have become complacent when considering HPV. Though medical professionals stress the urgency of the vaccine and treatment, it is so likely that an individual will be diagnosed with HPV and that individuals and professionals have come to expect it instead of combat it. This communication phenomenon can be referred to as, what I argue, is a “hyperbolized normalization.” Meaning, medical professionals exaggerated the urgency of the first vaccine while simultaneously disregarding its inadequacies. Though HPV is one of the fastest growing STIs (sexually transmitted infection), it is also one of the slowest growing viruses. As such, it is extremely likely that if infected, the virus will become dormant within two years. Therefore, individuals have been forced to believe in the danger of the virus, but then comforted when they are infected with the virus, making it practically a “normal” experience.

There are three areas that need to be explored to better understand how this conversation can change. First, school-based sexual education must be dissected, primarily with a focus on how we talk about sexually transmitted diseases and the rhetoric it creates. Next, a review of HPV and what research has been done specifically regarding the psychosocial effects of patients and the recent shifts in the field. Finally, an understanding of Uncertainty Management Theory is necessary to better understand an individual’s ability to handle health-related communication. Afterwards, autoethnographic research is used to delve

into my personal experience with HPV. After participating in an unsuccessful school-based sexual education program, receiving the vaccine in 2006, and still being diagnosed with the HPV virus in 2011, I will be able to offer insight into the psychosocial effects of HPV, the shift in the medical field, and the urgent call for change in sexual education programs.

Literature Review

There are two areas that I review to provide a healthy foundation for this study: sexual education and its relationship to slut shaming as well as the human papillomavirus. Because an individual's ability to cope with uncertainty is determined based on personal experience, the ways in which the American public talks about sex and women's agency directly coincides with how an individual handles the diagnosis of a sexually transmitted disease. Reviewing the literature circling sexual education and sexual agency provides a foundation for delving into the autoethnographic research. Furthermore, having an understanding of the way to analyze and research HPV will solidify the use of this specific method. The following section will first address different aspects of sexual education before addressing the research circling HPV.

There is no question that Miley Cyrus has spent the latter half of her career striving for something a lot of viewers are unable to put their finger on. Rather, many think she is a crazed child star going through a phase or an inspiration to female empowerment everywhere; the discourse surrounding Cyrus will always consider her age, gender, and raging sexuality. Lamb, Graling, and Wheeler's (2013) article analyzed a posted video of Miley "provocatively" dancing on stage at the Nickelodeon© Teen Choice Awards in 2009 on fifty different websites. Three specific areas received blame for her behavior as written in

the comment sections of the websites: media influence, the Cyrus family, and Miley herself. Lamb et al., concluded that these “conversation[s] revolve[d] around...what extent adolescents who believe they are empowered in their so-called self-sexualization are actually empowered, to what extent they are agents making choices or dupes of the media and marketers, and to what extent researchers need to trust the perspectives of girls on this subject” (Lamb, Graling, & Wheeler, 2013, p. 175). This suggests that the 17-year-old Miley had a lack of agency over herself or the agency she did have held no validity.

Miley’s development in Hollywood provides the perfect articulation not only of the impacts our society has on young women, but also of the unmissable embodiment of sexuality when a person feels as if she is constantly being watched, a typical insecurity for young ladies in America. This stripping of agency, suggested in the aforementioned study, lends itself to the development of sexual discourse and young women’s self-perception. As such, it is imperative to ask: At what point does a woman feel as though she has agency over her sexuality? Moreover, at what point does a woman’s agency over their sexuality become recognized on a larger scale?

Because individuals’ self-perceptions are directly impacted by the views of their surroundings, the only way to better understand a woman’s sense of agency is to look at the strongest criticism of said women. In order to delve into sexuality, we must delve into a world that is constantly in a state of criticism: The world of slut shaming. There are several points to discuss when reviewing the research that is surrounding slut shaming but two main areas remain consistent; education and discourse.

Whether a teenager learns about sex at home or at school, the approach and pedagogy lends to being ineffective and unrealistic. Though sexual education can be offered in a

plethora of forms and styles, the unfortunate truth is that the “discursive intersection between adolescence and sexuality yields a fundamental assumption: teens are hypersexual, their lives [are] driven by sexual desires and impulses” (Bay-Cheng, 2010, p. 62). This inadvertently creates an environment with lower expectations and even less resources. As such, if both parents and teachers are undermining the reality of teen sexuality, they are stripping said teenagers of the agency they have over their body.

First, school-based sexual education, or SBSE, is a curriculum focused on pregnancy prevention and sexual risk. This focus, though imperative in understanding the effects of being sexually active, disregards the motivators that teenagers are experiencing. The only way for a program to be successful is if they are “relevant and engaging [and] acknowledge how young people construct meaning about their sexual selves” (L. Allen, 2004, p. 215).

Bay-Cheng (2010) delves into the irony of this when she stated:

Despite a wealth of empirical research on the efficiency of SBSE in the transmission of information and the prevention of disease and pregnancy, there has been relatively little focus on the values and norms that are implicitly conveyed to teens in sexual education classrooms and the role of SBSE in the very construction of adolescent sexuality. Indeed, the relationship between adolescent sexuality and SBSE is not unidirectional...[which] makes this issue particularly compelling is that SBSE not only plays a significant role in guiding teen sexual behavior, as if adolescent sexuality is an absolute and naturally occurring entity, but also that it is a fundamental force in the very construction and definition of adolescent sexuality. (p. 61-62)

When combining the ideas that SBSE is only effective when there is an understanding of how young people construct meaning about their sexual selves while simultaneously being

one of the key constructors, it is astounding that programs have lead themselves to be so utterly ineffective in passing years.

Though at first glance, it may not seem that a child's education falls into the world of slut shaming, it does so in the way of instilling fear, and disregarding desire and sexuality. If students are constantly being taught that sex equals "bad things" as opposed to "these feelings" often lead to sex, then both the act of sex and the desire for it become engrossed in negative stigma that directly affects an individual's understanding of themselves and those around them. Arguably, an unhealthy school-based sexual education program could potentially be serving as the foundation of slut shaming.

This directly ties into parent involvement in sexual education. Much like how slut shaming results in individuals making false accusations towards others, "social policy, sex educators, teachers, and other adults" tend to incorrectly "construct teenagers as both too young to know about sex and too sexually driven to be trusted with sexual information" (Elliot, 2010, p. 192). In a 2010 *Symbolic Interactionism* article titled, "Parents' constructions of teen sexuality: Sex panics, contradictory discourses, and social inequality" author Sinikka Elliot explained that, "parents think of their own children as asexual [meaning] that parents did not describe their teenage children as sexually agentic [and] desiring subjects" (p. 198). By doing this, "parents cannot envision any good coming from teen sexual activity; rather, they articulated innumerable negative consequences, including death. This produces a tremendous social and psychological incentive for parents to asexualize their teens" (p. 206) directly stripping them of their sexuality and deeming their desires as not only too mature for their age, but literally lethal.

When a teenager's family structure and education system strip the student of his/her agency, the individual is left with only themselves and peers to effectively develop understanding and acceptance of their sexual desires. Unfortunately, Elliot (2010) explained that because a teenager's education is playing a primary role in their construction, it is without surprise that their discourse becomes laced with pretenses that are equally as harmful. These include an aggression towards peers and strangers, the articulation of desires, and an exposed passivity when interacting with others.

The participation of Hate speech is the catalyst of slut shaming. Unfortunately, "research suggests that *slut* and its derivatives are among the most common and the worst of possible pejoratives hurled in the high school social arena [explaining the] association between a woman's worth as a human being and her sexual practices" (Payne, 2010, p. 317). This aggressive and judgmental discourse creates an environment where teenagers, both those considered "promiscuous" and "prude" are directly reprimanded for their sexual choices. Elizabeth Payne, author of "Sluts: Heteronormative Policing in the Stories of Lesbian Youth" beautifully analyzed the creation of the high school slut in correlation to agency and humanness:

The high school slut is mythic...She is reduced to a defamed sexual orifice, demeaned for her sexual agency, for her pursuit of sexual partners, for desiring her own sexual pleasure with battery-operated devices, and for engaging in sex with another woman—all sins against heteronormative femininity. Her vagina is framed as something foreign, inhuman, rotting, disease-filled, and dangerous. The mythic character here portrayed seems more modern day Medusa than high school girl: the head of a female but the lower body of vile smelling serpent able to ruin lives at a

mere come-hither glance. She has not only ceased to be woman, she has ceased to be human. Here, a girls' sexual propriety is linked not with her moral goodness and value as a human being, but her very humanness itself. (p. 319)

Because this development of rhetoric becomes prominent during high school, young women are not only more likely to cast judgment on those around them, but also to judge themselves for their internal desires and interests leading to the next area of research: an inability to articulate their own personal desires.

An environment where women are shamed for their sexual desires creates an environment where they are less likely to talk about them. Unfortunately, not exploring these interests limits understanding and can lead to unsafe and harmful decisions that will construct an individuals present and future. However, even when attempting to engage in these conversations, research has suggested that girls are, "much more...focused primarily on their insecurities, confusion, anxieties and inner conflicts around desire" than the desire itself (Constable, 1999, p. 674). If a woman's sexual agency is to be accepted by others, women must ultimately accept their own desires first. Engaging in these discussions during sexual education is a key step in combating slut shaming and gaining more control over the perceptions of women.

When reviewing the research circling the discourse of sexual education, the final, and potentially most upsetting result, is the increase of passivity in women. If the act of slut shaming is creating an understanding that, "the construction of female sexuality is one of passivity and vulnerability [then women become] perceived as having less desire and achieve sexual pleasure less easily than men" (Allen, 2004, p. 163) which, yet again, strips a woman

of their agency. The creation of the passive woman then plays a role in the large-scale understanding of an entire gender.

With a combination of poor education and harmful external and internal discussions, the ability to uphold a positive and progressive understanding of the self becomes increasingly difficult. When considering the fact that so many elements are deconstructing a young woman's agency, it is hard to imagine a world without slut shaming. Having a better understanding of the domino effect derived from sexual education and slut shaming provides scholars with an insight to the chronological deterioration of sexual agency.

This deterioration of sexual agency seen through education and rhetoric has a direct correlation to the ways individuals handle uncertainty when being diagnosed with a sexually transmitted disease or infection. Therefore, the next area of research that demands overview is that of the human papillomavirus. When delving into the collection of research regarding HPV, there is a focus on the success of the first vaccine (Promo et al., 2013), vaccination programs in public education (Brown, Little, & Leydon 2009), and communication about sexually transmitted diseases between individuals and in media (Gross et al., 2015). There are some studies that also attempt to understand a woman's emotional state after finding out they are HPV positive (Waller, 2015) but little insight is exposed as there are little to no personal narratives that allow access to this information.

Research that focuses on the development of the first Gardasil vaccine creates an unclear and ineffective understanding its success. Recent studies exacerbate the importance of the vaccine and the implications of the virus, culminating with the fact that "60% of cervical cancer deaths can be averted by [the Gardasil] vaccine" (Promo & Fabio, 2013) and women who are "diagnosed with persistent HPV infection, [experience] higher levels of

anxiety about health” (Waller, 2015, n.p.) Additionally, it is consistently articulated that, “millions of adolescents and young adults [who have] not received the vaccine, will become infected and will experience physical and emotional consequences” (Daley et al., 2010). However, the research disregards the fact that the original Gardasil vaccine only protects women from four out of the forty strands of the HPV virus. When considering this collection of data we must ask what happens when we stress the danger of virus, but disregard the inadequacies of the vaccine? What about the psychological and social effects of the women who get both? Unfortunately, due to the rapid increase of HPV, positive individuals, and the implementation of the vaccine, these questions have been disregarded.

The next significant research that has been conducted considers vaccination programs in public education (Brown, Little, & Leydon 2009). Because the discussion circling HPV is obviously lined with sexual discourse, there is a huge concern that public education systems are facing. Not every public school in America has a sexual education program, and majority of stakeholders in public education hold a concern regarding the implementation of the vaccine in schools. Osazuma-Peters (2013) explained that even though almost half of ninth to twelfth graders in our nation are currently sexually active, there is a lack of comfort discussing sex to fully implement the vaccine into schools.

This lack of interest in communicating is directly correlated with the aforementioned literature review regarding sexual education. Thankfully, some of the current HPV research attempts to delve into the ways individuals not only talk about STIs, but also how media communicates information about HPV and the Gardasil vaccine (Gross et al., 2015). One study looked at the likelihood of physicians talking to 9 to 15 year olds about sex when they received the HPV vaccination. The study offered no specific findings, only that it is likely

this discussion would be had. However, there was little to no comment about the information that would be discussed (Askeslson et al., 2011). Another study addressed the insufficiency of the vaccine and viewed the ways health providers introduced new methods into the public. In his 2010 article, “Effective or ineffective: Attribute framing and the human papillomavirus (HPV) vaccine,” Bigman explains the efficacy of the vaccine during its implementation period:

A content analysis of media coverage of the HPV vaccine prior to its approval found that 20 (80%) of the articles reviewed did provide efficacy information about the vaccine. However, this information varied. About half of the articles gave vague descriptors like “successful” and “effective” to describe the vaccine, while the other half included percentages. A subsequent content analysis that included the time period in which the vaccine was introduced onto the market found 95% of news included HPV vaccine efficacy information. (p. 571)

Unfortunately, there is not a prevalent amount of research addressing the efficacy of the Gardasil 9 vaccine. However, this clearly illustrates that my concerns that HPV and the discussion circling it is laced with questionable intentions and exceptionally insufficient information.

Though I believe this to be one of the most important areas of research, there are only a few studies attempting to understand a woman’s emotional state after being diagnosed with HPV. A majority of the studies dealing with HPV have nothing to do with diagnosis, but have more to do with the decision to receive the vaccine. Miller-Ott et al. (2011) created a research study in which women participated in focus groups to discuss the HPV vaccine and how they made the decision whether or not to get the original vaccine. The article spends an

excessive amount of time discussing the role of social support. In fact, different types of social support were collected from data and further examined. Unfortunately, the sample did not identify who in the group had already received the vaccine and if it had been effective.

This collection of research is immensely lacking. Not only is the insufficiency of the original vaccine rarely discussed, but the ineffective communication that circles HPV and the general lack of social support is ignored. It is absolutely imperative to remember that the original Gardasil vaccine only protects women from two of the virus strands where the newest vaccine, Gardasil 9, only protects woman from five additional strands. This is the fastest growing sexually transmitted infection and there is little to no research provided regarding women who are diagnosed with the virus. This focus on the vaccine directly disregards the value of women and is a clear replication of the disregard society and medical professionals have of about women's bodies. Scholars need to acknowledge that though the implementation of the vaccine may serve as a role in eliminating the growth of this virus, disregarding the individuals it is directly impacting, and in some cases killing, is not going to increase the knowledge base needed to take action.

Theory

When scholars began to delve into the world of interpersonal communication there is no doubt that individuals were overwhelmed with the plethora of dyads that demanded analysis. Most of these relationships, rather familial or professional, are bound to evoke heightened emotions from one or both parties at some point in time. However, when looking at all of these dyads from a large scope, scholars may neglect specific aspects unintentionally, due to their intricate nature. Because of this, it is imperative that scholars

develop theories that assist in tightening this scope in order to show a closer, more in-depth look at these complex scenarios. This idea is clearly exhibited in the development of Uncertainty Management Theory, or UMT.

Dale E. Brashers developed UMT through the merging of two post-positivist theories: Uncertainty Reduction Theory, and the Cognitive Theory of Uncertainty in Illness. He found that together, the theories “neglect[ed]...ways of managing uncertainty” and was only studied “in the context of interpersonal communication related to illness” (Braithwaite & Schrodt, 2014, p. 104). However, when individuals are experiencing uncertainty specifically related to their health or well-being, they begin to partake in coping mechanisms that may not always be negative. As such, UMT was created with an “emphasis [on] the human inclination to anticipate consequences of action in terms of both their likelihood of occurrence and their desirability” (p. 104). This is because “when behavior is under our conscious, willful control, we choose...actions [that are] believed to be more likely to result in positive, rather than negative, outcomes” (p. 104).

To better understand the intention of UMT, I will review and discuss current research. As such, there must be an analysis of previous studies that used UMT to solidify scholars’ understandings of different types of relationships. Therefore, to maintain the objective of UMT and ensure that the scope in which these articles are viewing dyads remain focused, the upcoming articles will revolve solely around medical and health studies within interpersonal communication because “the most frequent thrust of research guided by the theory is developing descriptions of the ways in which people actively manage uncertainty, typically in the context of substantial illness” (p. 106). This will also offer greater insight into the ways individuals handle uncertainty when being diagnosed with HPV. After reviewing five

research articles, similarities between the studies will be discussed, followed by analysis of method, limitations and weaknesses, and a final evaluation of the theory and its association with HPV and this research study.

The obvious impact that the Internet has on information-seeking tendencies must be immediately addressed. Though there are overabundances of avenues individuals can take while seeking health-related information, it is no surprise that the Internet is the most convenient. As such, the following studies will address both internet-based inquiries, and person-to-person communication. After delving into broad studies addressing information-seeking tactics, more specific inquiries will be examined.

Stephan A. Rains (2014) examined the ways in which college students broached difficult topics such as cancer. Participants were asked to explain how they go about seeking health related information. They were then split into groups based off of how they obtained knowledge. These groups included information from, “friends, family members, doctors, nurses, or other health care providers, magazines, newspapers, television, brochure pamphlets, [and] the internet” (Rains, 2014). The study was meant to, “predict an interaction between cancer information-seeking behavior and desired uncertainty about cancer prevention for actual cancer-prevention uncertainty” (Rains, 2014).

Participants completed a web-based survey for each group and were asked to self-assess their experience using the Internet to acquire health-based information. The results suggested that, “there was a significant interaction between Web use and desired uncertainty for respondents’ actual level of uncertainty. The association between desired and actual uncertainty was significant for Web users, but not significant among respondents who did not seek cancer information” (Rains, 2014). This inadvertently supported Rains’ hypothesis that

an individuals' desired level of uncertainty about cancer prevention combined with their information seeking-behavior will result in a better understanding of their actual desired uncertainty.

Rain completed another study with Riva Tukachinsky, titled, "An Examination of the Relationships Among Uncertainty, Appraisal, and Information-Seeking Behavior Proposed in Uncertainty Management Theory" published in *Health Communication* in 2014. This study, though also surrounding cancer, was specified to skin cancer and examined the ways in which undergraduate students used search engines when seeking information. A program was used to collect data while they were searching. Once the data was reviewed, Rain and Tukachinsky began looking for common themes. Afterwards, an individual whose search tactics suggested a high level of uncertainty were asked to reflect on what it was they were feeling uncertain about. Rains and Tukachinsky explained that:

Respondents who reported desiring higher levels of uncertainty also reported appraising uncertainty as more of an opportunity and less of a danger, while those who reported desiring lower levels of uncertainty appraised it less as an opportunity and more as a danger. The connection between desired uncertainty and appraisal intensity demonstrated in this study is important [because]...little empirical research has been conducted to examine the appraisal process in UMT. The findings from this study contribute to theorizing about UMT by demonstrating the connection between appraisal and uncertainty. The results are consistent with the argument made in this project that, drawing from Lazarus's (1991) ideas about appraisal, desired uncertainty represents one's goal in regard to uncertainty. As such, knowing one's desired level

of uncertainty makes it possible to determine how one is likely to appraise uncertainty in a given context (p. 347).

This is crucial in the development of UMT because the foundation of the theory suggests that the ways in which individuals identify with their uncertainty will also determine the coping mechanisms they use to manage said uncertainty. Unfortunately, the theory itself becomes criticized in this study as it does not, “[distinguish] between actual and desired levels of uncertainty [that] is meaningful” suggesting, “it may be that only desired level of uncertainty is critical to the appraisal process” (p. 348).

The next study, though still utilizing the Internet as a form of analysis, also combines UMT with a different theory: Sense of Virtual Community, or SOVC. In this study, published by *The Iowa Orthopaedic Journal* in 2013, authors Florin Oprescu et al. collect data from parents of children with clubfoot regarding the communities they build online that are intended to play the role of a support system. Participants took a standard survey and were asked to analyze the level of uncertainty they experienced related to seeking information about clubfoot online. The survey collected the following measures: uncertainty, stress, knowledge, information-seeking behavior, perceived social support, and sense of virtual community. Unfortunately, most of the hypotheses were not met, “suggest[ing] that the UMT needs to be adapted for use in online contexts. One way is to include theoretical constructs (i.e., sense of virtual community) specifically developed to measure online interactions” (Oprescu et al., 2013). This criticism directly suggests that the use of UMT can obtain further credibility when associated with an additional theory.

Though this criticism implies a glitch in the use of UMT, it seems to only be prevalent in quantitative studies that use the Internet as a primary source of data collection.

Keisa Bennett et al. utilized UMT in an empirical study published in 2014 in *Qualitative Health Research* titled, “Vitamin D: An Examination of Physician and Patient Management of Health and Uncertainty.” The researchers collected data from two different groups: providers and patients. Patients were selected at random, and providers were selected from specific counties where the patients resided. Each group was asked open-ended question in order for themes to come to fruition regarding Vitamin D intake.

The study, though intended to garner an understanding of how uncertainty affects interaction between patients and providers, resulted in a further expansion of how the internet affects information-seeking habits:

In our study, both the providers and community members expressed significant uncertainty about vitamin D. These uncertainties affected the ways in which they communicated. In efforts to manage uncertainty, health care consumers actively sought more information about vitamin D from experts, friends and family, the Internet, and other media. Although PCPs wanted their patients to be proactive in their own health care, providers also expressed frustration with patients bringing in beliefs about vitamin D garnered from popular media and Internet sites. Providers nonetheless also admitted that they commonly used the Internet as a primary source of information. (Bennett et al., 2013, p. 206).

This observation, though expected from the previous studies, may be an insight into the ways in which UMT can be applicable to future studies. However, the focus group did attempt to address concerns that awareness only increased an individual’s level of uncertainty, and media did not provide information on how to cope with said uncertainty (Bennett et al., 2013). This ultimately suggests that though participants are being affected by mass media,

they are also acknowledging the negative effects it has on information seeking. Together, the uncertainty shared between providers and patient contradicts one another ultimately making it difficult to efficiently communicate accurate information about Vitamin D.

The final study used UMT through an analysis of recordings that women had with a genetics counselor and a physician regarding the breast cancer gene, or BRCA. In their study, “Sources of Uncertainty About Daughters’ Breast Cancer Risk that Emerge During Genetic Counseling Consultations,” published in *Journal of Genetic Counseling*, Carma L. Bylund et al. reviewed interviews with 17 mothers to better understand their level of uncertainty discussing BRCA. The three themes that were considered “sources of uncertainty relating to their daughters” (p. 295) were disease risk, cancer screening, and the way information was communicated to their daughters. This study was the first to pull away from the Internet as a form of information seeking and focused solely on communication between two specific participants. This was satisfying because UMT focuses so much on health communications that scholars’ patient-doctor communication would be at the forefront of analysis as opposed to the use of Internet.

Regardless of its importance, limitations of the study were present. The most impactful limitation Bylund et al. (2011) discovered was the fact that the uncertainties that daughters felt were provided by assumptions that the mothers had as opposed to the daughters themselves. Perhaps, UMT could have been used to further understand more dyads, focusing the lens of analysis even further. Additionally, because the study focused on uncertainty that the daughters may have felt instead of the mothers’ uncertainty, the understanding of a specific relationship becomes extremely limited.

After reviewing each article, it is clear that UMT is a theory that offers scholars an opportunity to form stronger understandings of specific relationships. However, one of the most prominent similarities is the fact that the theory does not need to be used when analyzing these specific dyads directly. Meaning, the first three studies discussed analyzed the relationship an individual had with himself or herself as opposed to someone else. This, though moving away from interpersonal communication and into intrapersonal communication, ultimately suggests that the theory not only focuses on a lens of analysis, but also can be applicable to a plethora of different mediums. Because the other two studies dissected an individual's level of uncertainty between themselves and their providers equally, it is clear that the versatility of UMT will better assist future scholars.

When considering the different avenues of research, it seems as though there is no specific style that suits UMT. However, in the aforementioned study, Rains did suggest that UMT should be combined with another theory that allows an alternative lens. This idea could have potentially enhanced the other theories as well. Because uncertainty management is something that an individual endures, keeping it in the realm of interpersonal communication, or any specific medium, may require an additional theoretic approach to ensure topical analysis. Regardless, it seems that both quantitative and qualitative studies reaped benefits from using UMT as its foundation.

The theory's limitations fall into the fact that an individual's level of uncertainty is ever changing and relatively ambiguous. Though these studies offer an insight to better determine the desired levels of uncertainty for an individual, it was clear in both of Rains' studies that participants' level of uncertainty altered with the course of action they took to manage it. Furthermore, participants in the Vitamin D study directly stated that seeking

information only heightened their level of uncertainty. If individuals desired level of uncertainty is constantly changing, than their ability to manage that uncertainty will also change. Additionally, in the realm of interpersonal communication, UMT would benefit more when paired with an additional theory, as suggested by Oprescu et al. (2014). Though the theory itself offers better understanding about the way in which one person may communicate in times of hardship, having another theory applied to a study will assist in understanding the dyad that would be affected by an individual's level of uncertainty.

Overall, UMT offers an alternative understanding of how individuals handle difficult situations. It, “recognize[s] that, when a person is certain that her or his situation is bad, communication creating or sustaining uncertainty can offer hope” (Braithwaite & Schrod, 2014, p. 108). After reviewing the five previous studies, it is clear that UMT may not be applicable for every type of research or may require an alternative theory to assist in specific investigations. However, its versatility is a huge benefit for scholars. UMT can provide a narrowed lens that can easily blend into a plethora of different mediums, ultimately enhancing the effect of research not only in the medium of interpersonal communication, but all fields.

UMT will be applicable to this study because of its versatility in addressing the current disconnect individuals are facing when being diagnosed with HPV. First, UMT is clearly relevant to health communication: Not only because its foundation considers illness, but also because majority of the studies that successfully use UMT provides patients and doctors with a grounded insight regarding uncertainty and management. Furthermore, because the reviewed articles suggest a vast versatility to the theory, it will serve as a healthy

foundation to this study since the research is both qualitative and regards information-seeking and interpersonal dyads.

Next, UMT will assist in better understanding the current disconnect individuals are facing when being diagnosed. The rhetoric that circles HPV is lined with urgency and fear. However, due to the nature of the virus and the fact that, in most cases, it will become dormant, a disconnect is created between the ways in which individuals handle diagnosis and the ways in which health care providers talk about it. Denying the Gardasil 9 vaccine has become nearly taboo. Parents are encouraged to believe their child will be diagnosed with cervical cancer at least once in their life if preventative measures are not taken. However, once an individual is diagnosed with HPV, it is often treated as an expected and common problem. This is an example of the aforementioned hyperbolized normalization. Because of this oddity, an individual's level of uncertainty will likely fluctuate throughout the treatment process. Uncertainty Management Theory offers a better understanding of how patients can be provided with better coping mechanisms on a physical, mental, and emotional level.

Method

The best way to understand autoethnography is through its name. “Auto” means to provide a personal experience, “ethno” suggests that it provides a better understanding of specific cultural experience and “graphy” suggests a strategic or systematic analysis of research (Ellis et al., 2011, p. 275). This relatively new form of research was developed when scholars began to consider the impacts that personal experience had on theories and understanding. Additionally, when acknowledging that everyone has a different experience and thus a different view of the world, it became obvious that there was a need for research that allowed us insight into these personal narratives. Carolyn Ellis, a Professor at the University of South Florida who is known for her autoethnographic research, has explained that because majority of the individuals “writing research are advocating a white, masculine, heterosexual, middle/upper-classed, Christian, able-bodied perspective...researcher[s] not only disregard other ways of knowing but also implies that other ways necessarily are unsatisfactory and invalid” (p. 282).

There are two areas relevant to understanding the credibility revolving around autoethnography: the narrator's credibility and the way in which other scholars view the style as a whole. To start, when using this style of writing authors need to consider various elements that impact their connection to the subject as well as their ability to get readers to connect with it. Essentially, the way individuals look at “truth” must be pre-determined to create credibility (Ellis et al., 2011). In addition to this, participating in evocative writing requires authors to consider how every choice they make creates a metonymic style that allows a genuine insight into specific cultures (Pollock, 1998).

This form of credibility needs to be defined, as it is the primary criticism that the style of research faces. Many autoethnographies are dismissed because they are deemed not “scientific” enough or too “creative” to be considered legitimate research. Ellis has suggested that there is a huge divide in the communication field in which autoethnographers are sometimes even considered vain and narcissistic to partake in research that is clearly biased (Ellis et al., 2010). However, Ellis further argued that this perception is exactly what autoethnography is trying to combat. If we are able to eliminate the divide between science and art, perhaps our findings will be more reachable to society and general public and thus, more impactful as a whole.

As previously suggested, the human papillomavirus has become so common that infection is virtually expected. With the hyperbolized normalization of HPV, it is imperative to delve further into different voices of individuals who experience these implications first hand. A majority of the studies, as I examined in the previous sections, considers the vaccine and how individuals make decisions relating to their sexual health. However, there has yet to be a personal narrative addressing the insufficiency of the vaccine and the impact the virus has on young women in today’s society. Therefore, because autoethnography allows others to explore elements of someones social lives in a deeper manner, it will be the foundation of this study. Though this form of research is often lined with questions of validity and ethics, the need for this style is pertinent in further developing the reach of communication and will be specifically helpful to this study. As someone who has been dealing with the implications of HPV since 2013, even after receiving the Gardasil vaccine in 2007, I hope to investigate the avenue of research that has been obviously avoided the past ten years.

In effort to best establish the use of autoethnographic research in this study, I will replicate two previously published pieces of work that emphasized the use of emotional and evocative writing. Sara L. Crawley (2002) explains that by “using autoethnographic scenes from...lived experience” she is able to truly articulate her personal experiences and how they have affected her way of life. This method will allow me to expose the most important parts of my journey with HPV the past year and a half. Similarly to Weaver-Hightower (2011), I “seek to tread a fine line between the analytic and evocation registers of autoethnography...[by] mak[ing] myself visible explicitly in the text and reflexive about this participation”(p. 463). To involve myself in my writing the same way Weaver-Higher did would clearly be beneficial to the purpose of this study since there is limited research addressing personal experience.

In order for this autoethnography to be effective it must be clearly divided into specific elements. Therefore, I will be breaking the entire piece into three different sections: school, sex, and HPV. In each of these section there may also be further subsections that attempt to split it up into specific moments that allow insight for the reader. For example, when looking at school I will provide an overview of my educational experience when it came to understanding sex and offer insight into both school-0based sexual education and discourse, whereas when discussing sexual experience it will be broken down by partner and will provide a further analysis of discourse and how viewing the topic of sex as taboo directly effected my agency. Finally, all of these themes and developments will be applied to my experience with HPV and how it affected me on a physical, mental, and emotional level.

This breakdown will hopefully allow me to evoke an emotional connection to my readers regardless of their relationship with HPV. Meaning, if an individual has never been

diagnosed with it, perhaps they will be able to relate to the effects that school-based sexual education had on me. After all, the human papillomavirus affects everyone who is sexually active. The more people are able to understand other experiences, the more likely our health providers can offer support in handling this virus. On a more specific note, I want to be able to provide individuals who have gone through the same experience as me comfort in knowing that they are not alone. I spent two years being told two things: I needed to protect myself from being diagnosed with HPV, but once I contracted HPV, I was told that I would be fine. This confusing synthesis threw me into a state of anxiety and depression that I hope I can help other individuals avoid or alleviate.

Research

In order to truly understand the effects of HPV on adulthood, an analysis of background and experience must be explored. As such, the only way to provide an accurate understanding of my mentality when going through HPV treatment, we must first look into my experience with school-based sexual education and my understanding of sex itself. This will allow readers to better understand how the construction of agency can be altered via individual experience as well as provide accurate insight into the psychosocial effects of HPV. As such, this autoethnography will attempt to best answer the following research questions:

RQ1: To what extent did school-based sexual education (c. 2000 – c. 2006) effect an the author's perception of self, sex, and sexually transmitted diseases/infections?

RQ2: In what ways do an individual's sexual activity and ability to discuss taboo topics with partners reflect on her education? Furthermore, what does this engagement reveal about said individual's sense of self and personal agency?

RQ3: When considering the impact of sexual education and sexual experience, how does the diagnosis of the Human Papilloma Virus, even after the necessary precautions, impact an individual on a personal and social level?

RQ4: To what extent do the recent changes in the gynecology field benefit or hurt individuals who were previously diagnosed with HPV or who will soon be diagnosed with HPV?

Though each research question is directly impacted by various outside elements, using them as a foundation for this autoethnography will only further solidify its credibility. As such, consider the following piece of research a desperate attempt to offer scholars, students, and doctors insight into how utterly traumatic insufficient understanding and exposure can be, not just to individuals, but entire communities of people.

Part 1: School

We talked about sex for the first time when I was in the sixth grade. I don't remember much about this day other than the fact that the boys and girls were split up into separate rooms. I remember wondering what the boys were learning about. I spent a significant amount of time confused as to what they could possibly be discussing that the girls could not know. It seemed like a secret club...of penises. And there I was, sitting in a room full of vaginas, still pretty grossed out by the whole monthly bleeding thing. At the end of the

lesson, the boys and girls came together in one room and were told that we were going to watch a movie. How exciting! Everyone knew that movie days were the best days, right?

It only took about three hours to stop crying after watching *The Miracle of Life*. I spent the next few lunch periods trading Barbie Dolls for snack packs, avoiding sitting next to boys, and being semi-afraid of my own vagina. All things that seemed completely reasonable at the time. Aside from the oblivion and fear, there is one good thing I remember about this day: Mr. Colliton. This was my sixth grade homeroom teacher, and the only person I saw after watching a live birth for the first, and thankfully, last time. A few other girls and I must have looked like walking question marks. One by one we each started to reveal a concern, attempting to understand our bodies in our own way but failing tremendously. This is when Mr. Colliton drew a vagina on the board. He labeled each part and explained one more time how our bodies worked. I left this discussion having developed two truths: 1) My body is pretty cool. I can make life. That's pretty impressive! 2) Clearly, boys don't think that my vagina is scary! I mean, if Mr. Colliton can talk about it, that means that the other boys can talk about it too, right?

The first truth held its ground through high school. The second truth crumbled to ashes the first time I witnessed a boy's facial expression when my tampon fell out of my purse in the hallway. It was the first time I felt ashamed of something that I had absolutely no control over. Mr. Colliton's educational speech was definitely not a reflection of an entire gender, and boy was this going to be difficult to explain to people the next few years.

In high school, boys and girls did not get split up during Sex Ed. Instead, I had to sit right next to them. Aside from feeling horribly uncomfortable, I also do not remember much from the lessons. We spent most of the semester talking about drugs. Whenever we talked

about STDs the discussions typically included a ridiculously intense image projected on the board followed by some horrible story about someone no longer being accepted in their community, or, even worse, dying. Sometimes teachers explained the difference between a deadly disease and one that could be cured, but very rarely did they explain how. The one thing that started changing that year were rumors. Everyone knew that Whitney had “The Clap” (even though most of us didn’t know what that meant). It became the biggest conversation in the hallways. People couldn’t help but think of the pictures we were shown and compare those to now. I never heard what Whitney had to say about this, but I remember that she switched schools a year later.

We spent the rest of the semester learning how to say no. We never discussed what to do when we wanted to say yes. I could only talk to my much older, much wiser step-sister (who was actually in the same grade as me). I remember walking home from school one day and me talking about how scared I was to start fooling around with boys. She claimed to have already given someone head (a term that I did not know at the time). When my facial expression suggested disgust, she immediately digressed, stated that she *obviously* had him wear a condom when she did it. When she felt satisfied with my non-verbals, she moved on from the conversation. It wasn’t until I discovered porn a month later that I realized she was lying. No one used condoms. Ever. Regardless of the minor feeling of deception, I was grateful for Noel. It’s not like I could talk to my teachers about this kind of stuff: They would just tell me it wasn’t school appropriate.

I took my ninth grade health class the same year the Gardasil Vaccine was released (2006), but learned nothing about HPV. I remember leaving the class feeling afraid of what I had done. At this point, I was still a virgin, but had been very sexually active with two

people. I remember coming home from school one day freaking out about every scenario that was possible. What if I still wanted to fool around with my boyfriend? What if he cheated on me? What would I do if I caught one of those disgusting diseases I had been shown so frequently in class? What if I was the next Whitney? The state of mind threw me into a loop of anxiety and concern. I had trouble focusing, I couldn't communicate to my friends, and I grew extremely questionable of toilet seats and whether or not I could get a disease from going to the bathroom. It was a difficult time. And it was made even more difficult when my boyfriend and I broke up a few weeks later. I guess he didn't have the same concerns that I did.

I was stuck in a state of puberty that I was forced to believe was wrong. My hormones were controlling my body, but my teachers were controlling my mind. Anything that I thought about quickly turned into a "what if" scenario. The stress only made the already awkward teenage years even more embarrassing. I was self-conscious, insecure, and getting acne by the minute. My mother quickly acknowledged this change in me and, to help out, decided to make a dermatologist appointment. Perhaps, being able to combat one of the problems would at least make the others more tolerable.

I was so grateful. I felt like clearing up my outside would help clear up my inside in a way. It was an illogical thought process, but a predominant one at that. The dermatologist asked me a bunch of questions about my daily routine, my current face wash, and even my period. This last one stumped me. I never associated my cycle with my skin. That is, until this day. After careful deliberation, the doctor decided that the best course of action would be to put me on birth control to regulate my hormones, reduce my current state of acne, and open me up to other options such as Accutane that require women to be on birth control

before beginning treatments. The next day, my mother made me an appointment with her gynecologist. I spent all afternoon calling my friends and asking what it would be like and what I should expect. I was terrified to go to the office and imagined it to look nothing short of a haunted house. Eventually, my friends were able to talk me down. They reminded me that this is something that every woman has to do and I may as well get it over with now.

Then came the appointment. It was the first time I would meet Doctor Dimagio, and also the first time Doctor Dimagio would meet my vagina. It's weird introducing your vagina to someone on a platonic level. There is a strange combination of wanting to provide a satisfactory first impression while simultaneously attempting to keep it professional. Shaving my legs and using a toe nail polish I thought screamed "responsible adult." I hopped into my mother's car, and sat patiently in the passenger's seat until we arrived.

Dr. Dimagio was a terrifyingly blunt Italian woman. She burst through the door, tossed her clipboard on the chair, began washing her hands, and paid little to no attention to me. Other than her intimidating presence, the only other things I remember were the stirrups. No one prepared me for this. My teachers did not tell me what a pap smear was and my family did not tell me what to expect. I spent all day prepping to be in what I thought was going to be the most vulnerable position ever. Dr. Dimagio must have sensed this feeling as she quickly readjusted her presence, sat next to me, and assured me that I would not be getting an exam today. I exhaled and immediately felt safe in her presence. She asked me if I ever had sex before, and when I said no, she congratulated me on being *responsible*. She quickly wrote a prescription for birth control and attempted to answer any questions I had.

Right when I thought I was safe to go, Dr. Dimagio asked if my mother or I had heard of the Human Papillomavirus. After extensive discussion and elaboration on the Gardasil

vaccine, my mother, who is a nurse, immediately decided that I should get the first of three shots that day. Suddenly, my fear of being vulnerable was quickly replaced for my general fear of needles. I did not have much say in the decision and was generally unsure how to feel. Dr. Dimagio made it sound like this shot was the key to not being the next Whitney. It was the way to get rid of my anxiety about STDs. It was the key to being an adult. She gave me the shot; I blacked out (per usual for me) and woke up to crackers and apple juice.

This was the perfect introduction to adulthood.

My step-sister began birth control at the same time. When we got on to the bus the next day, I felt different. I felt like people were looking at me. I felt like everyone knew that I was an adult. I was protected from a really common STD, I was not going to get pregnant, and...my bras finally required some kind of underwire. This was it. This was womanhood. I put my headphones in and slipped into a daydream of everything that would come. When we got near our stop, I turned off my music and turned to my friends to see what they were talking about. The first thing I heard was someone loudly ask, "Jamie, you're on birth control too!?" It took seconds for all eyes to be on me. I was shocked. My jaw laid slightly ajar as my eyes averted their attention to Noel. She was sitting in her seat with a huge grin on her face. Apparently, she thought it was *so cool* to be on birth control that she decided to tell everyone. I shamefully nodded my head up and down and slipped my headphones back in without turning on the music. I stared out the window and listened patiently to what they had to say about it. My eyes began to water as my peers ruthlessly announced all the things I was bound to do now that I was on *the pill*. When I walked off of the bus, I felt a constant buzzing in my head.

My breath heightened as my speed increased.

By the time I got to the front of the bus, the word *whore* zipped through my ear at least three times. I still do not know who said it: Them, or me.

Part 2: Sex

Foreplay

In the fifth grade, my mother accidentally bought me a Manga comic book filled with breasts and suggestive content because she was too busy tending to my brother who was pelvic thrusting his way to the teenage girls on the other side of the mall. When my mother finally realized what she had bought me, she was devastated; I was enthralled. I would spend hours reading the stories, fantasizing about situations, and making my Barbie's play lesbian under tented hardcover books. I never told my mom. Even though sex was a part of our culture, it was never a part of our conversation. As a kid, this worked for me. However, because "culture is a verb, a process, an ongoing performance, not a noun or a product or a static thing" (Denzin, 2003) I would ultimately have to have this conversation with someone, which was terrifying.

After reviewing the literature on slut shaming and sexual education, it came to my attention that very few scholars focused on the negative stigma associated with sexual communication. The following is a collection of sexual encounters broken into parts. Here, there is a focus on communication and virginity in hopes to establish a better understanding of my personal experience and how it contributed to my journal with HPV that will be dissected later.

Doing it: In 6 Parts

I. Sex was weird. It was this thing I only participated in when someone invested enough time in me to justify it. As if their time accrued enough interest to afford my body. There was no climax, I learned nothing about myself, and there was absolutely no talking about it. I spent years playing the role of silent vessel, only asking questions when criticized. Only enjoying myself when someone else was enjoying me. I spent ten years of my life doing this. There was no exchange. There was very little understanding of how the currency worked. In the end, they were the ones having sex, and I just happened to be there.

II. I was fourteen years old when I found myself naked in my boyfriend's bedroom. His grandmother was cooking spaghetti in the basement and every pang of the pans reminded me of my own grandparents. It was ridiculously awkward. Tommy and I had no idea what we were doing, but we did it anyways. We spent two years almost having sex: Acting like we understood the stock market, but never fully investing. It was a constant state of pulling-out.

The first time he asked about sex, I panicked, acted like it was a joke, and continued eating my spaghetti.

We broke up a week later.

III. The day Derek gave me a ring was the same day my mother got diagnosed with breast cancer. I was a seventeen-year-old enigma, morphing between bliss and terror in a matter of seconds. When I got to the hospital, the room was stale, the newly shined silver on my finger refused to glisten, and the silence was deafening. I remember my mother acting like she was okay. I remember my brother hugging me. I remember being the youngest person in the room. I remember getting in my car and driving thirty miles to Derek's house. I remember thinking that it was only rain; that I never once cried.

When I got there, we didn't say anything. We just fucked. My body was a silent auction, and my virginity was too loud of a guest. I wanted it to be quiet.

IV. Ryan and I had sex in the back of his father's pick-up truck behind the local Kroger. I had to bend my neck just right for it to work, but would always end up banging my head on the door. We jumped every time we saw headlights, laughed, and continued. His chuckle played the role of unspoken affirmation, assisting with every awkward thought I refused to say out loud. Afterwards we would stay up until four in the morning talking about everything else. We found comfort in foggy windows. Sometimes he would rub my neck. This was our way of talking about it.

V. After five years and two partners, I found myself on the floor of my parents' living room. This was the first time I had sex when I knew I did not want to. It started with hesitation, wondering what would happen if I said no. I spent too long weighing his reaction. Halfway through and I decided to accept his purchase, to solidify his investment. I could not provide him with any return policy or warranty. He was being gracious and I was to accept the offer.

When he asked if I was okay, I said yes.

It was the first time I talked about sex in five years.

VI. We had been memorizing each other's creases for about two months before he asked me about sex. It was mid-afternoon on a Sunday, minutes before my three and a half hour drive home and we didn't make any eye contact. We both just kind of smiled. There are not a lot of cool and collected ways to respond to, "how do you feel about sex?" except, of course, with incoherent babble, which, lucky for me, was my default state. My irresponsible mouth was met with his comfort. I was fully clothed on a futon in the middle of Ohio and had

no idea where I was. Two weeks and three conversations would pass before we had sex. It was hard, it was uncomfortable, but we did it. We had a conversation. This would be the first time I was truly satisfied.

Climax

It took me 24 years to talk about sex. It was fragmented, awkward, and borderline incoherent, but I did it and that was the important part. Similar to Sara L. Crawley's experience with writing her autoethnography, "They Still Don't Understand Why I Hate Wearing Dresses!" An Autoethnographic Rant on Dresses, Boats, and Butchness" I also feel that this method allowed me to bring to life a "story [that] is not so much about me as it is about the experience of gender and sexuality in...America" (Crawley, 2002, p. 71). I always thought that individuals who talked about sex would have a healthier sex life. However, upon reflection I realized that at no point was I dissatisfied with my relationships; I was merely disconnected from myself. By not engaging in these hard, taboo-filled conversations, I was not able to understand my needs as an individual as well as my partners. Additionally, satisfaction ultimately limits the ability to grow. In essence, the desire to improve will not surface through feelings of contentment, even if improvement is needed. It was not until I truly reflected on my role in this exchange before I realized just how costly the negative stigma was. It is the after-sex haze, the deep exhale after months of panting, the state of being honest in your own skin that truly gives us insight to our own worth.

Part 3: HPV

The following is a review of my experience with HPV. In order to provide a clear understanding of each step, I separated it into specific parts that were the most influential to me during this journey. Though some of these moments may seem like strange elements, it is imperative to remember that these are the only times in which I felt the most affected by my diagnosis.

The Dentist

I hate the dentist. I've spent five years refusing to get my teeth cleaned after a run-in with an orthopedic surgeon that did not end well on my part. But here I am, reclined in a plastic chair, staring at tools that should only be seen in one of those really shitty horror flicks. I'm due for x-rays and the nurse is attempting to keep my mouth shut for at least 10 seconds, so she can get the picture. My gag reflex is refusing to cooperate, and the general disinterest in shoving a plastic stick in the back of my mouth is not helping either.

She starts the typical sales pitch; reviewing the new cheap fluoride routine and the chance to win a free teeth-whitening packet. She begins her final sale, "If you're interested, we are doing cancer screenings this month. It's a five-minute procedure and won't cost much. Would you like me to get that set-up for you today?" She says this with a sweet, optimistic tone.

I check the clock. I've already been here for ten excruciatingly long minutes and I can feel my Netflix getting jealous of my absence. I tell her I can't today, and ask that she remind me next time. She turns to face me directly, waits to take the clipboard from my hands and says, "this screening could detect signs of cancer that stem from HPV. You know, the Human

Papillomavirus? It's really common in women your age. If you have it, you may want to complete the screening.”

She sounds less sweet this time. More irritated. She stares at me for what seemed like forever. My heart sank. It felt like the chair was tightening around me. I did my best not to react. I did not want her to see the results of my last pap smear exposed from my expression. I shake my head “no” and hand her back the clipboard. I spent the rest of the visit trying not to cry, trying not to fall apart in public.

This was the first time I had ever fit perfectly into a statistic. The first time “whore” and “cancer” were synonymous. The first time I realized that HPV is not going anywhere. I left the office feeling like nothing more than a walking percentage sign. I sat on my couch and checked my calendar. It was only December.

I would have to wait three more months before I knew if I was going to be okay.

The Phone Call

Three months before the dentist appointment I had been diagnosed with the human papillomavirus. I was at work when I got a phone call from my gynecologist. She left me a voicemail and asked me to call back as soon as possible. I was immediately concerned. I never had a problem with a pap smear and was terrified to think that something could have gone wrong. I called back on my lunch break only to find out that they were closed. I had to teach two more classes before I could get any kind of confirmation as to whether or not I was okay.

That particular day I was holding auditions after school for our competitive speech team. I would be seeing over fifty potential competitors and I needed to be focused the entire

time. Once my classroom was empty, I called the office back and hoped that there was just something wrong with my insurance, that I left something in the lobby, or even that they lost the swab and just needed me to re-do it: anything but a problem.

When the nurse told me that there were signs of HPV on my last pap smear, my heart dropped. I was thrown into the same state of panic that I was used to feeling in middle school. Because of that, I did exactly what a middle-schooler would do: I looked for the counselor. Kathryn was not just a co-worker, but also a friend. I stumbled into her office teary-eyed and confused. I did not understand what was happening to my body and for the life of me could not process what this meant. She did everything she could to calm me down before having to go to auditions. Once I felt like I could control myself, I went back into my room collected my papers, and did my best to focus on the silence. I knew that this would be the last time I could hear it for a while.

The Telling

My boyfriend at the time was an asshole. He was emotionally and mentally manipulative, boarder-line abusive, and, in general, scum. All of which are complete understatements. The only thing I knew when I left work was that I didn't want to do this alone and there was no way I could do it with him. So, I called my mom. This was potentially one of the most difficult things I have ever done.

My entire family hated my boyfriend (reasonably so), and this would only served as further ammunition. I remember trying my best to hold it together, but I eventually had to pull my car over because I could not stop crying. I remember being scared that my mother did not know a lot about HPV even though she was a nurse. The only thing she could really

tell me was that my sister and my aunt had both been diagnosed with it. She managed to hold it together and be my support system, but I found out later that it took most everything in her power to not break down as well. Blaming my partner was the first thing we both wanted to do, but the last thing we wanted to admit to.

Near the end of the conversation my mother asked if I knew what was going to happen next. I had already called my doctor a few times with questions and felt too embarrassed to call again. She encouraged me to look it up, but the only thing I could think about was all of the pictures they showed me in health class. I was horrified to see something scary or, more importantly, real. My mother offered to do the research for me. This would not be the first time I refused to answer my own questions.

I eventually told the person I was dating. He got mad at himself and then took it out on me. There was a day I felt desperate and I ended up calling him at two in the morning because I was scared. He came over out of frustration and stuck me in a corner between my fear and his fist. The only other thing I remember about the night is the smell of burnt rubber as he drove away.

He was the only person I did not use condoms with, even though I wanted to.

It is still hard to not blame him for everything.

The Process

My doctor tells me I need to come in as soon as possible. She tells me I have to get a colposcopy, which is described as “a longer pap smear.” When I got there, they remind me of the probability that I will be fine. They said that this is just a precaution; something they have everyone do. In six months, I would come back for an actual pap smear and there will be a

ninety percent chance that everything will be normal. Every time they tell me this, I feel the weight of that ten percent on my chest.

Everything feels normal as the chair reclines. It feels like the same procedure I was used to having every single year. When my feet go in the stirrups they tell me I will “feel a slight pinch” and suggest that I slow my breathing. This would become the single moment my body would refuse to forget. This is the first time I asked my mother to come with me since I was seventeen.

This was nothing like a normal pap smear.

The entire process took ten minutes. A normal pap smear takes less than twenty seconds. I had never felt so violated. I spent majority of the evening crying. There was a constant pain in my abdomen, a pulsing reminder that screamed *impurity*. I felt incredibly broken.

The next part is hard to explain. Not because it is deep or emotional. Not even because of some difficult-to-understand science. The first time I tried to explain this moment in text it was too specific, too gross, too detailed. Whereas the second time I tried to explain it, I left my reader confused with ambiguity. I think it is hard to explain because I never expected it.

The doctor never explained to me what a colposcopy was. I learned later that they took a biopsy of my cervix. A biopsy includes scraping my cervix to get a sample for testing. When part of your body is scrapped, it develops a scab that eventually falls off. I was not prepared for this. When the scab of my cervix fell off, it came out as something the doctor referred to as an odd *discharge*. But this was not a discharge. This was literally a part of my body I saw floating in the toilet. It was terrifying. I remember worrying that something went

wrong. I remember wondering if I had a miscarriage. I remember walking out into my sisters' living room, shaking.

I wish this were the last time it made me shake.

The next morning I called the nurse in a panic. She tried to comfort me and admittedly, this did work the first time I called. The third time, she was less sincere. When I asked more questions about the virus, she just brought up the vaccine. When I finished her sentences she sounded shocked. After she reviewed my records she stopped taking my phone calls.

The next time I saw her, she stressed the importance of condoms.

This was the only thing she had left to give me: blame.

Six Months Later

Three months after the dentist appointment, after almost forgetting that all of this existed, I found myself reclined in the same chair I got the colposcopy in. I was here for a normal pap smear. The only difference was now I had to get one every six months until I received four normal pap smears. This is what they did to those infected.

This marked a pattern of crying my doctor was not expecting. When they were done with the procedure I found myself in the fetal position in the corner of the room reliving the colposcopy. I felt as vulnerable as the time I had sex when I did not want to. It took twenty minutes before the doctor was welcome in the room.

The first thing Dr. Dimagio did was comfort me. The comfort turned into unsolidified logic, which ended in a frustrated affirmation. She realized that nothing she said was helping me. This is when she decided to revert back to the statistics.

Ninety-percent of the time it turns out fine.

Ninety-percent of the time it turns out fine.

Ninety-percent of the time it turns out fine.

This became my new mantra for the next seven days.

Seven days later, the doctor called me.

I wasn't fine.

I was still one of the *infected*.

They told me to come back again in six months. As I was leaving, she put her hand on my shoulder and offered me the same statistical security:

Ninety-percent of the time, it turns out fine.

Right now, I just happen to be a part of the ten.

The Explaining

When my friends ask me why I was sulking, I share the results. When I explain that HPV is an STI, I did not look them in the eye. I immediately address my misfortune and confirm that my vaccinated body felt too confident to become broken. My friends try their best not to react. When I explain that there are two different kinds of HPV: Strands that give you genital warts and strands that lead to ovarian cancer, they grimace. When I told them I do not have the strand that gives you warts, they look...relieved.

I will never understand how someone could be relieved when they hear the word cancer. I will never understand the fact that *warts* sounds so much like *whore* that *cancer* becomes comfortable.

I still do not want to admit my own relief.

I am ashamed of the support I find in pity all because I didn't want to be a *slut*.

One Year Later

I sit myself in the same chair I am now used to, knowing there are other rooms in this doctor's office. My nurse asks how I am feeling. This is the same nurse that didn't explain the discharge. The same nurse that asked why I didn't get the vaccines (even though I did). The same nurse who suggested I use a condom as if you always have the choice to.

I did not bother to respond. When the doctor finishes the pap smear, she asks if I had any questions. When I inquire about hysterectomies, she thinks I am joking. It is in this moment I realize that she has no idea how seriously this is affecting me.

She tries to remind me that ninety percent of the time it turns out fine. I remind her that is what she said last time. She tells me I was aggravating. She says that this just *isn't that big of a deal*.

When I ask her why my body is not that big of a deal, she does not have an answer. When I ask her to tell me what six months of waiting sounds like, she did not make a single sound. When I tell her the amount of times I have felt disgusted in my own body, she grimaces at the statistics.

I tell her that preparing for the worst is better than idly waiting for it. She eventually stops avoiding my questions. I tell her that I was not a walking percentage sign. I tell her that I will always be worried about the ten percent until I know I am a part of the ninety.

The Results

It has been three years since I was diagnosed with HPV. I continue to see disgusted faces and incorrect information weave through the mouths of adults, children, and

professionals. A year after I was diagnosed, I finally received a pap smear that came back normal. It was a giant weight lifted off of my shoulders. I had gone through a journey I thought I prepared myself to avoid. When I started writing this, I was on a two-year watch in which I had to complete four normal pap-smears before my doctors stopped being concerned that the virus will grow or come back.

My fourth and final appointment was on Tuesday, September 8, 2015. This was the day that I waited two and a half years for. I only needed one more normal pap smear to be taken off of the watch and return to being treated *normal*. The nurse brought me to a new room this time. I sat patiently in the chair and told myself that I was not going to cry. This was a day to be celebrated, a day that was years in the making. When Dr. Dimagio came in, she told me she had *great news*. She said that due to recent changes in the medical field, I would not be getting a pap smear.

I just started crying. I had waited two and a half years to receive the final confirmation that I was finally *okay*. I was officially a part of the ninety-percent she kept talking about, but instead of getting that confirmation, instead of feeling the culmination of this entire journey, I literally got nothing. Apparently, the United States Preventive Services Task Force announced in March 2012 that women my age only needed to receive a pap smear once every three years. In addition to this, no one under the age of 21 should receive a pap smear because treating abnormalities as soon as they are detected “can lead to cervical incompetence and miscarriage down the road” (Brawley, 2012). Because HPV is such a slow growing virus, doctors felt that they were able to detect it through examinations. But there is no longer a need for an immediate colposcopy. Instead, women who receive an abnormal pap smear should receive a gene test that will determine whether or not they have strands 16 or 18

of HPV, the two strands that cause cervical cancer (Brawley, 2010). She explained that making someone get a pap smear every six months was sparking too much urgency around the virus and creating high stress situations for young woman.

I'm writing this thesis five months after that last appointment. I did not know until today, February 10, 2016, that these changes were actually announced in 2012. The same year I was diagnosed with HPV. My doctor made it out to seem that this was a brand new finding; something that was just now being adopted in the medical field when in all actuality this was here all along. It took three years for my hospital to adopt the very clear, very necessary changes and because of their untimeliness, I received one colposcopy and five pap smears in exactly three years. That is six procedures that were not only mentally and emotionally exhausting, but could potentially have been physically damaging.

Though I am thankful to be a part of the ninety percent, it genuinely sucks that I had to experience such a harmful experience with my gynecologist. Though certain precautions can be taken to avoid contracted HPV, the chance is always there. There are still several women who spent months waiting just to hear that the virus grew, that their chances of ovarian cancer have increased, and that they need to take further actions. And just because there is light at the end of my story, we should not disregard the longevity of dark. To be innocent and still attacked in a dentist office, to worry that you miscarried a child because the effects of invasive procedures were not explained, to feel shame and blame cast on you from doctors and nurses: That never goes away. We do have to remind ourselves that yes, the virus is dangerous; yes, the vaccine is helpful; and yes, the statistics are not there just to comfort you. We have to do all of this without forgetting that there are still 38 strands that the vaccine does not protect you from. There is still information that needs to be spread. There are

thousands of women out there that do not know about these changes and cannot advocate for their own bodies. We must remember that everyone deserves to be more than just a percentage.

Limitations

There are a few limitations that need to be addressed regarding my study that will hopefully serve as a motivator for further inspection regarding HPV, sexual education, agency, and health communication. Because my understanding of “truth” and evidence may differ from that of a canonical medium, it is imperative to consider any contributing factors that may deteriorate or negatively affect my relationship with this study. The three most prominent areas would be my vaccination, my age, my relationship with education, and finally, my demographic.

First of all, I received the Gardasil vaccine in 2007. This needs to be considered because at this point, everyone getting vaccinated is receiving a more updated treatment. Therefore, the insight that I can provide may only be relevant to individuals who received their vaccination before 2014. Additionally, I participated in safe sex before receiving my final shot of Gardasil. There is no relevant or popular research circling how this could affect the efficiency of the vaccine and though it likely had little to no impact on my future diagnoses with HPV, it is definitely something that should be considered.

Next, my age needs to be considered. As a 25 year old, I took a school-based sexual education course as an eighth grader and a tenth grader. This means, the last time I was in a class that taught these elements was back in 2004 and 2006. Not only would this suggest that my experience with school-based sexual education is outdated, but it was also before and

during the time in which Gardasil was being introduced. Therefore, the ability to teach me about this virus was obviously impossible. I would hope that, at this point, schools have enhanced their education programs and figured out a way to effectively discuss HPV and ways to prevent infection. Unfortunately, I find it highly unlikely that we have figured out how to do so in a way that does not instill fear and confusion or strips young people of the agency they should have over their bodies.

Another element that should possibly be considered is the fact that I am a high school teacher. I've been teaching for three years now, and my relationship with education could have a direct impact on my passion and concern with school programs. Though I do not feel that this element would create a negative contribution to my study, I do think it creates a clearly biased one. I do not teach sexual education at my school, but as a literature teacher I am constantly discussing touchy issues about virginity, intimacy, and body image. Perhaps, it is this connection that creates a concern for the young women in my class and further instills my desire to protect them from the harmful and confusing language circling HPV.

Finally, the last element that could be a potential limitation is my demographic. Because Carolyn Ellis addresses the fact that the stereotypically research has a white, male, middle-class perspective, it is important to note that I am a white, middle-class, female. I have never struggled to receive health care. I have always been given support from my friends and family when dealing with medical issues, and my friend group consisted of people that were also educated about the disease at some point in their life. This would definitely put me at an advantage than most people in America who are at risk of contracting this disease. Though I may not have had the privilege to avoid the virus, I absolutely have the privilege to be able to learn and write about its effects.

Each of these elements affect my bias in a way that I cannot avoid. Though my autoethnography attempted to be as truthful and factual as possible, it is clear that further research as to be done. Perhaps, when considering these limitations scholars will be better able to broach studies regard school-based sexual education, sexual agency, and HPV in a way that is immediately applicable and assist in the prevention of more individuals having to deal with these procedures.

Future Research and Investigation

More research about the human papillomavirus is absolutely imperative. Hopefully, my autoethnography will spark scholars to focus more specific on elements that have been disregarded in the past years. By doing this, we will better be able to bridge the gap between autoethnographic research and canonical studies as well as further establish the validity and relevance to the communication field as a whole. The following will break down potential research topics and investigations that could be examined in the future between four different areas: School-based sexual education and sexual agency, disposal of the taboo-talk circling sex and STIs, further analysis and understanding of HPV, and finally, the use of autoethnographic research in this field.

First, scholars need to continue working on revamping school-based sexual education programs. Majority of the programs seek to shine light on the elements that negatively effect students. Though this allows us to understand the issues with school programs, it does not allow us to figure out what we need to do to change them. Instead, scholars need to focus on what has been effective and what the students need to better understand themselves and their bodies. By doing this, we will be able to create a program that is informative, accurate, and

positive. Additionally, scholars need to consider alternative ways to address young peoples' sexual agency. Because this conversation seems to be so utterly difficult for parents and educators to engage in, we need to figure out a safe and educational environment that allows students to get their questions answered, instead of encouraging them not to question things to begin with.

Next, scholars should further examine the rhetoric that is being used when discussing sex and sexually transmitted disease. Because school-based sexual education is not the only means used by young people to understand their bodies, we need to consider how these sources could be negatively affecting individuals. Furthermore, if there is a disconnect between the way our schools talk about sex and STIs and the way the media does, we need to, at the very least, address these difference and attempt to understand why it is happening and what needs to be done to change it. Particularly addressing the rhetoric of "taboo" and how terms become associated with it would be immensely helpful. Personally, I feel that eliminating this term from our vocabulary would provide insight into a plethora of areas that truly demand more support from scholars and society in general.

When looking into studies circling HPV, there were a lot that examined developing nations. Though this is a great detection of validity in the study of HPV, the lack of information circling HPV in the US needs to also be addressed. Perhaps, taking the same approach these scholars had, but regarding national demographics, would allow us to better understand what kind of support needs to be created in what areas. I imagine school systems that have lost funding or public services that have been shut down by the government have had a negative impact on the surrounding citizens and their accessibility to the Gardasil 9 vaccine amongst other health-related assistance. If we can pinpoint the areas that require the

most help, we may be able to develop a plan that will be highly effective in reducing the number of cervical cancer victims from HPV.

Additionally, one element about HPV that must be explored is the recent changes in the gynecology field. Because the amount of pap smears that a woman received has been reduced to every three years (depending on their age), scholars need to look further into why this happened and how it could positively and negatively affect individuals. One specific element to be considered is how this affects insurance coverage and what people are able to charge to their companies. Women of all ages are seeing their gynecologists for a plethora of different reasons. If we fail to effectively communicate the changes in the system, we are failing to support an entire gender of people, potentially prompting more problems like HPV.

A finally element that I believe would be extremely beneficial when responding to this study is an autoethnographic counter that provides insight to different stakeholders particularly, individuals who are against the mandating of the Gardasil 9 vaccine. By receiving personal insight into these ideas, we will better be able to create plans and decrees that are beneficial to everyone and consider all points. Because there has been a recent uproar in vaccinations as a whole, breaking it down one vaccine at a time would also provide a more distinct scope to address specific issues.

In general, this study was meant to serve as a call for more: More research, more time, more care. If women's health care is to be considered a real issue in America, than women's lives need to be viewed as worthwhile subjects. Cervical cancer is continuing to kill people, and the human papillomavirus is continuing to spread. The rhetoric we are using is insufficient in leaving people like me confused with what actions to take. We need to look further into these issues to figure out the best way to talk about them. Doing this will allow

us to provide our citizens with a compassionate and informative environment while simultaneously combating the fast spreading and extremely dangerous sexually transmitted virus: HPV.

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