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SHAME, GUILT, AND KNOWLEDGE OF HPV IN WOMEN RECENTLY DIAGNOSED WITH HPV-RELATED CERVICAL INTRAEPITHELIAL NEOPLASIA (CIN)

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Abstract of Dissertation

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The Graduate School
University of Kentucky
2010

SHAME, GUILT, AND KNOWLEDGE OF HPV IN WOMEN RECENTLY DIAGNOSED WITH HPV-RELATED CERVICAL INTRAEPITHELIAL NEOPLASIA (CIN)

ABSTRACT OF DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Arts and Sciences
at the University of Kentucky

By
Sarah E. Flynn

Lexington, Kentucky

Co-Directors: Dr. Suzanne Segerstrom, Professor of Psychology;
Dr. Jamie Studts, Assistant Professor of Behavioral Science

Lexington, Kentucky

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ABSTRACT OF DISSERTATION

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The current study investigated the relationships between state shame, guilt, and disease knowledge in women recently diagnosed with cervical intraepithelial neoplasia (CIN) caused by the human papillomavirus (HPV). Recent research has indicated that diagnosis of HPV can elicit negative self-directed affect, including persistent experiences of shame. Studies have also shown that knowledge of HPV is low in the general population, even though it is the most common sexually transmitted infection. It is important to understand how shame affects those with HPV because shame is related to a decline in important immune parameters that may be essential in HPV clearance. A sample of young women (ages 18-28) recently diagnosed with HPV were given measures of shame and guilt-proneness, state shame and guilt, depression, impact of diagnosis, and HPV knowledge. A comparison group of women diagnosed with infectious mononucleosis caused by the Epstein-Barr Virus (EBV) were also given these measures. It was predicted that women diagnosed with HPV would have higher levels of shame and guilt than women diagnosed with EBV. It was also predicted that disease knowledge would moderate negative affect in women with HPV, where increases in HPV knowledge would neutralize feelings of shame and guilt. The results of this study supported the first hypothesis: women with HPV experienced more shame and guilt than women with EBV. Shame largely mediated the relationship between diagnosis of HPV and depression, as well as HPV and distress, but these relationships were not significant for guilt. The hypothesis that disease knowledge would moderate feelings of shame was not supported in this study. Because of the biological and psychological consequences of shameful experiences, research should continue to measure factors that may predict shame after diagnosis of HPV.

Keywords: HPV, shame, guilt, knowledge, depression

Sarah E. Flynn
Student's Signature

May 12th, 2010
Date

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DISSERTATION

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To my family—for all their love, support, and faith.

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Section One: Introduction

Cervical intraepithelial neoplasia (CIN), also commonly known as cervical dysplasia, is an abnormal growth of squamous cells on the surface of the cervix. If left untreated, a small percentage of women with CIN will develop cervical squamous cell carcinoma (Agorastos et al., 2005). The major cause of CIN development is infection with the Human Papillomavirus (HPV), with types 16 and 18 implicated in most cases of cervical cancer (Bosch et al., 2003). HPV is now recognized as the most common sexually transmitted infection (STI), with estimates of the prevalence of the disease ranging from 14-90% (Revzina et al., 2005). Despite the high prevalence of HPV, research has shown that knowledge of HPV biology and transmission is relatively low among the general population (Baer et al., 2000; Kahn et al., 2007).

Although HPV is biologically linked to the development of cervical cancer (Bosch et al., 2002), there are also psychosocial consequences that arise from being diagnosed with HPV. Studies have shown that diagnosis is often associated with anxiety, distress, shame, and concerns about sexual relationships (Kahn et al., 2007: Maissi et al., 2004). Perceptions of social threat (i.e., threats to one's social self-esteem or acceptance), such as diagnosis of an STI, can produce negative self-evaluative emotions such as shame and can have a detrimental impact on immune parameters (Dickerson et al., 2004). Additionally, prolonged feelings of shame and guilt have been associated with immunological declines in disease populations (Weitzman et al., 2004: cited in Dickerson et al., 2004). Because cellular immune responses have been associated with regression of CIN, and shameful emotions have been linked to immunological declines, shame and guilt experiences may be very important to study in populations diagnosed with HPV or CIN.

The primary aim of the current study was to compare shame and guilt in female college students recently diagnosed with cervical intraepithelial neoplasia (CIN) to a comparison group recently diagnosed with infectious mononucleosis (IM) caused by exposure to the Epstein-Barr virus (EBV). Epstein-Barr virus is a comparable infection in regards to prevalence and immunosuppression, yet there is little social stigma associated with IM diagnosis. A second aim of the study was to explore whether knowledge of the disease is related to lower levels of shame and guilt in HPV patients.

HPV: A Common Disease

Human papillomavirus (HPV) is a virus transmitted via skin to skin contact that causes either genital warts or cervical abnormalities. However, some types of HPV never present any infectious symptoms. There are over 100 different types of the virus that have been identified, and HPV is now the most common sexually transmitted infection (STI) in the United States (Revzina et al., 2005). One research study estimated that at any given time, 28.6% of women ages 14-59 are infected with HPV (Dunne et al., 2007). Of these women, it was estimated that around half are infected with the high-risk types of HPV (e.g., types 16 and 18) that have the highest chance of developing into cervical cancer (Bosch et al., 2003). According to the Centers for Disease Control (CDC, 2008), 80% of women will be infected with at least one type of HPV by the time they reach the age of 50.

The HPV Prognosis

Low-risk types of HPV can cause genital warts (i.e., condylomata acuminate), which are benign skin growths on the surface of the genital area. Individuals presenting

with genital warts are most likely infected with types 6 or 11, which are thought to cause up to 90% of benign genital skin growths (Greer et al., 1995). The types of HPV that cause genital warts are deemed "low-risk" because they are unrelated to the development of genital cancer. Treatment for genital warts usually involves removal of the warts via liquid nitrogen cryosurgery. In some cases, warts are treated with topical cream or by laser cauterization (Sheinfeld et al., 2006).

Other strains of HPV, deemed "high-risk" types, can cause cancer of the genital region of both males and females. Women with HPV that are at risk for cervical cancer first develop CIN, commonly known as cervical dysplasia, which presents as abnormal squamous cell growth on the surface of the cervix (Agorastos et al., 2005). CIN is graded according to how far the abnormal cell growth spans the epithelium of the cervix. CIN1, known as grade I, corresponds to a low grade squamous intraepithelial lesion (LSIL), and is confined to the basal one-third of the epithelium. CIN2, known as grade II, corresponds to high grade squamous intraepithelial lesion (HSIL) or moderate dysplasia, and is confined to the basal two-thirds of the epithelium. CIN3, known as grade III, also corresponds to HSIL and often referred to as severe cervical dysplasia. CIN3 spans more than two-thirds of the epithelium and can involve the entire thickness of the cervix. CIN3 is also sometimes referred to as cervical carcinoma in situ, which is related to the development of invasive cervical cancer (Park et al., 1998).

According to the American Cancer Society (ACS, 2010), 11,270 women in the U.S. will be diagnosed with cervical cancer this year. Of these women, it is estimated that approximately 3,870 of them will die of the disease. The ACS has stated that regular cervical cancer screenings that begin at age 18 or at the onset of sexual activity can greatly reduce the risk of dying from cervical cancer.

CIN Prevention, Detection, and Treatment

Prevention. The use of condoms may not offer full protection from HPV due to the fact that HPV is spread through direct skin to skin contact. However, research has shown that the use of condoms is associated with decreased risk of HPV contraction and cervical cancer (Steiner, et al., 2006). In one study, HPV infection occurred in 37.8% of women whose partners used condoms in all cases of sexual intercourse and 89.3% in women whose partners reported using condoms less than 5 percent of the time (Winer et al., 2006).

In 2006, the FDA approved a vaccine for the prevention of cervical cancer. The vaccine, known as Gardasil, is a substance containing human papillomavirus-like particles (VLP's) that produce an antibody response preventing infection with four types of HPV (Lowy et al., 2006). Gardasil protects against HPV types 6 and 11, as well as 16 and 18, which are thought to produce 90% of genital warts cases and 70% of cervical cancer cases, respectively. The vaccine is given in a series of three injections over the course of six months. The cost of the vaccine is 120 dollars per injection, totaling 360 dollars for the full vaccine course. Although this vaccine can lower the risk of developing HPV related cervical cancer, this vaccine does not protect against all HPV types (Lowy et al., 2006). Moreover, the cost of the vaccine may be a deterrent in individuals from lower income families. Cervarix, a new bivalent vaccine for HPV types 16 and 18, is currently under FDA review. Unlike Gardasil, this vaccine would protect against cervical cancer but not genital warts (Harper, 2008).

Detection. Papanicolaou "pap" smears are the most common means of detecting CIN and pre-cancerous lesions on the cervix. Since the mid 1990's, a liquid based monolayer cytology technique for pap tests has become increasingly popular. This test involves scraping cells from the outer opening of the cervix and placing them in a vial containing a liquid medium for preservation. The cells are then processed into a thin cell layer, stained, and examined under a microscope by a pathologist. This technique has been shown to have a sensitivity rate (i.e., correctly identified cell abnormalities in women who truly have these abnormalities) of between 61-66% and a specificity rate (i.e., correctly identified negative cell abnormalities in women who truly do not have these abnormalities) of between 82-91% (Kulasingam, et al., 2002). Once abnormal cells are detected, women can undergo a colposcopy procedure where the cervical tissue is illuminated and magnified, allowing for a sample of the tissue to be removed for further pathological evaluation to determine the severity of the abnormality (ASCCP, 2008). Although a colposcopy procedure is relatively low risk, it is often painful and can cause bleeding and severe cramping.

Treatment. For many women, HPV is suppressed by the immune system and never leads to the development of CIN or cervical cancer (Bollen et al., 1999). The regression of HPV is suggested to occur as a result of a cell-mediated immune response (Scott et al., 1999). This response involves T helper type 1 (Th1) cells that produce different types of immunoregulatory cytokines following exposure to an antigen. These cytokines upregulate tumor immunity and prevent T helper 2 (Th2) cells from producing cytokines that inhibit tumor immunity (Alcocer-Gonzoles et al., 2006; Jensen et al., 2007). Following established infection with HPV, research has shown that T-lymphocytes that infiltrate the cervical epithelium, such as CD4+, may also be associated with the regression of HPV related cervical lesions (Coleman et al., 1994).

Several surgical techniques are used to treat CIN that has been determined to be HSIL grade II or III (often via colposcopy procedure, Aerssens et al., 2008) including cone biopsy, cyrotherapy, laser evaporation, and loop electrosurgical excision procedure (LEEP). A LEEP procedure involves the cauterization of the surface of the cervix with an electrical current transmitted through a wire loop. LEEP is generally performed in an outpatient setting with local anesthetic. LEEP may have less symptom burden than other surgical treatments for resecting CIN cells, but may still cause some hemorrhage or cramping after treatment (Nuovo et al., 2000). Aerssens and collegues found that after treatment with cyrotherapy or LEEP, HPV clearance rates were 80-90% in CIN patients after two years. These results suggest that women infected with HPV have treatment options that may dramatically reduce their risk of developing cervical cancer in the future.

Psychosocial Effects of HPV/CIN Diagnosis

Diagnosis of HPV or HPV-related CIN has significant medical implications, but less is known about the psychosocial and behavioral aspects of diagnosis (Kahn et al., 2007). Reactions to diagnosis of HPV may include anger, anxiety, depression, concerns about sexual relationships, and feelings of stigmatization (Kahn et al., 2007; Maissi et al., 2004). Feelings of shame have also been implicated as emotional reactions to diagnosis of HPV. Clark and colleagues (1996) found that two-thirds of HPV infected individuals in their sample (n =468) felt significant feelings of shame as a result of their diagnosis, and one-third of these individuals continued to experience these feelings after one year.

Furthermore, they suggested that HPV patients are dissatisfied with the amount of emotional support and information provided by their healthcare practitioners.

Although HPV is a common disease, factual knowledge of HPV transmission, prevention, and etiology seems to be low in the general population. Tiro et al. (2007) found that in their sample of U.S. women ages 18-75 (n = 1,248), 40 percent had never heard of HPV. Moreover, of those women who had heard of HPV, over half of them were unaware that the virus caused cervical cancer. One study by Maissi et al. (2004) found that a significant number of HPV patients in their sample did not understand their test results. The authors suggest that anxiety and distress may be reduced after diagnosis if healthcare practitioners provide clear and salient information about HPV to patients. Without adequate knowledge of HPV risk, etiology and transmission, diagnosis of the disease may cause significant and prolonged shame, confusion, anxiety, and frustration.

There are inconsistencies in the literature about whether or not HPV knowledge has increased since the Gardasil vaccine was commercially introduced to the public in 2006. Several studies have shown that many individuals are still generally under-educated about the effects of HPV (Goldsmith et al., 2007; Tiro et al., 2007; Walsh, 2008). However, a recent study by Ragin and colleagues (2009) found that more than 82 percent of their sample was aware that HPV caused cervical cancer. These results may give the impression that HPV knowledge is improving, but the authors did find that more specific knowledge of HPV was lacking in their sample. For example, only 18 percent of their sample knew that the types of HPV that caused genital warts were different than the types of HPV that caused cervical cancer. Taken together, these results suggest that although HPV awareness may be improving, factual knowledge of HPV may still be limited in the general population. .

Shame, Guilt, and Immune Function in HPV/CIN

Shame vs. guilt. Shame and guilt have been labeled "self-conscious" emotions that involve reflective thinking about oneself (Eisenberg, 2000). Shame and guilt have been identified as distinct emotions that differentially affect emotional and physical health. Although both emotions are negatively self-evaluative, they differ in the way negative self-relevant events are construed and have very different implications for one's global self-concept. Shame contains both internal (i.e., how one sees the self) and external (i.e., how he or she believes others see the self) components (Gilbert, 1998). Shameful experiences involve the entire self as the focus of evaluation and often include feelings of powerlessness and worthlessness (Tangney & Dearing, 2002). Shame involves negative self appraisal that is broad, enduring, and directly related to one's view of the self that stretches beyond the behavior that sparked the emotional experience. In contrast, guilt involves scrutiny of one's specific negative behavior, not one's global self (Taylor, 1985). Experiences of guilt may involve tension, regret, and remorse over a behavior but do not generalize to the entire self (Tangney et al., 1996). It is important to distinguish between these two overlapping emotions because guilt has shown to be mostly adaptive, whereas shame in particular has been associated with maladaptive functioning. Research suggests that guilt may foster moral behavior (Tangney and Dearing, 2002), whereas shame is often psychologically maladaptive and is related to anger, personal distress, anti-social behavior, psychosis, and reduced empathy for others (for a review, see Ayfer & Yagmurlu, 2008). Research has also indicated that shame, and not guilt, may be strongly related to depression (Orth, Berking, & Burkhardt, 2006). In a study with 149

adults undergoing marital separation, Orth and colleagues found shame had a strong, unique effect on depression but that shame-free guilt did not. It was discovered through subsequent meditational tests that shame elicits periods of event-related rumination, which in turn contributed to depressive symptomology. This finding may be particularly relevant to HPV diagnosis, as shameful emotions may be largely responsible for the strong association found between diagnosis and depression.

Shame is often the outcome of situations that involve threats to one's perceived social status or acceptance (Dickerson et al., 2004). Moreover, shame involves situations where individuals feel their negative self is exposed to others in the form of either real or imagined audiences (Tangney et al., 1996). Being diagnosed with a sexually transmitted infection such as HPV can create these situational conditions. For example, an HPV positive woman may experience feelings of internal worthlessness, but she may also feel that her social acceptance is threatened when deciding whether to tell her partner about her diagnosis. She may feel that she will be rejected by her current or future partners and will be forever plagued with concerns about sexual relationships. She may also feel that society will evaluate her negatively for belonging to a stigmatized group of individuals who have been diagnosed with an STI. Perceived negative evaluation and rejection by others are feelings that have been expressed in previous studies with women diagnosed with HPV (Kahn et al., 2007).

Shame and immune function. Experiences of shame and guilt, similar to those that may happen upon HPV diagnosis, are also related to compromised immune functioning. Shame has been shown to be associated with increases in cortisol activity (Gruenewald et al., 2004) and proinflammatory cytokine activity (Dickerson et al., 2004) in acute situations. Moreover, several studies have shown that negative self-evaluative emotions can cause changes in CD4+ T helper cells in disease populations over the long term. Segerstrom et al. (1996) found that self-blame was related to faster declines in these cells over a 1 ½ year follow up of HIV positive men. Similarly, Weitzman et al. (2004) (as cited in Dickerson et al., 2004) found that persistent feelings of shame and guilt in HIV positive men over 7 year follow-up predicted significant CD4+ declines. Other distressing emotions such as sadness, anger, and anxiety were not related to CD4+ outcomes in this study, suggesting that there is something unique about the experience of shame that can produce detriments to immune function. In a later review summarizing the Weitzman results, the co-authors stated that "…these findings support the premise that shame, experienced in response to possession of a stigmatizing condition, is an important predictor of disease-relevant immunological change (Dickerson et al., 2004, p. 1209)." Like HIV, HPV has been found to be stigmatizing in those diagnosed with the virus due to the fact that it is a sexually transmitted infection (Massi et al., 2004). Therefore, persistent shame experiences in HPV patients may very well be associated with declines in CD4+ cells, and these are among the cells shown to be vital in the clearance of HPV cervical lesions (Coleman et al., 1994).

Comparison with Epstein-Barr Virus (EBV)

Over 90 percent of individuals will be infected with Epstein-Barr Virus (EBV), and the infection will persist through the course of a person's lifetime (Cohen, 2000). Most infected individuals will never develop symptoms of infection, but exposure to EBV in adolescence or adulthood can cause infectious mononucleosis (IM), which generally presents as a series of symptoms such as fever, swollen glands, and pharyngitis

(Straus et al., 1993). The cell-mediated immune response in the body is primarily credited with the control of EBV infection. Natural killer cells, CD4+ and CD8+ cytotoxic T-cells are responsible for controlling primary infection of EBV, and HLA-restricted cytotoxic T-cells are important in controlling the virus after the acute infection and preventing recurrence of infectious symptoms (Cohen, 2000).

Like HPV, EBV can remain in its host over the course of its lifetime, and the body relies heavily on the immune system for suppression. Unlike HPV, however, diagnosis of EBV or IM does not cause considerable social stigma in adults. EBV is contracted by the exchange of saliva, which is common after two people share eating utensils or drink after one another (Straus et al., 1993). Using patients recently diagnosed with EBV as a comparison group to measure shame and guilt experiences allows one to rule out the possibility that these emotions can be produced by mere diagnosis of a non-curable virus. By comparing emotional reactions to HPV with those of EBV, there will be a stronger argument for the social stigma attached to HPV as the likely cause of shameful experiences.

Summary

To date, there is relatively little quantitative research on the psychosocial sequelae of HPV diagnosis. The research that exists suggests that diagnosis is often associated with emotional distress, feelings of stigmatization, and decreased sexual satisfaction (Kahn et al., 2007, Maissi et al., 2004). Negative self-evaluative emotions, especially experiences of shame, have been showed to be markedly high in patients recently diagnosed with HPV (Maissi et al., 2004). Not only are individuals with HPV experiencing shame after learning about their diagnosis, but research has shown that individuals continue to feel shameful about their disease months to years after the initial experience (Clark et al., 1996). In other words, shame is a common and enduring experience in HPV diagnosis. Shame experiences related to HPV diagnosis not only have psychological and behavioral implications, but they can also have implications for disease progression. Cell mediated immune responses, most notably CD4+ activity, are thought to be a vital component of HPV regression and cervical lesion clearance. However, research has shown that persistent feelings of shame (such as the ones shown to endure during and after HPV diagnosis) are related to declines in CD4+ cells. Therefore, it is quite possible this psychological–immunological link may play a vital role in the disease course of HPV.

Some studies have speculated that providing patients with adequate knowledge regarding the prevalence of HPV, treatment, and actual risk of cancer can reduce patients' distress (Kahn et al., 2007). However, this claim has not been empirically demonstrated in the literature using actual HPV patients. The current study explored the experience of shame and guilt among individuals diagnosed with HPV, and examined whether factual knowledge of HPV is related to these emotions. It was thought that if knowledge of HPV prevalence and risk could reduce shame and guilt in HPV patients, then low-cost educational interventions may be effective in improving patients' psychological and biological outcomes.

Hypotheses

Hypothesis (1). The primary prediction was that women with HPV related-CIN will experience significantly more feelings of shame and guilt than women diagnosed with EBV, but that guilt and shame proneness would not differ between diagnoses.

Hypothesis (2a). It was also predicted that women with HPV-related CIN will have higher depression and disease-specific distress scores than women with EBV.

Hypotheses(2b). Based on work by Orth and colleagues (2006) where shame was related to depression due to event-specific rumination, it was predicted that the relationship between HPV diagnosis and depression would be at least partially mediated by state-shame but not by state-guilt. The same prediction was tested for the relationship between HPV diagnosis and disease-specific distress.

Hypothesis (3). Finally it was predicted that increased knowledge of disease risk, etiology and transmission (of HPV or EBV, depending on the group) would be significantly and negatively related to feelings of shame and guilt in CIN patients but that no such relationship would exist in EBV patients given a psychometrically equivalent knowledge measure (see appendices G and H for measures).

Section Two: Method

Participants

Participants were female college students (ages 18-28), who were recently diagnosed with an abnormal pap smear indicating HPV related CIN (test group) and female students in the same age range recently diagnosed with Epstein-Barr Virus (comparison group). A power analysis indicated that for the hierarchical linear regression models, 77 participants would be needed to reach 80% power with a predicted effect size of $r = 0.30$ (a medium effect size, Cohen, 1988) and an error rate of $\alpha = 0.05$. Previous research (Clarke et al., 1996) suggests that shame is a common experience after HPV diagnosis; therefore, a medium to large effect size was predicted. The current study recruited 80 participants (40 in each group). Power calculations for other analyses (i.e., t-tests and correlations) reveal that 68 participants were needed for 80% power at $d = 0.7$, $\alpha = 0.05$.

Procedure

Participants were females recently diagnosed with HPV-related CIN *(*$n = 40$), or infectious mononucleosis ($n = 40$). Participants were recruited through the University Health Services, the UK Women's Health Clinics, and the community. Patients were told by the clinic staff that they were eligible to participate in a research study, and if they indicated that they were interested in participating they were contacted by the researcher. Once contacted, the patient was told that she was eligible to participate in a research study on experiences after diagnosis of CIN/infectious mononucleosis, and an appointment time was scheduled to complete the study at place of her convenience. Some patients chose to complete the study at the clinic after their initial appointment. After informed consent was obtained, the patient was asked to complete a questionnaire packet containing the pertinent measures. After completion of the questionnaire packet, participants were paid and thanked for their time.

Flyers advertising a confidential study on HPV/infectious mononucleosis experiences were also posted throughout the cities of Lexington and Richmond Kentucky in local gynecology offices and women's health clinics. Participants who called about the study were assessed for eligibility and scheduled for participation at a time and place convenient to them. Recruitment took place from July 2009 to January 2010.

Measures

Demographic Information Sheet. Participants first completed an information sheet that asked them to provide demographic information such as age, race, and ethnicity. Other items included insurance type, student status, relationships status, and household income (see appendix A).

Guilt and Shame Proneness Scale. The GASP is a 20 item measure with two subscales measuring guilt-proneness as negative behavior-evaluations ($\alpha = .54$) and approach responses following private behaviors ($\alpha = .83$), and two subscales measuring shame proneness as negative self-evaluations ($\alpha = .69$) and avoidance responses following public behaviors ($\alpha = .78$) [1] (Cohen, Wolf, Panter, & Insko, 2009).

Examples of items from the GASP include "You secretly commit a felony. What is the likelihood that you would feel remorse about breaking the law?" and "You take office supplies home for personal use and you are caught by your boss. What is the

[1] Reliability estimates were calculated from the data in the current study.

likelihood that you would replace what you broke?" Each item is measured on a scale of 1(*very unlikely)* to 7(*very likely).* As predicted by Cohen et al. (2009), the guilt subscales were significantly correlated ($r = 0.54$, $p < .001$), but the shame subscales were not, ($r = 0.14$, $p > .05$); therefore, the guilt subscales were collapsed to yield a total guilt proneness score, raising the reliability estimate to an acceptable level (.81), ($M = 5.31$, $SD = 1.03$). Both shame subscales were retained separately for subsequent analyses (see appendix B).

State Shame and Guilt Scale (SGSS). The SGSS is a 15 item scale that measures state guilt, shame and pride (Marschall, Sanftner, & Tangney, 1994). The authors discovered that the scale consists of three 5 item subscales for assessing shame ($\alpha = .89$), guilt ($\alpha = .82$), and pride ($\alpha = .87$) in the moment. This measure was developed to assess state emotions and does not rely on respondent's ability to distinguish between the words 'shame' and 'guilt.' Items that measure shame include a component of the global self such as: "I feel worthless, powerless." Guilt items include a behavioral component such as: "I feel bad about something that I have done." Each item is measured on a scale from 1 (*not feeling this way at all*) to 5 (*feeling this way very strongly*). The pride subscale was not used in the analyses. Patients were instructed to take a minute and think about their recent diagnosis of HPV-related CIN or EBV-related IM before responding to these items (see appendices C and D).

Five items measuring disease specific shame and 8 items measuring behavioral indicators of shame were added to the scale. Disease specific shame included items such as "I feel like my body is damaged" and "I now feel like I no one will ever love me because of my diagnosis." These items were rated on the same 1 to 5 scale as the original SSGS items. Behavioral shame indicators asked the respondent to rate on a scale of 1 (*extremely unwilling)* to 5 (*extremely willing)* how willing they would be to perform such behaviors as "Tell my current/future partner I have HPV/EBV" and "Talk to sororities on campus about my experience with HPV/EBV."

The estimated reliabilities for the original SSGS shame and guilt subscales in the current study were high ($\alpha = .92$) and ($\alpha = .91$), respectively. Estimates of the reliability coefficient for the added disease specific shame ($M = 2.50$, $SD = 1.28$), ($\alpha = 0.93$) and behavioral shame ($M = 2.49$, $SD = 0.98$), ($\alpha = 0.88$), subscales were also high[2]. The correlations between all of the SSGS shame subscales were significant (see Table 2.1); therefore, these subscales were collapsed to yield a total shame score ($\alpha = .95$), ($M = 2.37$, $SD = 0 .98$).

Center for Epidemiological Studies Depression Scale (CES-D). Some research has indicated that shame may overlap with symptoms of depression (Orth et al., 2006). Therefore, the current study included the CES-D in order to understand the potential relationships between these two constructs. The CES-D short form is a 10 item self-report measure that assesses depressive symptomatology in the general population. Examples of items from the CES-D short form include "I felt hopeful about the future" and "People were unfriendly." Each item is scored on a response scale from 0 (*rarely or none of the time)* to 3 (*all of the time*). Psychometric evaluation of the CES-D short from has supported its validity and reliability ($\alpha = .85$), and it correlates highly with longer scales of clinical depression symptoms (Radloff, 1977). The reliability for this measure in the

[2] Items for the behavioral shame scale were reverse-scored in analyses, due to the fact that low scores indicated an unwillingness to perform the potentially shameful behavior.

current study was also adequate[3] (α = .85), and a total scale score was created by summing the score of all items for each participant (M = 9.14, SD = 6.11) (see appendix E).

Impact of Event Scale (IES) – Revised. It is possible that shame and guilt may be partially explained by the overlap with the stress caused by the event of diagnosis itself. The IES-R was included to understand the potential relationships between these two constructs along with depression (see above). The IES-R is a 22 item scale that measures intrusion (α = .86), avoidance (α = .87), and hyper-arousal (α = .85)[4] due to a specific event, which in this study was disease diagnosis (Weiss & Marmar, 1996). The original IES only contained 15 items and the subscales measuring intrusion and avoidance (Horowitz, Wilner, & Alvarez, 1979). Examples of items from the IES include "Any reminder brought back feelings about it" and "I had waves of strong feelings about it". Items were measured on a scale of *0 (not at all) to 4 (extremely).* The three subscales were significantly and highly correlated (r's > .69, p's < .01) (see Table 2.2), therefore a total scale score was created using the item sum total (M = 21.71, SD = 17. 57), (α =.94). Using this sum score rather than the specific subscales is an accepted technique and gives an overall picture of event-specific distress (Weiss & Marmar, 1996) (see appendix F).

HPV and EBV Knowledge Index. A 14 item measure was created to assess HPV knowledge. Eleven items were taken from a previously validated knowledge measure created by Kahn et al. (2003). This measure contains items that assess knowledge regarding HPV transmission, detection, and treatment in a true/false format. Two items were added to assess knowledge regarding HPV's direct relation to genital warts and cervical cancer, and one additional item was added to assess knowledge of a vaccine to prevent cervical cancer. A parallel measure was created for the Epstein-Barr Virus, assessing knowledge of EBV's transmission, detection, and treatment. There is also an item pertaining to EBV's direct relation to Infectious Mononucleosis (IM). Both measures contained an item assessing knowledge of disease diagnosis rate (see Appendices G and H).

HPV Health Index. Participants diagnosed with HPV were given a health index questionnaire that assessed date of diagnosis, previous. STI infections, and subjective knowledge of HPV. This measure was included in order to confirm that individuals met the criteria for participation as having a new abnormal pap smear diagnosis within the last two months. Subjective knowledge was strongly correlated with actual knowledge, indicating HPV participants were accurately aware of their own understanding of HPV (r = .65, p < .01) (see appendix I).

[3] Items 3 and 6 were reverse scored

[4] Reliabilities given were calculated with the data from the current study

Table 2.1
Correlations Between the SSGS Shame Subscales

Subscale	Disease	Behavioral
Behavioral	0.65**	
State	0.88**	0.61**

Note. *p<.01

Table 2.2
Correlations Between the IES Subscales

Subscale	Intrusion	Avoidance
Avoidance	.78**	
Hyperarousal	.80**	.69**

Note. *p <.01

Section Three: Results

Demographic Information

The current study consisted of 80 women recently diagnosed with HPV-related CIN (n = 40) and EBV related IM (n = 40). The average age of the participants was 21.39 years (SD = 2.95). Participants were predominantly Caucasian (81%), but the sample also included women with other race/ethnic backgrounds: African American (10%), Hispanic (6%), and other (1%). One person in the sample did not indicate her racial/ethnic background. There were no differences between the diagnoses for ethnicity $\chi^2(1, N = 80) = .24$, $p = .62$, relationship status $\chi^2(3, N = 80) = 4.01$, $p = .26$, education level $\chi^2(4, N = 80) = 2.08$, $p = .72$, type of insurance $\chi^2(2, N = 80) = 3.63$, $p = .16$, or income, $t(76) = -1.93$, $p = .06$. There was a significant difference between the two diagnoses in student status, where there were more graduate students in the HPV group (40% vs. 28%), and more undergraduate students in the EBV group (60% vs. 5%) $\chi^2(3, N = 80) = 8.16$, $p < .05$. Although student status differed between groups, there was no significant difference between the groups in age $t(78) = .42$, $p = .68$.

Hypothesis (1): Group Differences in Shame and Guilt

As predicted, women diagnosed with HPV (M = 2.94, SD = 0.97) had significantly higher state shame scores than women diagnosed with EBV (M = 1.80, SD = 0.60), $t(78) = 6.34$, $p < .05$, d =1.14. Similarly, women with HPV (M = 2.08, SD = 1.00) had higher state guilt scores than women with EBV (M = 1.57, SD = .92), $t(78) = 2.40$), $p < .05$, d = 0.53. These results were also consistent across subscales (all p's < .05, all d's > 0.2). However, the two groups did not differ in either the negative evaluation or avoidance scales measuring shame proneness ($t(78) = -1.26$, $p = .40$ and $t(78) = 0.02$, $p = .48$) or the total scale measuring guilt proneness ($t(78) = .01$, $p = .94$) (all d's < 0.2), signifying that there is something unique about HPV diagnosis that elicits these negative affective emotions.

The within subjects differences between shame and guilt were also significant for women with HPV $t(39) = 6.01$, $p < .001$ as well as the women with EBV $t(39) = 2.08$, $p < .05$) (see above analysis for means and standard deviations). This result suggests that shameful experiences were more prevalent than guilt experiences for both groups.

Hypothesis (2a): Group Differences in Depression and Disease-Specific Distress

Women with HPV (M = 11.15, SD = 6.42) had higher CES-D scores than women with EBV (M = 7.13, SD = 5.10), $t(78) = 3.10$, $p < .05$, d = 0.69. This pattern was also present for disease-specific distress scores, where women with HPV (M = 27.95, SD = 17.12) had higher scores on the IES than women with EBV (M = 15.47, SD = 2.51), $t(78) = 3.38$, $p < .01$, d = 1.02.

These results make it difficult to understand whether depression and disease-specific distress are a direct consequence of HPV diagnosis, or if shame and guilt mediate the direct effect between these variables (see Table 3.1 for correlations). To test these theoretical models (see figures 1 & 2), meditational analyses were conducted using the bootstrapping method for multi-mediator models developed by Preacher and Hayes (2008).

Hypothesis (2b): Mediational Relationships between Negative Affect, Depression, and Disease-Specific Distress

The first model tested the effect of diagnosis status on depression with state shame and guilt scores as the mediating variables. This model showed a significant

relationship between diagnosis status and shame (where HPV diagnosis predicted shame) (a_1 path), $B = -1.14$, $p < .01$, between shame and depression (b_1 path), $B = 5.01$, $p < .01$, between diagnosis and guilt (a_2 path), $B = -0.52$, $p < .05$. However, the relationship between guilt and depression (b_2 path) was not significant, $B = 0.79$, $p = .13$. The 95% bootstrapping confidence intervals for the indirect effects (ab_1 and ab_2 paths) were significant for shame (-8.13 to -3.69) indicating partial mediation, but not for guilt (-1.14 to 0.31). The relationship between HPV diagnosis and depression can be partially explained by shame but not by guilt (see Figure 3.1). Moreover, guilt was shown to be unrelated to depression in the model.

The second model tested the effect of diagnosis status on disease-specific distress with state shame and guilt scores as the mediating variables. Both a_1 and a_2 paths were identical to model 1 (above). The relationship between shame and disease-specific distress (b_1 path) was significant, $B = 10.45$, $p < .001$, as was the relationship between guilt and disease-specific distress (b_2 path) $B = 5.19$, $p < .01$. The 95% bootstrapping confidence intervals for the indirect effects (ab_1 and ab_2 paths) were significant for shame (-19.12 to -6.29) indicating partial mediation, but not for guilt (-6.24 to 0.41). The relationship between HPV diagnosis and disease-specific distress can be partially explained by shame but not by guilt (see Figure 3.2).

Hypothesis (3): State Shame, State Guilt, and Disease Knowledge

Hierarchical linear regression analyses were conducted to test the relationship between HPV diagnosis and knowledge on state shame and guilt. It was predicted that diagnosis status (HPV or EBV) and disease knowledge would predict a significant amount of variance in both shame and guilt, and that there will be a significant group by knowledge interaction on affect, where shame and guilt will be significantly lower in the HPV group if knowledge of the disease is high. The total state shame score from the SSGS was regressed onto diagnosis status and total disease knowledge scores in the first step ($R^2\Delta = 0.37$), and also onto their interaction in the second step ($R^2\Delta = .00$, $R^2_{tot} = .37$). The same procedure was conducted for guilt step 1 ($R^2\Delta = .07$), step 2 ($R^2\Delta = .08$, $R^2_{tot} = .16$). The effect of knowledge on shame was not significant ($\beta = -0.23$, $p > .05$); neither was the effect of knowledge of guilt ($\beta = 0.19$, $p > .05$). The interaction between diagnosis status and knowledge on shame was not significant, ($\beta = .06$, $p > .05$) (see Table 3.2); neither was the interaction between diagnosis status and knowledge on guilt, ($\beta = -0.29$, $p > .05$) (see Table 3.3), failing to support the study's third hypothesis.

Because previous literature has suggested that prevalence information may reduce negative affect associated with HPV diagnosis, identical regression analyses were conducted using item 15 on the knowledge index "What percentage of women will be diagnosed with HPV/EBV in their lifetime?" as the knowledge predictor. Total shame scores from the SSGS were regressed onto diagnosis status and item 15 in the first step ($R^2\Delta = .40$) and onto their interaction in the second step ($R^2\Delta = 0.02$, $R^2_{tot} = .42$). The effect of knowledge on shame was significant ($\beta = -0.60$, $p < .05$), where increased prevalence knowledge predicted decreases in shameful emotion. This effect was not present for guilt ($\beta = 0.29$, $p > .05$). The interactions between diagnosis status and knowledge where also not significant for shame ($\beta = 0.43$, $p > .05$) or guilt ($\beta = -0.26$, $p > .05$) (see Tables 3.4 & 3.5).

Table 3.1

Correlations Between Diagnosis, Knowledge, Shame, Guilt, Depression and Distress

Variable	Diagnosis	State Shame	State Guilt	IES-R	CES-D	Knowledge	Prevalence	GuiltProne
State Shame	-.58**							
State Guilt	-.26*	.60**						
IES	-.36**	.73**	.63**					
CES-D	-.32**	.79**	.60**	.80**				
Knowledge	.04	-.20	-.08	-.09	-.09			
Prevalence Item	.11	-.21	.04	-.12	-.25*	.14		
Guilt Prone	.14	.09	.30**	.16	.04	.10	.21	
Shame Prone (apb)	-.02	.01	-.05	-.09	.02	-.01	.05	.14
Shame Prone (nse)	.14	.01	.09	.13	.05	.06	.09	.57**

Note. *$p < .05$, **$p < .01$; HPV = 0, EBV = 1

Table 3.2
Hierarchical Linear Regression Model for Diagnosis X Total Knowledge on Shame

	R	Rsq.	Rsq. Δ	Beta	partial r	*p*-value
Model 1	.61	.37	.37			
Diagnosis				-.57	-.59	<.01
Total Knowledge				-.18	-.22	.52
Model 2	.61	.37	.00			
Diagnosis				-.58	-.59	<.01
Total Knowledge				-.23	-.09	.39
Diagnosis X Knowledge				.06	.02	.84

Note: HPV = 0, EBV = 1

Table 3.3
Hierarchical Linear Regression Model for Diagnosis X Total Knowledge on Guilt

	R	Rsq.	Rsq. Δ	Beta	partial r	*p*-value
Model 1	.27	.07	.07			
Diagnosis				-.51	-.26	.21
Total Knowledge				-.07	-.07	.52
Model 2	.29	.08	.01			
Diagnosis				-.26	-.26	.02
Total Knowledge				.19	.07	.55
Diagnosis X Knowledge				-.29	-.10	.39

Note: HPV = 0, EBV = 1

Table 3.4

Hierarchical Linear Regression Model for Diagnosis X Prevalence Knowledge on Shame

	R	Rsq.	Rsq. Δ	Beta	partial r	*p*-value
Model 1	.63	.40	.40			
Diagnosis				-.60	-.61	.21
Total Knowledge				-.20	-.25	.03
Model 2	.65	.42	.02			
Diagnosis				-.60	-.62	<.01
Total Knowledge				-.60	-.24	.03
Diagnosis X Knowledge				.43	.17	.13

Note: HPV = 0, EBV = 1

Table 3.5

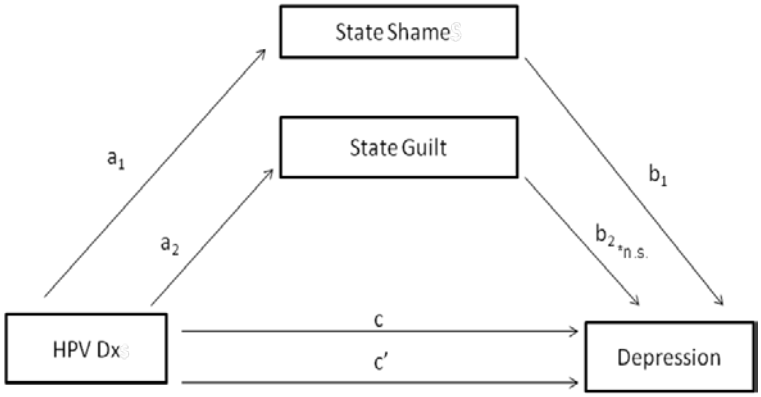
Hierarchical Linear Regression Model for Diagnosis X Prevalence Knowledge on Guilt

	R	Rsq.	Rsq. Δ	Beta	partial r	*p*-value
Model 1	.30	.09	.09			
Diagnosis				-.30	-.30	.01
Total Knowledge				.04	.04	.72
Model 2	.32	.10	.01			
Diagnosis				-.30	-.30	.01
Total Knowledge				.29	.01	.41
Diagnosis X Knowledge				-.26	-.09	.45

Note: HPV = 0, EBV = 1

Figure 3.1

The Relationship between HPV Diagnosis and Depression with Shame and Guilt as Mediators



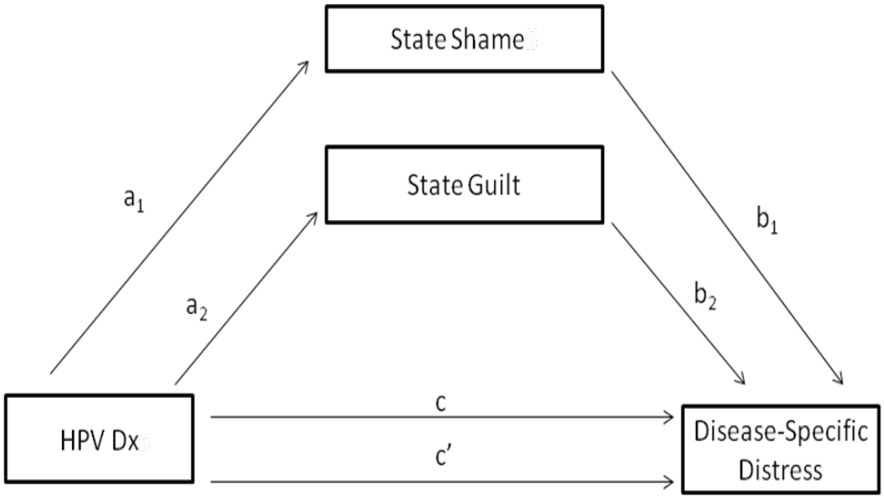
Indirect Effect with Shame (ab_1) = (-8.13 to -3.69) Significant

Indirect Effect with Guilt (ab_2) = (-1.14 to 0.31) Not significant

*Guilt was unrelated to depression in the model, b_2 was not significant

Figure 3.2

The Relationship between HPV Diagnosis and Distress with Shame and Guilt as Mediators



Indirect Effect with Shame (ab_1) = (-19.12 to -6.29) Significant

Indirect Effect with Guilt (ab_2) = (-6.24 to 0.41) Not significant

Section Four: Discussion

Summary

Recent literature has suggested that diagnosis of HPV can lead to persistent experiences of distress, most notably shame and guilt, as well as perceived social threat (Clark et al., 1996; Kahn et al., 2007; Maissi et al., 2004). Not only does HPV diagnosis impact psychosocial functioning, but these negative self-conscious emotional states have been associated with compromised immune function. In several studies, persistent shame was related to declines in CD4+ cells (Dickerson et al., 2004). These cells have shown to be vital in the clearance of HPV lesions. The current study also found that shame was responsible for the relationships between HPV diagnosis and depression/distress.For these reasons, it is important to investigate how to reduce negative self-conscious emotions, particularly shame, in women diagnosed with HPV. Some research has suggested that increases in HPV knowledge may mitigate negative affective experiences such as shame (Kahn et al., 2007; Waller et al., 2007), especially knowledge related to the high rates of diagnosis. The primary goal of this study was to understand how knowledge of HPV diagnosis would affect feelings of shame in guilt in a sample of recently diagnosed young women.

Women ranging in age from 18 to 28 who were recently diagnosed with HPV-related cervical intraepithelial neoplasia (CIN) were given measures of shame and guilt proneness, state shame and guilt, depression, disease-specific distress, and HPV knowledge. A comparison group of women recently diagnosed with Infectious Mononucleosis (IM) due to Epstein-Barr Virus (EBV) were also given identical measures, including EBV-specific knowledge.

Hypothesis (1): Group Difference in Shame and Guilt

As predicted, women with HPV reported greater shame and guilt than women diagnosed with EBV. Women diagnosed with HPV had higher incidence of both state shame and guilt than women diagnosed with EBV, supporting the first hypothesis and results of previous studies. The strength of this result can be bolstered in this study due to the inclusion of a comparison group of women diagnosed with an immunologically-similar disease. This was the first study of its kind to use this type of comparison condition. Additionally, the differences in negative affect between the groups were not due to individual differences in shame and guilt proneness, suggesting that there is something unique about the experience of being diagnosed with HPV that elicits this negative self-directed affect.

Hypothesis (2a): Group Differences in Depression and Disease-Specific Distress

Women with HPV had higher levels of both depression and disease-specific distress as indicated on the CES-D and IES-R, respectively. One possibility for these differences could be that HPV diagnosis leads to feelings of depression and lingering distress from the impact of diagnosis, which in turn spark negative self-directed affective states such as shame and guilt. Another possibility is that HPV diagnosis directly leads to negative self-directed affect, which in turn leads to depressive and distressful states.

Hypothesis (2b):Mediational Relationships between Negative Affect, Depression, and Disease-Specific Distress

The latter model (above) has been supported in other stressful life events, such as a marital separation (Orth et al., 2006). It was predicted that the relationship between HPV diagnosis and depression would be mediated by shame but not by guilt. The same

result was predicted for the relationship between HPV diagnosis and disease-specific distress.

In order to test these theoretical models (see figures 1 & 2), mediational analyses were using the multi-mediator bootstrapping method (Preacher & Hayes, 2008). The results suggested that shame partially mediated the relationship between HPV diagnosis and both depression and disease-specific distress, but this was not true for guilt. Moreover, in the first model, the path between guilt and depression was not significant, indicating that guilt was unrelated to depression in the model. These results are in line with previous research that has suggested that shame overlaps with depression, but guilt does not (Orth et al., 2006).

We can argue from the results of these mediational tests that HPV diagnosis can lead to negative psychological states such as depression and distress, but it does so through shameful experiences. Guilt, on the other hand, cannot account for the relationship between diagnosis and these negative states. Not only is shame responsible for a decline in important immunological parameters (Dickerson et al., 2004), but the results from this study show it is also related to detriments in psychosocial functioning.

Hypothesis (3): State Shame, State Guilt, and Disease Knowledge

It was also predicted that knowledge would moderate the diagnosis-shame relationship, where increases in disease knowledge would lead to decreases in negative affective states (i.e., shame and guilt) in women diagnosed with HPV, but that no such relationship would exist in EBV patients. This hypothesis was not supported in the current study for total disease knowledge. However, when the specific item "What percentage of women will be diagnosed with HPV/EBV in their lifetime?" from the knowledge questionnaire was used in the regression model, there was a significant main effect for knowledge but no significant interaction. Increases in this percentage predicted lower shame scores overall, but did not do so differentially by diagnosis status. There were no significant effects for guilt using this item.

HPV Diagnosis: The Role of Knowledge

Literature continues to suggest that HPV diagnosis is related to negative affective states, including shame. One study by Waller, Marlow, and Wardle (2007) suggested that increases in HPV knowledge, such as levels of prevalence, decrease feelings of shame and perceived stigma. However, this study only asked individuals to imagine that they were diagnosed with HPV. The current effort was the first known study using actual HPV patients to test this hypothesis. Even though knowledge of higher disease preference rates did predict shame, it did so for both HPV and EBV patients. It may be reasonable to suggest that information regarding high prevalence rates for any disease d iagnosis may decrease shameful emotions, as increased prevalence may decrease the possibility for stigma.

In contrast to their previous study, Waller and colleagues (2009) found that HPV information actually increased anticipated shame and worry, although this was most apparent in non-white ethnic groups and individuals with lower levels of education. These competing results, along with the results of the current study, suggest that the relationship between HPV knowledge and negative affect is still largely unclear.

Researchers do agree, however, that levels HPV-related knowledge remain low in the general population, even after the introduction of the Gardasil vaccine (Wong & Sam, 2010). Moreover, research continues to suggest that healthcare providers continue to give

incomplete or unclear information to their patients regarding HPV and cervical cancer (Cermak, Cotrell, & Murnan, 2010). Even though the relationships between HPV knowledge and affect are still ambiguous, it is important for individuals to understand the transmission and etiology of HPV in order increase preventative behaviors such as vaccination (Devereaux Walsh, Gera, Shah, Sharma, Powell & Wilson, 2008). HPV knowledge may also improve screening adherence (Miller, Micshel, O'Leary & Mills, 1996).

Limitations and Future Directions

The cross-sectional design of the current study made it difficult to determine the causal mechanisms between HPV, knowledge, shame. With a larger sample size, a structural equation model could have been used to evaluate pathways and compare the fit of these data to the two theoretical models proposed in this study. It is also worth noting that a longitudinal design would provide even greater evidence regarding the causal nature of these relationships. Nevertheless, this study suggested that the relationship between HPV diagnosis and negative psychological states such as depression and distress were partially explained by shameful experiences.

Shame's relation to decreased CD4+ cells and negative psychosocial functioning such as depression and distress should continue to be the driving force for future research, considering shame is an enduring aspect of HPV diagnosis (Clark et al, 1992). Decreasing shameful experiences may give women with HPV a better disease prognosis, as CD4+ cells are vital in the clearance of HPV lesions (Coleman et al., 1994). Measuring immune parameters may be a way to understand how HPV-related shame contributes to disease progression. Moreover, improvement in psychological functioning may improve HPV prognosis through treatment adherence.

Conclusions

This study was able to show that HPV diagnosis is related to negative affective states such as shame and guilt. Because this study used a comparison group of women diagnosed with another viral illness, it can be concluded that the HPV experience is inimitable. Shame's relationship to HPV is much more broad and complex than guilt, as it is the mediating variable between the diagnosis and negative psychological states such as depression and disease-specific distress.

Shame's relationship to negative psychosocial outcomes may also have subsequent behavioral consequences in HPV diagnosis. It may be possible that persistent shame experiences would decrease preventative behaviors and treatment adherence. If shame decreases the likelihood of future screening behavior, than increases in cervical cancer morbidity and mortality would result.

There are competing theories of how knowledge of HPV affects affective states (Maissi et al., 2004; Waller et al., 2007; Waller et al., 2009). This study was unable to show that knowledge mitigated HPV-related shame. However, knowledge of disease prevalence decreased shame in both groups, which may suggest that providing adequate knowledge to patients may still be beneficial, especially if it increases prevention behaviors or adherence to treatment guidelines.

Appendix A: **Demographic Information Sheet**

Age: _____ (years)

Ethnicity:

☐Non- Hispanic

☐Hispanic

Race:

☐Hispanic

☐Caucasian

☐African Descent

☐Asian

☐Native American

☐Other_____

Highest level of education completed

☐Some high school

☐High school or GED

☐Some college

☐Bachelor's Degree

☐Graduate or Professional Degree

What type of health insurance do you have?

☐ Private health insurance

☐ Medicare/Medicaid

☐I do not have health insurance

Relationship Status:

☐ Single

☐ Serious Relationship

☐ Married

☐ Separated

☐ Other _____

Estimated yearly household income

☐ less than $10,000 per year

☐ $10,001 - $20,000 per year

☐ $20,001 - $40,000 per year

☐ $40,001 - $60,000 per year

☐ $60,001 - $80,000 per year

☐ greater than $100,000 per year

☐ $80,001 - $100,000 per year

Current student status:

☐ Undergraduate

☐ Graduate or Professional School

☐ non-student - employed

☐ non-student – unemployed

Appendix B: **GASP**

Instructions: In this questionnaire you will read about situations that people are likely to encounter in day-to-day life, followed by several common reactions to those situations. As you read each scenario, try to imagine yourself in that situation. Then indicate the likelihood that would react in the way described.

1	2	3	4	5	6	7
Very Unlikely	Unlikely	Slightly Unlikely	About 50% Likely	Slightly Likely	Likely	Very Likely

_____ 1. After realizing you have received too much change at a store, you decide to keep it because the salesclerk doesn't notice. What is the likelihood that you would feel uncomfortable about keeping the money?

_____ 2. You are privately informed that you are the only one in your group that did not make the honor society because you skipped too many days of school. What is the likelihood that this would lead you to become more responsible about attending school?

_____ 3. You rip an article out of a journal in the library and take it with you. Your teacher discovers what you did and tells the librarian and your entire class. What is the likelihood that this would make you would feel like a bad person?

_____ 4. After making a big mistake on an important project at work in which people were depending on you, your boss criticizes you in front of your coworkers. What is the likelihood that you would feign sickness and leave work?

_____ 5. You reveal a friend's secret, though your friend never finds out. What is the likelihood that your failure to keep the secret would lead you to exert extra effort to keep secrets in the future?

_____ 6. You give a bad presentation at work. Afterwards your boss tells your coworkers it was your fault that your company lost the contract. What is the likelihood that you would feel incompetent?

_____ 7. A friend tells you that you boast a great deal. What is the likelihood that you would stop spending time with that friend?

_____ 8. Your home is very messy and unexpected guests knock on your door and invite themselves in. What is the likelihood that you would avoid the guests until they leave?

_____ 9. You secretly commit a felony. What is the likelihood that you would feel remorse about breaking the law?

1	2	3	4	5	6	7
Very Unlikely	Unlikely	Slightly Unlikely	About 50% Likely	Slightly Likely	Likely	Very Likely

_____ 10. You successfully exaggerate your damages in a lawsuit. Months later, your lies are discovered and you are charged with perjury. What is the likelihood that you would think you are a despicable human being?

_____ 11. You strongly defend a point of view in a discussion, and though nobody was aware of it, you realize that you were wrong. What is the likelihood that this would make you think more carefully before you speak.

_____ 12. You take office supplies home for personal use and are caught by your boss. What is the likelihood that this would lead you to quit your job?

_____ 13. Because of your carelessness, you break something you borrowed from a friend, though your friend never notices. What is the likelihood that you would replace what you broke?
_____ 14. You make a mistake at work and find out a coworker is blamed for the error. Later, your coworker confronts you about your mistake. What is the likelihood that you would feel like a coward?
_____ 15. You make a strong argument in a debate but the moderator points out to everyone that your facts are incorrect. What is the likelihood that you would feel like an idiot?
_____ 16. You falsify some information in a job application though it is never discovered. What is the likelihood that you would feel that the way you acted was despicable?
_____17. While you are out with friends, someone you knowingly deceived tells your friends that you are a liar. What is the likelihood that you would quickly leave and go home?
_____ 18. At a coworker's housewarming party, you spill red wine on their new cream-colored carpet. You cover the stain with a chair so that nobody notices your mess. What is the likelihood that you would feel that the way you acted was pathetic?
_____ 19. While discussing a heated subject with friends, you suddenly realize you are shouting though nobody seems to notice. What is the likelihood that you would try to act more considerately toward your friends?
_____ 20. You lie to people but they never find out about it. What is the likelihood that you would feel terrible about the lies you told?

You are finished with this section. Please turn the page and continue.

Appendix C: **SSGS-HPV**

Take a minute and think about your recent abnormal pap smear that indicated that you had cervical dysplasia caused by HPV. The following are some statements that may or may not describe how you are feeling **RIGHT NOW.** Please rate each statement using the 5 point scale below. Remember to rate each statement based on how you are feeling **RIGHT AT THIS MOMENT.**

	Not feeling this way at all	Feeling this way somewhat	Feeling this way very strongly
1. I feel good about myself.	1----------2----------3----------4----------5		
2. I want to sink into the floor and disappear.	1----------2----------3----------4----------5		
3. I feel remorse, regret.	1----------2----------3----------4----------5		
4. I feel worthwhile, valuable.	1----------2----------3----------4----------5		
5. I feel small.	1----------2----------3----------4----------5		
6. I feel tension about something I have done.	1----------2----------3----------4----------5		
7. I feel capable, useful.	1----------2----------3----------4----------5		
8. I feel like I am a bad person.	1----------2----------3----------4----------5		
9. I cannot stop thinking about something bad I have done.	1----------2----------3----------4----------5		
10. I feel proud.	1----------2----------3----------4----------5		
11. I feel humiliated, disgraced.	1----------2----------3----------4----------5		
12. I feel like apologizing, confessing.	1----------2----------3----------4----------5		
13. I feel please about something I have done.	1----------2----------3----------4----------5		
14. I feel worthless, powerless.	1----------2----------3----------4----------5		
15. I feel bad about something I have done.	1----------2----------3----------4----------5		

16. I feel like my body is damaged. 1----------2----------3----------4----------5

17. I feel others would treat me differently if they knew about my diagnosis. 1----------2----------3----------4----------5

18. I feel like I'm now part of a stigmatized group of people. 1----------2----------3----------4----------5

19. I feel like no one will ever love me because of my diagnosis. 1----------2----------3----------4----------5

20. I feel like others will see me as damaged. 1----------2----------3----------4----------5

Please rate each statement below as an indicator of how **WILLING** you would be to do the following:

	Extremely Unwilling		Somewhat Willing		Extremely Willing

1. Tell my friends I have HPV…….. 1----------2----------3----------4----------5

2. Tell a family member I have HPV…….……1----------2----------3----------4----------5

3. Tell my current/future partners that I have HPV…….. 1----------2----------3----------4----------5

4. Tell another healthcare provider that I have HPV…… . 1----------2----------3----------4----------5

5. Talk to a group of high-school students about my experience with HPV. 1----------2----------3----------4----------5

6. Talk to sororities on campus about my experience with HPV…….. . 1----------2----------3----------4----------5

7. Attend a support group for women diagnosed with HPV……. 1----------2----------3----------4----------5

8. Have my picture and my HPV
status featured in an advertisement
for HPV prevention……..... 1----------2----------3----------4----------5

You are finished with this section. Please turn the page and continue.

Appendix D: **SSGS-EBV**

Take a minute and think about your recent diagnosis of Infectious Mononucleosis "mono" that caused by exposure to the Epstein-Barr Virus (EBV). The following are some statements that may or may not describe how you are feeling **RIGHT NOW.** Please rate each statement using the 5 point scale below. Remember to rate each statement based on how you are feeling **RIGHT AT THIS MOMENT.**

	Not feeling this way at all	Feeling this way somewhat	Feeling this way very strongly
1. I feel good about myself.	1----------2----------3----------4----------5		
2. I want to sink into the floor and disappear.	1----------2----------3----------4----------5		
3. I feel remorse, regret.	1----------2----------3----------4----------5		
4. I feel worthwhile, valuable.	1----------2----------3----------4----------5		
5. I feel small.	1----------2----------3----------4----------5		
6. I feel tension about something I have done.	1----------2----------3----------4----------5		
7. I feel capable, useful.	1----------2----------3----------4----------5		
8. I feel like I am a bad person.	1----------2----------3----------4----------5		
9. I cannot stop thinking about something bad I have done.	1----------2----------3----------4----------5		
10. I feel proud.	1----------2----------3----------4----------5		
11. I feel humiliated, disgraced.	1----------2----------3----------4----------5		
12. I feel like apologizing, confessing.	1----------2----------3----------4----------5		
13. I feel please about something I have done.	1----------2----------3----------4----------5		
14. I feel worthless, powerless.	1----------2----------3----------4----------5		
15. I feel bad about something I have done.	1----------2----------3----------4----------5		
16. I feel like my body is damaged.	1----------2----------3----------4----------5		
17. I feel others would treat me			

differently if they knew about my diagnosis. 1----------2----------3----------4----------5

18. I feel like I'm now part of a stigmatized group of people. 1----------2----------3----------4----------5

19. I feel like no one will ever love me because of my diagnosis. 1----------2----------3----------4----------5

20. I feel like others will see me as damaged. 1----------2----------3----------4----------5

Please rate each statement below as an indicator of how **WILLING** you would be to do the following:

	Extremely Unwilling		Somewhat Willing		Extremely Willing
1. Tell my friends I have EBV……..	1	2	3	4	5
2. Tell a family member I have EBV…….……	1	2	3	4	5
3. Tell my current/future partners that I have EBV……..	1	2	3	4	5
4. Tell another healthcare provider that I have EBV…… .	1	2	3	4	5
5. Talk to a group of high-school students about my experience with EBV.	1	2	3	4	5
6. Talk to sororities on campus about my experience with EBV……..	1	2	3	4	5
7. Attend a support group for women diagnosed with EBV…...	1	2	3	4	5
8. Have my picture and my EBV status featured in an advertisement for EBV prevention……...	1	2	3	4	5

You are finished with this section. Please turn the page and continue.

Appendix E: **CES-D Short Form**

Below is a list of some ways you may have felt or behaved. Please indicate how often you have felt this way during the **PAST WEEK:** (*check* **ONE** *number on each line).*

	Rarely or none of the time (Less than 1 day)	**Some or a little of the time (1-2 days)**	**Occassionally or a moderate amount of time (3-4 days)**	**All of the time (5-7 days)**
	0	**1**	**2**	**3**
During the Past Week….				
1. I was bothered by things that usually don't bother me	☐ 0	☐ 1	☐ 2	☐ 3
2. I felt that I could not shake off the blues even with help from my family	☐ 0	☐ 1	☐ 2	☐ 3
3. I felt that I was just as good as other people	☐ 0	☐ 1	☐ 2	☐ 3
4. I had trouble keeping my mind on what I was doing	☐ 0	☐ 1	☐ 2	☐ 3
5. I felt that everything I did was an effort	☐ 0	☐ 1	☐ 2	☐ 3
6. I felt hopeful about the future	☐ 0	☐ 1	☐ 2	☐ 3
7. I thought my life had been a failure	☐ 0	☐ 1	☐ 2	☐ 3
8. I felt fearful	☐ 0	☐ 1	☐ 2	☐ 3
9. I felt lonely	☐ 0	☐ 1	☐ 2	☐ 3
10. People were unfriendly	☐ 0	☐ 1	☐ 2	☐ 3

Appendix F: **IES Revised**

Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you **DURING THE PAST SEVEN DAYS** with respect to your diagnosis, how much were you distressed or bothered by these difficulties?

	Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
Any reminder brought back feelings about it	0	1	2	3	4
I had trouble staying asleep	0	1	2	3	4
Other things kept making me think about it	0	1	2	3	4
I felt irritable and angry	0	1	2	3	4
I avoided letting myself get upset when I thought about it or was reminded of it	0	1	2	3	4
I thought about it when I didn't mean to	0	1	2	3	4
I felt as if it hadn't happened or wasn't real	0	1	2	3	4
I stayed away from reminders about it	0	1	2	3	4
Pictures about it popped into my mind	0	1	2	3	4
I was jumpy and easily startled	0	1	2	3	4
I tried not to think about it	0	1	2	3	4
I was aware that I still had a lot of feelings about it, but I didn't deal with them	0	1	2	3	4
My feelings about it were kind of numb	0	1	2	3	4

I found myself acting or feeling as though I was back at that time	0	1	2	3	4
I had trouble falling asleep	0	1	2	3	4
I had waves of strong feelings about it	0	1	2	3	4
I tried to remove it from my memory	0	1	2	3	4
I had trouble concentrating	0	1	2	3	4
Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart	0	1	2	3	4
I had dreams about it	0	1	2	3	4
I felt watchful or on-guard	0	1	2	3	4
I tried not to talk about it	0	1	2	3	4

You are finished with this section. Please turn the page and continue.

Appendix G: **HPV-KQ**

Please circle the correct response to each question as either TRUE or FALSE.

1. A person may be infected with HPV and not know it.	**TRUE**	**FALSE**
2. Those with HPV may need pap smears more often.	**TRUE**	**FALSE**
3. HPV is spread by sexual intercourse.	**TRUE**	**FALSE**
4. Pap smears can detect HPV.	**TRUE**	**FALSE**
5. HPV can be cured with antibiotics.	**TRUE**	**FALSE**
6. HPV causes abnormal menstrual periods.	**TRUE**	**FALSE**
7. Smoking increases the chance of developing cervical cancer.	**TRUE**	**FALSE**
8. Condoms do not help protect you from HPV.	**TRUE**	**FALSE**
9. HPV goes away with the right treatment.	**TRUE**	**FALSE**
10. Certain types of HPV always cause cancer.	**TRUE**	**FALSE**
11. HPV can cause problems with pregnancy.	**TRUE**	**FALSE**
12. HPV is the leading cause of genital warts.	**TRUE**	**FALSE**
13. HPV can cause cervical cancer.	**TRUE**	**FALSE**
14. Some types of HPV can be prevented with a vaccine.	**TRUE**	**FALSE**

Approximately what percentage of women will contract HPV by the time they reach the age of 50 years old? _____%

You are finished with this section. Please turn the page and continue

Appendix H: **EBV-KQ**

Please circle the correct response to each question as either TRUE or FALSE.

1. A person may be infected with Epstein-Barr Virus (EBV) and not know it.	**TRUE**	**FALS E**
2. A blood test can detect EBV	**TRUE**	**FALSE**
3. EBV is spread by the exchange of saliva.	**TRUE**	**FALSE**
4. EBV can be cured with antibiotics.	**TRUE**	**FALSE**
5. Exposure to EBV always causes a person to develop infectious mononucleosis or "mono".	**TRUE**	**FALSE**
6. Children rarely get mono from EBV.	**TRUE**	**FALSE**
7. EBV goes away with the right treatment.	**TRUE**	**FALSE**
8. EBV can cause swollen glands and a sore throat.	**TRUE**	**FALSE**
9. Covering your cough helps prevent the spread of EBV.	**TRUE**	**FALSE**
10. EBV can cause problems with your spleen.	**TRUE**	**FALSE**
11. People with EBV can show symptoms for months at a time.	**TRUE**	**FALSE**
12. Smoking increases the chances of developing mono.	**TRUE**	**FALSE**
13. EBV has been associated with some types of cancer.	**TRUE**	**FALSE**
14. Some types of EBV can be prevented with a vaccine.	**TRUE**	**FALSE**

Approximately what percentage of people will contract EBV in their lifetime?

_____%

Appendix I: **Health Index - HPV**

1. How many days has it been since you were told about your diagnosis of HPV?
_____

2. Have you ever been diagnosed with a previous Sexually Transmitted Infection?

☐YES

☐NO

3. Have you ever previously had an abnormal pap smear?

☐YES

☐NO

4. If so, when? _____

5. Have you ever been diagnosed with HPV before this time?

☐YES

☐NO

Please circle **ONE NUMBER** to indicate your response.

6. How would you rate your knowledge of HPV?

I have no knowledge					*I am very knowledgeable*
0	1	2	3	4	5

7. How much research did you do on HPV after learning about your diagnosis?

I did no research					*I researched it a lot*
0	1	2	3	4	5

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