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UNCERTAIN KNOWLEDGE OF A CERTAIN VIRUS

HUMAN PAPILLOMAVIRUS AND ABNORMAL PAP SMEARS: AN INTERNET SURVEY OF KNOWLEDGE AND BELIEFS AMONG A UNIVERSITY POPULATION IN HAWAI'I

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DEDICATION

This dissertation is dedicated to the memory of three compassionate people whose influence was profound: my mother, Helen Cramer; my father, Irving Cramer, M.D.; and my mentor, Benjamin Branch, M.D..

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ABSTRACT

Despite the fact that 3.5 million (7%) U.S. women have abnormal Pap smears every year that require further evaluation (Wright, Cox, Massed, Twigg, & Wilkinson, 2002), and despite the high prevalence of Human Papillomavirus, the primary causative agent in cervical carcinogenesis, there is an inordinately low level of knowledge about HPV and abnormal Pap smears both among patients with abnormal Pap smears and among the general public.

This study focused on the assessment of knowledge and beliefs about HPV and abnormal Pap smears among an Internet-using university student population in Hawai`i. Specific nuances of knowledge or lack of knowledge about HPV and abnormal Pap smears among the sample population were described. This study is unique methodologically in that it utilized an Internet-based survey instrument. The independent variables examined were age, gender, ethnicity, HPV risk behavior, and experience with an abnormal Pap smear. The dependent variable was a 14-question knowledge composite (HPVAPK) that addressed issues related to HPV and abnormal Pap smears.

The theory of uncertainty in illness (M. Mishel, 1981–1988), which addresses adaptive and maladaptive responses to the disclosure and experience of acute and chronic illness, supports this study conceptually. Complexity, ambiguity, lack of information, and an unpredictable prognosis are the hallmarks of uncertainty. Each of these factors of uncertainty describes the experience of women with abnormal Pap smears.

The survey showed that there was a low level of knowledge about HPV and abnormal Pap smears in an educated, reproductive-aged population in Hawai`i, and that

although women with a history of an abnormal Pap smear were more knowledgeable than those without experience, even those women with abnormal Pap smears had a low level of knowledge about certain issues related to HPV and abnormal Pap smears. Females in the older age group were slightly more knowledgeable, but also had more direct experience in having an abnormal Pap smear than the younger age group. Caucasians scored slightly higher than Asians, Hawaiians, Filipinos, and Hispanics, despite a lack of significant experiential differences among ethnicities. Those with a higher risk of HPV exposure were more knowledgeable than those at lower risk. Individual item analysis of HPVAPK responses and belief item responses reveals underlying issues and beliefs related to knowledge.

Knowledge is vital as a moderator of stress and adaptation among women who experience the uncertainty of cervical disease. Western medicine's gift of early detection and cancer prevention undoubtedly saves lives. By taking more time to place the concept of impending disease into a more realistic perspective, healthcare practitioners can reduce the uncertainty in the lives of patients and thereby increase their ability to adapt and cope with subsequent health-related events.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

PROBLEM AND PURPOSE

Problem Statement

Among the 50 million Papanicolaou (Pap) smears obtained annually in the United States, approximately 3.5 million (7%) reveal cytological abnormalities requiring follow-up (Wright, Cox, Massad, Twigg, & Wilkinson, 2002). Human Papillomavirus (HPV) has been identified as an etiological agent in the development of cervical cancer and cervical precancer. It is now established that 99.8% of the 320,000 cervical cancers that occur annually worldwide involve HPV (Cox, Buck, Kinney, & Rubin, 2001). Cervical cancer remains the second most common gynecologic cancer in developing countries, where routine Pap-smear screening is less accessible than in developed countries with national screening programs (Smith et al., 2003). In the United States, cervical cancer incidence in 2002 was 13,000 cases and 4,100 deaths. Cervical cancer now ranks 10th among cancers in U.S. women. This represents a decrease in incidence and mortality by as much as 50% in the past 30 years (American Cancer Society [ACS], 2003). This success is attributed to early detection and treatment of precancerous lesions. However, the gift of cancer prevention is bundled with the uncertainty inherent in identifying impending disease.

The presence of Human Papillomavirus (HPV), a sexually transmittable virus, is necessary for the development of cervical cancer, although it alone is not sufficient to cause cancer (ZurHausen, 2002; Schiffman & Castle, 2003). It is only recently that HPV has been clearly identified as an etiological agent involved in this process. Estimates of

the incidence of HPV infection among young women are as high as 50% within the first two years of sexual debut (Bekkers, Massuger, Bulten, & Melchers, 2004). HPV prevalence estimates based on positive HPV DNA detection have wide variance (ranging from 24% to 60%) but appear to be highest in people between the ages of 19 and 25 (Gerhardt, Pong, Kollar, Hillard, & Rosenthal, 2000). It has been reported that at least 20 million Americans have acquired HPV infection and approximately six million new infections occur per year (Unger & Duarte-Franco, 2001). A large majority of these are asymptomatic infections, many of which resolve spontaneously. Since a majority of women infected with HPV never develop cervical cancer or precancer, it is suspected that there are cofactors promoting disease as well as protective factors that can prevent HPV from causing disease.

The Pap-smear screening test is widely used for the early detection of cervical disease. It is capable of detecting cervical cancer, cervical precancer, and less portentous cervical changes. HPV testing is not clinically useful as a primary screening tool since positive HPV status alone is not predictive of persistent disease. HPV testing is currently used as an adjunct to clinical decision-making when an abnormal Pap smear has detected cervical disease. An abnormal Pap smear represents evidence that HPV has been present and persistent under the necessary conditions to establish cervical disease.

For female patients, the abnormal Pap smear is the first sign that a problem exists during an otherwise asymptomatic process. A paradigm shift is occurring in the management of abnormal Pap smears as a result of advances in the scientific understanding of the natural history of HPV. During disclosure of an abnormal Pap smear, information about HPV is now beginning to be introduced by health-care

providers. Previously, women who had abnormal Pap smears were told by their health-care providers that the cause of their abnormal Pap smear was unknown, but that their condition was treatable, and cervical cancer could most certainly be prevented. It is now necessary to acknowledge that HPV, a sexually transmittable virus, is involved in the development of cervical cancer and cervical precancer. Health-care providers must now consider the ethical necessity of fully informing patients about the nature of this condition.

When HPV is acknowledged as an etiological agent during or after disclosure of an abnormal Pap smear, female patients are simultaneously faced with the distressing concepts of cervical cancer risk and sexually transmitted viral infection. Women with abnormal Pap smears may experience the fear of cancer and the fear, shame, or anger that may be associated with a sexually transmitted infection. Health-care providers can reassure those affected that early detection and treatment of cervical dysplasia can prevent cervical cancer, but it must be acknowledged that many aspects of HPV are yet unknown. Questions regarding HPV latency, patterns of infectivity, host immune response, and determinants of the spontaneous resolution, persistence, or recurrence of infection are currently under clinical and laboratory investigation. Female patients may have urgent questions regarding threats to their future reproductive capacity, ethical questions regarding partner involvement, questions about prognosis, fear of painful or expensive procedures, or fear of genital disfigurement. They may experience a disruption in self-esteem, sexual guilt, or feelings of powerlessness regarding their future sexual health. The partners of women with abnormal Pap smears are also affected. They may blame themselves, may suspect their partners of infidelity, or may be concerned about how HPV will affect their own sexuality.

There is a need for dissemination of a focused strategy of patient education for those who have had an abnormal Pap smear, to provide relevant information, decrease the complexity of the issue, and provide reassurance that cervical cancer is preventable. It may be necessary to address issues such as blame or guilt that may be associated with sexually transmitted disease, and provide patients with supportive resources to address these issues. There is also a need to educate the general public about HPV. Despite the increasingly high prevalence of HPV, those people at risk of exposure lack knowledge about the existence of HPV, its relationship to cervical cancer, as well as a reasonable perspective regarding HPV consequences (Gerhardt et al., 2000; Holcomb, Bailey, Crawford, & Ruffine, 2004; Lambert, 2001; Waller, McCaffery, Forrest, & Wardle, 2004; Yacobi, Tennant, Ferrante, Pal, & Roetzheim, 1999).

The U.S. Department of Health and Human Services' (DHHS) project goals for public-health issues, known as Healthy People 2010, identifies sexual health and sexually transmitted disease as a priority area for research and intervention (Healthy People, 2010). The DHHS, Centers for Disease Control (CDC), Division of STD Prevention supported the convention of a consensus panel in 1999 to address HPV prevention, infection, and sequelae. A consensus statement was developed by this expert panel to identify research priorities which included:

1. Assessment of counseling/education needs of patients/partners (high priority)
2. Determination of psychosocial impact of diagnosis of HPV and of disclosure to partners (intermediate priority)
3. Surveys of knowledge and attitudes of the general public (intermediate priority)

4. Pilot public education programs to assess optimal form and content and drawbacks of messages (high priority) (DHHS, 1999)

A primary focus of nursing science is the adjustment to illness, utilizing a holistic approach that acknowledges the patient's environmental influences, coping strategies, and informational needs. If health-care providers can better understand the psycho-social effects and informational needs of women and the partners of women who develop abnormal Pap smears, they will be better prepared to provide adequate information, framed and timed appropriately so as to optimize patients' adaptation to a medical condition. It is necessary to understand a population's knowledge and beliefs regarding HPV and abnormal Pap smears in order to assess their informational needs.

This study focuses on the assessment of knowledge and beliefs about HPV and abnormal Pap smears among a multiethnic population at risk in Hawai`i. Specific nuances of knowledge or lack of knowledge about HPV and abnormal Pap smears are described among the sample population. This study is unique methodologically in that it utilizes an Internet based survey instrument.

Purpose Statement

The purpose of this study is to describe knowledge and beliefs about HPV and abnormal Pap smears among a multi-ethnic student population by utilizing an Internet-delivered survey.

Variables

The dependent variable, knowledge about Human Papillomavirus and abnormal Pap smears, is measured by the use of a fourteen-item composite within the survey, the Human Papillomavirus and Abnormal Pap Smear Knowledge (HPVAPK) composite. The

independent variables examined in this study are experience, behavioral risk, age, gender, and ethnicity.

The Research Questions

1. What is the level of knowledge about HPV and abnormal Pap smears as measured by the Human Papillomavirus and Abnormal Pap Smear Knowledge (HPVAPK) composite?

2. What are the predominant beliefs and opinions regarding the particular HPV-related issues presented in this survey?

3. Which questions about HPV and abnormal Pap smears have the highest frequency of an uncertain ("don't know") response?

4. Are there gender, age, or ethnicity differences in HPVAPK scores among the study participants?

5. Do participants categorized as having behaviors at high risk for HPV infection differ in HPVAPK scores when compared to participants with low-risk behaviors?

6. Do participants who have direct experience, indirect experience, or no experience with HPV or abnormal Pap smears differ in their knowledge about HPV and abnormal Pap smears as measured by the HPVAPK?

7. Are there age or ethnicity differences among participants with direct experience of an abnormal Pap smear?

Natural History of HPV

Virally Induced Carcinogenesis

In order to understand the complexity of this unique process of virally induced carcinogenesis, a description of the natural history of HPV is necessary. Human Papilloma viruses are small, double-stranded DNA viruses. Among over 100 types of HPV, there are 30 genital subtypes. The genital subtypes of HPV are categorized as low risk or high risk according to their potential to contribute to carcinogenesis. Fifteen high-

risk HPV types have been identified as etiological agents in cervical carcinogenesis; among these, type HPV-16 accounts for approximately 50% of cervical cancers worldwide (Schiffman & Castle, 2003).

HPV contains genes that encode for proteins with particular functions in the virus's lifecycle. The Early Region (E region) of the HPV genome encodes for proteins important to viral replication early in the viral life cycle. At least seven areas of the E region have been identified: E1, E2, E3, E4, E5, E6, and E7 (Cox et al., 2001). Among high-risk HPV types, the role played by E6 and E7 is unique. The E6 and E7 proteins allow HPV to successfully take control of an infected host cell for its own replication and survival, which ultimately can result in the host cell's transformation into an immortalized cancer cell (Cox et al., 2001).

A normal host cell contains two important tumor suppressor genes (p53 and pRb) that act as the guardians of the cell. Among high-risk HPV types like HPV 16, proteins E6 and E7 interfere with the p53 and pRb host-cell tumor-suppressor genes, causing a disruption in the normal cell life cycle. In a normal non-replicating cell, pRb is bound to another protein, E2F, which is required for DNA replication. When HPV viral protein E7 displaces the connection between pRb and E2F, the control that pRb usually exerts over cell replication is disabled. Unbound E2F causes a normally non-replicating cell to begin the complex sequence of cell replication necessary for the survival and reproduction of HPV. Usually if pRb is dysfunctional, the other guardian of the cell (p53) recognizes this dysfunction and initiates a mechanism that suspends the cell cycle processes in order to repair the damage. Normally, when p53 recognizes that the damage is not repairable, it triggers apoptosis (programmed cell death), preventing the damaged cell from future

replication (Bertram, 2000; Stern & Stanley, 1994; ZurHausen, 2002). However, HPV also disables p53, thereby allowing damaged cells to escape death and HPV to thrive.

In summary, the HPV virus has evolved a clever mechanism for its own survival. The viral E6 and E7 proteins knock out both of the host-cell guardians, p53 and pRb respectively, allowing HPV to successfully take control of the host cell, replicate, and survive. E7 disables the control of pRb over E2F, inducing cell replication, and E6 disables the control of p53 over DNA repair or apoptosis, resulting in uncontrolled cell replication. Moreover, the loss of p53 makes this aberrant replicative process susceptible to gene mutation. An unstable genome gives rise to carcinogenesis. Thus, HPV is able to cause cell transformation, uncontrolled growth, and cell immortalization (Cox et al., 2001; Bertram, 2000; Stern & Stanley, 1994; ZurHausen, 2002) unless other host immune defenses interfere with this parasitic hijacking. This process, which may occur over several years of persistent HPV infection, provides definitive evidence for the mechanism by which HPV can cause cervical cancer. However, several questions remain unanswered.

HPV Transmission and Successful Infection

HPV enters the cervix presumably through micro-trauma during sexual intercourse. The virus passes through the cervical epithelium to the basal cell layer, where it enters the normally replicating basal cell (ZurHausen, 2002). HPV does not kill its host cell. The virus exploits the replicating machinery of the basal cell to establish itself and begins to reproduce insidiously. It then accompanies the host cell through natural epithelial cell maturation until it is detectable in the normally non-replicating suprabasal cells and surface epithelium, where HPV E6 and E7 disable p53 and pRb.

HPV might exist as a latent infection for one to eight months (Cox et al., 2001). After latency, it enters its productive phase. At this stage, the virus produces a protective capsid that allows it to survive attached to superficial and exfoliated squamous cells. This protective capsid makes HPV highly infectious and sexually transmittable. It has been suggested that a productive infection usually lasts between three and six months (Cox et al., 2001), although further studies are required to confirm this.

It is unknown at what point cell-mediated immunity is activated during this process of infection: during latency, productivity, or integration. Likewise, it is unknown why the host immune response may or may not effectively resolve the infection (clearance). The factors that determine the transition from latency to productive infection are also unknown (Cox et al., 2001; ZurHausen, 2002). The influences of endogenous and exogenous hormones that may be present in reproductive-aged women are also under investigation. The natural history of HPV in males is just beginning to be understood.

Clinical Management of HPV and Abnormal Pap Smears

In order to understand the complexity of a patient's experience in having an abnormal Pap smear, it is useful to describe the abnormal Pap smear terminology and the accepted standards of clinical management. In the U.S., Pap-smear screening is a routine part of an annual gynecologic examination. Many women obtain their first Pap smear when they are seeking a contraceptive method or seeking screening for sexually transmitted infections. According to the 2001 Bethesda Guidelines that inform the American College of Obstetrics and Gynecology's cervical cytology guidelines, the first Pap smear should be obtained three years after sexual debut or by age 21 (Waxman, 2003).

Since the Pap smear is considered a screening test, not a diagnostic test, further investigation is done if an abnormal Pap smear is detected.

Abnormal Pap smears are categorized according to the 2001 Bethesda classification system in which there are two types of usually benign findings: atypical squamous cells (ASCUS) and low-grade squamous intraepithelial lesions (LSIL). The more ominous, precancerous lesions are either high-grade squamous intraepithelial lesions (HSIL), carcinoma in situ (CIS), or glandular lesions (AGUS). With the exception of adolescents and postmenopausal women, the clinical management of all abnormal Pap smears includes a colposcopy and usually a biopsy. The colposcopy and biopsy provide diagnostic accuracy, based on direct observation of the cervix under magnification, and tissue pathology evidence, whereas the Pap smear provides only cytology of exfoliated cells for screening purposes.

Colposcopy and biopsy are done within an office setting and usually do not require sedation. Further treatment to prevent cervical cancer depends on the colposcopic impression and the biopsy result. Cervical pathology specimens are described in terms of cervical intraepithelial neoplasia (CIN), whereby CIN I is descriptive of mild disease and CIN II and III are descriptive of precancerous lesions. CIN I is most often managed by surveillance rather than surgery. A pooled analysis of studies published from 1950–1993 reported a 57% probability of spontaneous regression of CIN I lesions (Unger & Duarte-Franco, 2001). Since CIN II and III have a higher risk of progression than CIN I lesions, the higher-grade lesions are usually managed by surgical intervention in the form of an excision or ablation procedure to remove the portion of the cervix that includes the precancerous lesion (Wright et al., 2002).

Thus, young women may have a benign disease process that resolves spontaneously and does not affect their fertility or their long-term health, or they may be faced with higher-grade disease requiring surgical intervention. If surgical intervention is necessary, it frequently can be limited to a focused area of cervical excision. Cervical cancer is entirely preventable among women who have access to early Pap-smear screening and obtain appropriate treatment and follow-up surveillance.

Review of Literature

Abnormal Pap Smears and HPV: Psychosocial Issues

Various investigators have addressed psychosocial issues among women with abnormal Pap smears. Survey instruments have been tested and utilized that document the psychosocial impact of HPV and abnormal Pap-smear diagnosis and management. The American Social Health Association (ASHA) conducted a survey (N=489) among subscribers to *HPV News,* a quarterly publication for people with HPV. The survey addressed medical history, health-care experiences, personal impact, and demographic information. Although selection bias should be acknowledged, 75% of their sample reported feelings of depression and anger. Sixty-six percent (66%) reported shame. Respondents also expressed dissatisfaction with the limited information and counseling provided by their health-care providers regarding HPV (Clarke, Ebel, Catotti, & Stewart, 1996).

Bennetts et al. (1995) developed a survey tool, the PEAPS-Q, to measure the psychosocial effects of women with abnormal Pap smears. This instrument identified four dimensions of distress: experiences associated with medical procedures, beliefs and feelings about cervical disease, changes in self-perception, and worry about infectivity.

Although the instrument was validated and was utilized to quantify distress, its application in subsequent studies has been infrequent.

A qualitative study (Taylor, Keller, Eagan, 1997) utilizing content analysis described the advice that female and male patients (N=61) with HPV (primarily genital warts) would give to newly diagnosed patients with genital warts. This study also revealed the psychosocial and emotional consequences of having a viral STD (Taylor et al., 1997). The resultant categories of advice included issues about treatment, attitude, sexual risk behavior, self-care, disclosure to partners, and seeking of information. An interesting finding in this study was the participants' advice that newly diagnosed patients should seek as much information as possible, and that ambiguous or inconsistent information should be expected.

Linnehan and Groce (1999) conducted a survey among 143 health-care providers in college-based health clinics to explore provider perceptions of the educational and psychosocial needs of women at risk of acquiring HPV. They concluded that eighty-six percent (86%) of surveyed providers acknowledged that HPV has a variety of psychosocial effects on young women, and that fifty-four percent (54 %) spent at least ten minutes providing education and counseling to their patients. The survey identified very general areas of discussion and lacked assessment of message content, provider knowledge, or provider comfort with the topic. Linnehan and Groce (2000) subsequently published a review suggesting that there is a knowledge deficit regarding HPV among women at risk, which impacts patients' ability to cope with diagnosis, as well as the likelihood that they will adhere to their treatment plan. Reitano (1997) also published a review regarding the particular complexities of psychosocial responses to having an abnormal Pap smear and

HPV. In this review, Reitano concludes that patient–provider communication, lifestyle modification, and long-term clinical management are topics that should be addressed. Maissi et al. (2004) examined anxiety, distress, and concern about test results in women with borderline or low-grade abnormal Pap smears who also received HPV testing (N=536). Younger age, higher perceived risk of cervical cancer, and reporting a lack of understanding about test results were independent predictors of anxiety. In their conclusions, the authors recommended that patients should be educated reassuringly about the absolute risk of cervical cancer, the prevalence of HPV, and the meaning of mildly abnormal Pap-smear results.

Knowledge about HPV and Abnormal Pap Smears

Mays (2000) conducted a qualitative study of women with abnormal Pap smears to describe the knowledge and beliefs of adolescent and adult women about abnormal Pap smears. Her study demonstrated that pre-existing health-care beliefs affect concepts of disease, compliance with follow-up recommendations, coping, and preventive behaviors. A recurrent theme among her interviewed subjects was the inability to differentiate between sexual and non-sexual genital matters.

Various studies have investigated knowledge and behaviors regarding HPV among college students (Gerhardt et al., 2000; Lambert, 2001, Vail-Smith & White, 1992; Yacobi et al., 1999). Yacobi et al. (1999) evaluated knowledge, attitudes, and behaviors of university students regarding HPV. This study involved a random sample of 500 university students in Tampa, Florida, who were mailed a self-administered survey that assessed knowledge about HPV and other STDs. Among the 289 respondents, only 37% had ever heard of HPV. The median score on a 13-item knowledge scale was only three (3). The

lowest knowledge scores were among males who engaged in higher-risk sexual behaviors such as involvement with multiple partners and absence of condom use. Additional studies have corroborated a lower level of HPV knowledge among males (Baer, Allen, & Braun, 2000; Dell, Chen, Ahmad, & Stewart, 2000).

In a study that differentiated between knowledge about abnormal Pap smears and knowledge about HPV, Pitts & Clarke (2002) surveyed female employees of a university in the United Kingdom (N=400) and found that although women were familiar with Pap-smear screening and treatment for abnormalities, awareness and knowledge about HPV was very limited. Past experience of an abnormal Pap smear was not associated with higher HPV awareness. This implies that health-care providers rarely discussed HPV with their patients during or after disclosure of an abnormal Pap- smear result.

Gerhardt et al. (2000) examined knowledge of HPV and cervical dysplasia among a university clinic population in Ohio (N=50). This study included demographic information about the ethnicity of the study population, which was 88% African American and 12% Caucasian. Interviews utilizing a questionnaire were done 2.5 years after the diagnosis of HPV or cervical dysplasia. Although 86% responded correctly to basic knowledge questions addressing the relationship between HPV and cervical dysplasia, the study revealed that participants nevertheless had low levels of knowledge about salient HPV-related issues: 52% did not know that smoking increased cervical cancer risk, 42% believed that HPV was always symptomatic, 22% did not know that condoms could decrease HPV transmission. There were no conclusions that addressed ethnic differences, perhaps due to the skewed representation of ethnicities and the small sample size.

Waller, McCaffery, and Wardle (2003) conducted a study in the U.K. among female clinic patients (N=1,032) that included a wider age range of participants than previous studies. Although women were familiar with Pap-smear screening and cervical cancer, there was a low level of knowledge about HPV. Holcomb et al. (2004) addressed HPV knowledge among adults (N=289) who attended three family practice offices in Michigan. This study utilized the knowledge questionnaire developed by Yacobi et al. (1999) and revealed significant differences in HPV knowledge depending on age, education, gender, and marital status, although in general knowledge scores were low.

Summary

Quantitative studies have effectively described distress, coping, and compliance behaviors among women with abnormal Pap smears. Studies that utilize mailed or in-person questionnaires as survey instruments have effectively documented the complexities of the psychosocial response to HPV and abnormal Pap smears, as well as a general lack of knowledge about HPV. There are no published studies that employed an Internet survey to assess knowledge of HPV and abnormal Pap smears.

The following study is unique among the literature on HPV and abnormal Pap-smear knowledge in that it addresses a population of mixed ethnicity, with predominance of Asian and Polynesian students, and in its use of the Internet as both a survey-delivery tool and an educational resource. Age, gender, ethnicity, behavioral risk, and prior experience are the independent variables in this study. The study addresses not only basic knowledge of HPV, but also surrounding issues that are relevant to patient education. The use of the HPVAPK composite introduces a new instrument to measure knowledge about HPV and related issues such as treatment of male partners, fertility, and risk factors for

cervical cancer. The complexity of knowledge issues, the ambiguity of issues and the admission of lack of knowledge about HPV-related issues are highlighted.

Internet Surveys

Although Internet-using participants are more directly accessible and less expensive to recruit than participants available for in-person, telephone, or mail surveys, there are several caveats that must be acknowledged about this particular forum for data collection in survey research. A certain level of sampling error is inherent in any Internet survey. Those students who respond may be different from those who don't due to their interest in the subject, available time, personality factors, time spent using the Internet for recreation or other unidentified biases. Internet users tend to seek information independently and, therefore, may represent a better informed population compared to the general population. One must also acknowledge the uniquely anonymous relationship that the participant has with the researcher. This anonymity may decrease barriers that may otherwise exist in relation to sensitive issues or admission to socially unacceptable behaviors, resulting in more honest responses to questions. Alternatively, participants can anonymously feign responses or provide frivolous responses, which may be entirely undetectable to the researcher. Errors due to mistaken key strokes may also be undetectable.

Operational Definitions

Abnormal Pap smears: A range of abnormal cellular changes of the uterine cervix detected by a cytology screening test, the Papaniculou smear (Pap smear).

Composite: A scoring process that transforms categorical variables or test results into a new summative variable.

Direct experience: A personal medical history of an abnormal Pap smear.

Indirect experience: Prior exposure to issues related to HPV or abnormal Pap smears as a result of knowing someone with HPV or with an abnormal Pap smear; as a result of obtaining health education from a health-care provider or from a university course that addresses HPV or abnormal Pap smears; as a result of a prior Internet search; or as a result of participation in a local clinic based HPV study conducted by the Cancer Research Center of Hawai`i.

Ethnicity: Self-identified genetic or familial cultural groupings.

HPV: Human Papillomavirus, a sexually transmitted virus that includes at least 30 genital subtypes, some of which are associated with genital warts, and others with cervical dysplasia and cervical cancer.

HPVAPK: an instrument developed for this study to measure knowledge about HPV and abnormal Pap smears.

HPV and abnormal Pap-smear knowledge: Awareness of facts and/ or clinical practice regarding HPV and the consequences of HPV, including cervical disease detected by Pap smears.

HPV and abnormal Pap-smear beliefs: Personal ideas, including value-laden thoughts, about HPV-related issues.

Internet survey: A survey that is delivered electronically from a web site, with subsequently asynchronous collection of data.

Paradigm shift: A major change in the predominant way of thinking about or way of knowing about a body of knowledge.

Risk factor: Predisposing behaviors or conditions that are associated with an increased incidence of disease. In this study, there are risk factors for cervical cancer, risk factors for precancerous or non-cancerous changes detected by Pap smears, and behavioral risk factors for exposure to HPV.

Risk behavior: A composite of four risk factors used in this study: a history of having an STD, self-perceived risk, a relationship characterized by multiple sexual partners, and lack of condom use.

Theory of Uncertainty: Both a concept and a nursing theory developed by M. Mishel.

Uncertain response: Indication of "don't know" in response to a survey question.

Uncertainty: A concept characterized by four factors: complexity, ambiguity, lack of information, and an unpredictable prognosis.

CHAPTER 2

CONCEPTUAL FRAMEWORK

The Concept and Theory of Uncertainty

This study is conceptually supported by the theory of uncertainty in illness. This theory, originally formulated in 1981 by M. Mishel, addresses adaptive and maladaptive responses to the disclosure and experience of acute and chronic illness. The concept of uncertainty well describes the phenomenon of having an abnormal Pap smear. In this context, the concept is situation specific. The theory of uncertainty, a midrange theory, recognizes the process of informational need and information seeking in the process of adaptation and coping to a diagnosis of illness. Uncertainty is exemplified by the process whereby women are informed of an abnormal Pap smear and comprehend the facts and implications of the surrounding issues, or do not obtain adequate information and do not comprehend the facts and issues regarding their abnormal test result.

Mishel (1981) is credited with the development of the concept of uncertainty as well as the theory of uncertainty within the framework of adaptation to stress. The concept and theory of uncertainty in illness was based on Mishel's observations that:

> Uncertainty arises when the diagnosis of the disease is not fully established or when it is unclear which course the disease will follow in a particular case. The uncertainty experienced during this time is an unpleasant state that generates a need for further information. Detailed information about the disease and treatment is needed in order to reduce the uncertainty and give the patient a sense of control over the situation. (Mishel, 1984, p. 164)

Information seeking has been proposed as the primary means for reducing uncertainty (Mishel, 1984). Mishel's model recognizes that there is a process in which patients have

informational needs that must be addressed in order to positively adapt to a health threat or condition.

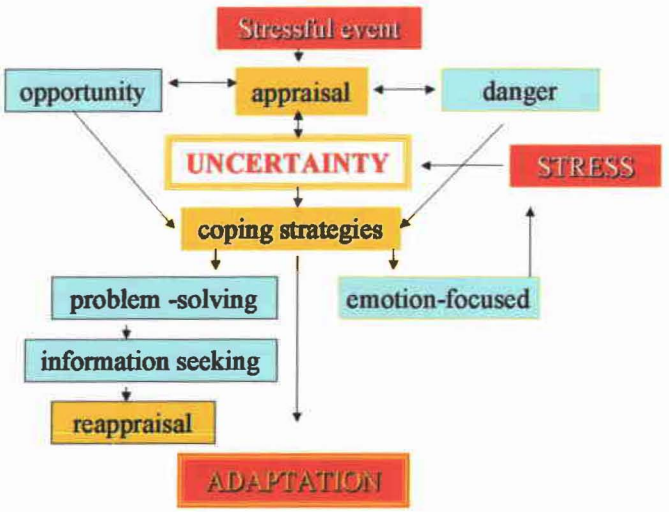


Figure 1. Theoretical Model of Uncertainty in Illness

Conceptual Definitions

Theories are defined as a system of relations among concepts (Nicoll, 1997). The major concepts of Mishel's original theory were uncertainty, cognitive appraisal, stress, coping, and adaptation. As the theory matured, the concepts of stimuli frame and structure providers were added as antecedents to uncertainty. In 1991, mastery and coping were added as mediating concepts.

The definition of uncertainty according to Mishel is

> the inability to determine the meaning of illness related events. Uncertainty occurs in a situation in which the decision maker is unable to assign definite value to objects or events and/or is unable to predict outcomes accurately. (Mishel, 1988, p. 225)

The term *cognitive appraisal,* originally described by Lazarus and Folkman (1984), has been defined by Mishel as a process whereby an individual attempts to establish a basis for understanding an issue, and subsequently categorizes the issue in terms of its potential effects. Cognitive appraisal requires a cognitive structure; a patient must have a frame of reference in order to assess his/her situation and make decisions based on that assessment. If a cognitive structure does not exist due to an absence of pattern recognition, also known as configuration, then appraisal is hampered. Primary appraisal results in the perception of an event as a threat, a challenge, or as innocuous (Lazarus & Folkman, 1984).

Folkman and Lazarus (1988) define coping within a psychoanalytic model as a cognitive and behavioral response to a stressor that serves to reduce anxiety and distress. Coping mechanisms include automatic psychological processes such as denial, repression, suppression, intellectualization as well as problem-solving behaviors (Folkman & Lazarus, 1988). Coping approaches do not necessarily result in problem resolution or in successful adaptation. This model identifies an emotional response as a type of dysfunctional coping that delays adaptation and increases uncertainty. A direct-action or problem-solving type of coping includes information-seeking, which is considered a more effective means of reducing uncertainty.

Stress is a term originally developed by Selye (1950) that has broad applications in health and illness. In the context of uncertainty theory, stress is a stimulus that produces the biophysical response that Selye termed "fight or flight." This translates into a mental state of heightened awareness, anxiety, or alarm and a physical state of adrenal-cortical stimulation, a normal physiological response to a threat. Sustained stress is associated with multiple disease states and a reduced functioning of the immune system.

For purposes of theory building, Mishel defines adaptation as psychosocial adjustment, recovery, life quality, or health (Mishel, 1988). Adaptation is defined by the expectations and optimal outcomes that apply to health and healing phenomena, and it implies a reduced perception of stress or threat.

Measurement

The Mishel Uncertainty in Illness Scale (Mishel, 1981) operationalized the concept of uncertainty by the use of a 34-item Likert format scale. Factor analysis resulted in a four-factor construct that further refined the components of uncertainty. These include ambiguity, complexity, deficient information, and unpredictability. Between 1981 and 1999, the theory of uncertainty was tested, modified, and applied to multiple settings, including both acute-care hospital settings and chronic-care community settings. The theory of uncertainty and the instruments used to measure uncertainty have also been translated, both literally and conceptually, into other languages, including Chinese (Taylor-Piliae & Molassiotis, 2001).

Theory Process

Mishel (1981) proposed a cognitive appraisal model as central to the process of coping, uncertainty, stress, and adaptation to stress. Cognitive appraisal includes perception of an illness-related event, followed by a recognition and classification task in which a frame of reference must exist or be established. The primary appraisal of a health problem includes perception of a threat or danger. The secondary appraisal of the problem leads to either problem-solving coping or emotion-focused coping. Problem-solving coping includes information seeking. Emotion-focused coping includes avoidance or

vigilance. Emotion-focused coping, in this early model, is viewed as an impediment to adaptation, leading to a sustained perception of stress.

Mishel proposed that a person must first have a cognitive frame of reference in order to develop an understanding and sense of mastery regarding one's medical condition. The concept of uncertainty exists when a person is unable grasp the complexity, meaning, and implications of a medical problem. Theoretically, as uncertainty increases, the perception of stress is sustained and adaptation is delayed (Mishel, 1981; 1984; 1988).

Information-seeking as a problem-solving coping strategy may not alter the uncertain nature of a problem, but it may establish an appraisal of risk, which can place the health event in a manageable perspective. The need to learn—or the need to seek information and clarity, thereby decreasing the enigmatic nature of a life- or health-threatening event or diagnosis—is a positive response to the condition of uncertainty, leading to successful coping and adaptation.

The model places information-seeking behavior initially within the process of active coping. Direct-action coping, vigilance coping, and avoidance coping, as postulated by Lazarus and Folkman (1984), are forms of coping that involve a simplified dichotomy of emotive response (vigilance, avoidance) vs. rational response (direct action). Although this resembles the fight-or-flight dichotomy of Selye's (1950) original theory of stress, it does not seem to acknowledge that all three types of coping could occur simultaneously, nor that a person may fluctuate temporarily among all three coping mechanisms.

In 1990, Mishel updated and reformulated her theory to reflect a less mechanistic and more probabilistic paradigm, one in which coping strategies and informational needs fluctuate over time and uncertainty can result in positive as well as negative

consequences. In this context, uncertainty could stimulate rather than delay active coping and could result in a newly constructed cognitive framework with which to assimilate information.

In the circumstance of having an abnormal Pap smear, the disclosure of the Pap-smear result from a health-care provider is the initial stressful event. According to the model, the next step depends on whether an individual possesses the cognitive framework to comprehend what is happening or not. If such a framework does not exist or has not yet been constructed, then uncertainty will ensue. Uncertainty, which consists of complexity, ambiguity, lack of prognostic indicators, and lack of clear information, may lead to an emotional response that may take the form of vigilance or avoidance. This emotive coping may lead to more stress, difficulty comprehending available information, and possibly delayed or negative adaptation. Alternatively, or possibly simultaneously, the condition of uncertainty may lead to a proactive, problem-solving coping strategy in which the person is motivated to seek information and ultimately decrease some parameters of uncertainty.

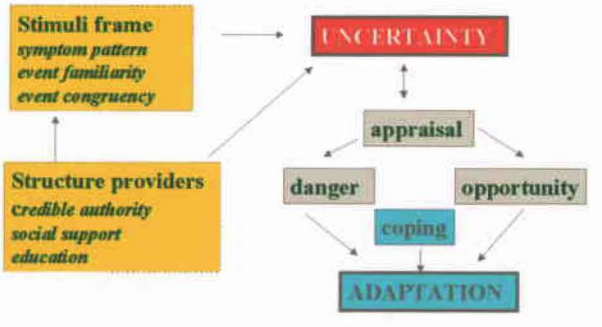


Figure 2. Antecedents of Uncertainty (Mishel, 1988)

Antecedents of Uncertainty

Mishel tested and incorporated into the uncertainty model certain antecedent conditions that included the concepts of stimuli frame and structure providers (Figure 2) (Mishel, 1988). *Stimuli frame* refers to aspects of the medical problem that are recognizable due to symptoms, familiarity with the terminology, or a logical grasp of the issues involved. *A structure provider* refers to the availability of a credible authority for consultation, social support, and education about the medical condition and its implications. Testing of the model showed an inverse relationship between existence of the stimuli frame and resultant uncertainty; an inverse relationship between the existence of structure providers and resultant uncertainty; and a positive unilateral relationship between structure providers and stimuli frame. It is therefore the antecedent conditions that provide an opportunity for patients to access appropriate, understandable information that may result in a lower level of resultant uncertainty.

The situation-specific antecedents of uncertainty within the context of a woman's experience in having an abnormal Pap smear begin with the event of having a Pap smear performed and receiving information about the abnormal result. For these events to occur, it is necessary that the woman has accessed health care and has sought or received some form of preventive health care, including a pelvic examination. It is worth noting that in industrialized countries, having a physical exam, a Pap smear, or other preventive health-screening measures has become a norm and an expectation. The conditions would therefore vary among countries that do not engage in preventive health practices, and among subcultures within a westernized country that are not aware of or do not obtain preventive health screening.

Because it has been confirmed that Human Papillomavirus (HPV) is implicated in cervical cancer development and in the majority of abnormal Pap smears (Schiffman & Castle, 2003; ZurHausen, 2002), it follows that onset of sexual activity must also be an antecedent condition to having an abnormal Pap smear and also, therefore, to the experience of resultant uncertainty. This does not, however, mean that current sexual activity is an antecedent, since the time between exposure to HPV and the onset of an abnormal Pap smear is variable. Nor does it imply a history of multiple sexual partners or a non-monogamous current relationship; exposure from one HPV-infected partner is sufficient to cause an infection that could exist asymptomatically for a period of several months or years.

After the abnormal Pap smear has been detected, the antecedent conditions of uncertainty in this context include stimuli frame and structure providers. Most women with persistent HPV that results in an abnormal Pap smear are entirely asymptomatic. The Pap smear itself may be the first indication of any problem at all. This represents an inability to recognize a *symptom pattern* and therefore a lack of control even over symptom recognition. Without symptom recognition, *event familiarity* is hindered. From a wider perspective, lack of personal knowledge and a dearth of public knowledge about HPV and abnormal Pap smears contribute to the lack of a cognitive structure upon which to build familiarity.

Event congruency, the third element of the stimuli frame in the theory of uncertainty, refers to the consistency between what is expected and what is experienced in an illness-related event. The lack of event congruency involves cognitive dissonance due to misconceptions about the disease process. For example, a woman with a prior

history of a bacterial sexually transmitted disease who was treated with antibiotics may erroneously expect that HPV could be treated with antibiotics. Similarly, a common public belief that most cancers are hereditary may lead a woman to the misconception that cervical cancer must be hereditary. Event congruency can also be lacking when one experiences a recurrence of disease despite treatment that was expected to be effective.

Structure providers in the theory of uncertainty include credible authority, social support, and education. *Credible authority* refers to the trust and confidence a patient has in her health-care provider's advice, knowledge, and information. Patients frequently rely on their health-care providers as their primary source of information, and a resource for the development of event familiarity, symptom recognition, and, to some extent, event congruence. Indeed, structure providers did have a direct effect on stimuli frame in the testing of the model of uncertainty (Mishel, 1988). *Social support* not only refers to emotional support, but refers to access to discussion and supportive interactions with others. Social support can take the form of patient–provider communication. Social support can be provided by friends or family members who have had similar experiences, or by patient support groups. Many patients now access Internet chat groups as a support forum. Indeed, there are multiple web sites in operation for women with abnormal Pap smears, some of which include a professional moderator. There are also unmoderated chat groups that are unfortunately susceptible to the dissemination of misinformation.

Education, one of the structure providers in this model, refers to the patient's level of formal education. Mishel (1988) suggests that those with a higher level of education are able to modify their uncertainty more rapidly than those with a lower level of education. The construction of meaning from illness-related events requires more time

for those with a lower level of education. However, education in this context may be related to intelligence, experience, or familiarity with the learning process.

Consequences of Uncertainty

According to the theory of uncertainty in illness, the consequences of the event of having an abnormal Pap smear involve the initiation, delay, or avoidance of a coping strategy (Mishel, 1981; 1990). Whether a patient employs emotion-focused coping or problem-solving-based coping may depend on her degree of uncertainty, its acuteness or chronicity, the disposition of the patient, and her ability to understand and process information. Information-seeking behavior, as a consequence of uncertainty, represents a problem-solving coping strategy (Mishel, 1981; 1984; 1988).

Aside from Mishel's theoretical model of uncertainty, other consequences result from the uncertainty of having an abnormal Pap smear. These consequences may or may not include an alteration in self-concept or sexual self-concept; an alteration in some aspect of the patient's intimate relationship; feelings of vulnerability due to perceived risk of possible impending disease; new concerns about future fertility, and anticipatory fears about uncomfortable diagnostic or treatment procedures. These consequences may be temporal and may be affected by variables such as social support, information, trust in a health-care provider, disposition, hope, self-confidence, perceived threat, and effective coping (Bennets et al., 1995; Lauver, Kruse, & Baggot, 1999; Rajaram, Hill, Rave, & Crabtree, 1997). Ultimately, the consequence of uncertainty as a result of having an abnormal Pap smear will be dissipated by spontaneous resolution of the disease process, or treatment of the disease process, which will reduce the health threat as well as the uncertainty.

Theory Structure

The structure of the theory of uncertainty in adaptation to stress depends partly on what version of the theory one is concerned with. The original mechanistic structure of the theory assumes that adaptation is a linear process: A stressor, such as disclosure of a diagnosis of a condition, is followed by the primary appraisal of the condition as a threatening or non-threatening. An individual either possesses or does not possess the cognitive frame of reference required in order to understand what is occurring. Factors such as social support, education, and credible authority may influence the perception of uncertainty. Next, mechanisms of coping are activated. The type of coping that occurs may be affected by individual habit, degree of uncertainty, pessimism vs. optimism, locus of control, perception of danger, or inability to comprehend. The end result of effective coping is adaptation. This is a simple linear conceptualization that does provide a clear pattern. However, theories are not meant to be full representations of reality. They are meant to provide a means of envisioning conceptual relationships. The theory of uncertainty does not necessarily exclude other processes that may be simultaneously occurring.

Mishel (1990) later refined her theoretical model of uncertainty with new insights. She observed patients in community settings and recognized that adaptation was not an ultimate fixed event that occurred as a result of coping. Mishel's reformulation of uncertainty (1990) recognized that uncertainty could also result in a positive appraisal (opportunity) involving personal growth and change in which hope could exist within an otherwise bleak prognosis. From this perspective, adaptation is a continuous, natural process. Particular environmental factors such as isolation, lack of support, other

caretaking obligations of the patient, and provider communication style may facilitate or impede the patient's process of growth and change (Mishel, 1990).

If one considers the theory of uncertainty in adaptation to illness according to Mishel's reformulated version (Mishel, 1990), the structure of the theory changes. Within the context of a probabilistic paradigm, the structure is no longer linear. Uncertainty may still be involved in adaptation to stress but it no longer follows that maladaptive coping will occur as a result of uncertainty. This version of the theory has a different, more open-ended perspective of reality and in this way is more observational and less predictive. Broader concepts of coping, hope, and new self-concept are suggested along an evolving continuum of human response to a stressor. In other words, adaptation is no longer an endpoint, but a continuous process.

Theory Purpose

The purpose of the theory of uncertainty is to explain a process of coping and adaptation. The theory of uncertainty in illness, grounded in a theory of adaptation to stress, is a midrange theory that can provide a construct for predicting human behavioral response to illness, a focal nursing concern. Mishel's theory of uncertainty in illness serves to explain a phenomenon whereby individuals exhibit varying behavioral responses to receiving a diagnosis, to negotiating the health-care labyrinth, to living with chronic illness, and to coping with medical or surgical diagnostic procedures or treatments. The value of having a predictive theory of coping and adaptation to uncertainty resides in the potential for nurses to be proactive on behalf of patients and to gain insight into a patient's needs within an adaptive continuum. In practice, by interpreting clinical phenomena through the lens of this theory, one might recognize when a patient is both in need of and

able to process more information, and how providing access to further information could lead to positive coping and adaptation. One might also recognize that a lack of information-seeking behavior or a lack of information-receiving behavior might indicate either an alternative or more emotive stage of coping, an inability to cognitively appraise a health problem or condition, or an ultimate delay in coping. Additionally, familiarity with the concept of uncertainty itself will improve recognition of the phenomenon of uncertainty, as it exists in both clinical and global contexts.

Theory Application

The condition of a woman's experience of having an abnormal Pap smear contains the aforementioned elements of uncertainty. There is complexity in the process of diagnosis and in the terminology used to explain the condition. The determinants of spontaneous resolution of HPV or a low-grade lesion are unpredictable despite an excellent prognosis. Ambiguity occurs due to inconsistent information among various sources, and due to issues that remain under scientific investigation. Questions about such matters as patterns of HPV infectivity, options for management of HPV in partners, determinants of HPV persistence, and cofactors for progression of cervical lesions remain unanswered at this time. There is also frequently an emotional component involved in the diagnosis, as it often elicits fear of cancer and simultaneous concerns about sexual transmission. Women may experience alterations in self-concept, alterations in sexuality, alterations in trust in relationships, fear of cancer, and what Rajaram refers to as "biographical disruption" (Rajaram et al., 1997; Lauver et al., 1999; Mays et al., 2000).

The theory of uncertainty in adaptation to illness provides a unique perspective with which to view the phenomenon of coping and adaptation to having an abnormal Pap

smear. If the theory is credible, one may gain insights into the processes of information-seeking behavior and informational needs within the broader context of uncertainty and adaptation to illness. One might consider the factors necessary to reduce the stress of both the initial uncertainty and the sustained uncertainty involved in this condition.

The arm of the theory of uncertainty that informs this dissertation on the assessment of knowledge about HPV and abnormal Pap smears suggests that the antecedent conditions influence the patient's resultant uncertainty. Antecedent conditions may be modifiable depending on how and what information is conveyed, the credibility of the health-care provider, and the availability of social supports. These conditions influence not only uncertainty, but also the ability to learn about HPV and abnormal Pap smears, thereby affecting event familiarity and congruency. A lack of knowledge, a lack of a conceptual framework to understand information, and a lack of information-seeking behavior is associated with greater uncertainty, greater stress, and delayed adaptation.

Thus, the assessment of knowledge about HPV in the study population could be predictive of the level of uncertainty of individuals from the study population who are personally faced with the issue of HPV or abnormal Pap smears at some time in their lives. Although this study is intended to describe knowledge, not to test the theory of uncertainty, the theory does serve to provide a conceptual and theoretical structure to this endeavor. Because an estimated 50% of U.S. reproductive-aged women and men have been exposed to HPV (Koutsky, 1997), the issue of uncertainty and informational need associated with HPV and abnormal Pap smears is an escalating public-health and nursing concern.

CHAPTER 3

METHODOLOGY

This was a cross-sectional, descriptive study utilizing an Internet-delivered survey. The sampling frame consisted of female and male University of Hawai`i at Manoa undergraduate students with access to a university email account. The students (N=8,668) received an email from the researcher, a doctoral student from the University of Hawai`i School of Nursing and Dental Hygiene, inviting them to participate in an Internet survey. The listserv included 8,838 university email addresses of undergraduate students; 8,668 were current addresses. The sampling procedure involved sending batches of 1,000 to 2,000 emails five times within a two-week period to the listserv, inviting participation in the Internet survey. Those students who responded to the email invitation accessed a hyperlink to a website. The website included an "about us" page, a consent form, the survey, and additional hyperlinks to an explanation page, recruitment for a separate clinical study conducted by the Cancer Research Center of Hawai`i (CRCH), and other educational resources (Appendix A, B, C, D).

The first two-week period of email invitations began in March, 2003. Two weeks after the initial mailing was completed, in an attempt to attract more responses, a second email invitation was sent using the same listserv. Participants who completed the first survey and also responded to the second email were instructed to indicate "second response" in the comments section. This could be done without indicating a name or email address. Very few responded twice (n=2). These second responders were excluded from the final data analysis.

The Research Questions

This survey was designed to describe knowledge and beliefs about HPV and abnormal Pap smears among a multiethnic population of female and male University of Hawai'i at Manoa students who responded to an Internet survey. The following research questions were formulated:

1. What is the level of knowledge about HPV and abnormal Pap smears as measured by the Human Papillomavirus and Abnormal Pap Smear Knowledge (HPVAPK) composite?

2. What are the predominant beliefs and opinions regarding the particular HPV-related issues presented in this survey?

3. Which questions about HPV and abnormal Pap smears have the highest frequency of an uncertain ("don't know") response?

4. Are there gender, age, or ethnicity differences in HPVAPK scores among the study participants?

5. Do participants categorized as having behaviors at high risk for HPV infection differ in HPVAPK scores when compared to participants with low-risk behaviors?

6. Do participants who have direct experience, indirect experience, or no experience with HPV or abnormal Pap smears differ in their knowledge about HPV and abnormal Pap smears as measured by the HPVAPK?

7. Are there age or ethnicity differences among participants with direct experience of an abnormal Pap smear?

Instrument Development

This section describes how the Internet-based survey was developed. Prior to conducting formal research, the researcher, a women's-health nurse practitioner, observed anecdotal phenomena within a clinical setting in which women obtained Pap-smear screening. The researcher began to keep an informal, anonymous journal of these

observations, and also documentation of misconceptions that appeared to be common among women with a history of an abnormal Pap smear. When an abnormal Pap smear was detected, the physicians and nurse practitioners informed patients of the results, naturally utilizing various styles of communication. Some, but not all, providers initiated discussion about HPV during the disclosure of the abnormal Pap smear. Usually women were given the opportunity to ask further questions. Although some did not ask further questions initially, sometimes questions arose several weeks, months, or years. The researcher noticed that many of the patients' questions were of a predictable nature, addressing similar underlying themes. Female patients commonly asked the following questions during disclosure of an abnormal Pap smear that included discussion about HPV: How did I get this? When did I get this? Does my partner have it? Should he get treated? Will I still be able to have children? Is it contagious? or When is it contagious? Is it curable? Is it serious? What can I do about it? Many patients had some understanding about Pap smears, but many had never heard of HPV. Some confused the terms HPV with herpes simplex virus (HSV) or with Human Immunodeficiency Virus (HIV). There appeared to be confusion about the relationship between genital warts and cervical cancer.

A survey was developed with the intent of including these predominant areas of questioning as well as more general knowledge about HPV and abnormal Pap smears. Demographic questions including gender, ethnicity, citizenry, socio-economic status, age and area of study were added to determine how representative the sample was compared to the general population of University of Hawai`i at Manoa students as well as to further evaluate possible demographic differences in HPV and abnormal Pap-smear knowledge.

Questions regarding risk of HPV infection and prior experience with this topic, either direct or indirect, were also added to the survey. Five HPV knowledge surveys reported in the literature were obtained for comparison. Each had a somewhat different emphasis in questioning and approach (Dell et al., 2000; Gerhardt et al., 2000; Pitts & Clarke, 2002; Waller et al., 2003; Yacobi et al., 1999).

The survey was given to three physicians and one nurse practitioner for expert commentary on content and clarity. Revisions were made based on their comments and recommendations. For further comment on content and clarity, the questionnaire was then given to five university professors: two in the School of Nursing and Dental Hygiene, two in cancer epidemiology, and one in cancer biochemistry and genetics. Revisions of the survey were again made after consultation with a professor of sociology at the University of Hawai`i who teaches a course in survey development, and yet again, after obtaining a critique from twelve of his survey-course participants.

The resulting survey was pilot-tested on ten University of Hawai`i students in person as a group. The pilot sample consisted of nursing, social work, and medical students. After completion of the survey, which required ten minutes of the students' time, there was an opportunity for students to make comments about the clarity of questions and to suggest revisions. The pilot study results revealed a variety of responses. Although the age range was fairly small, there was demographic variety in ethnicity, socioeconomic status of family of origin, and experience with the topic. The majority of students in the pilot study were female, though male students were also represented. All of the students were in the health field, but they represented three different schools of study. There were also a variety of responses to the questions that addressed HPV and

abnormal Pap smears. After completion of the pilot test, final revisions to the survey were made.

An explanation page that addressed each survey question was developed, using current sources from the HPV and abnormal Pap-smear literature, patient education materials, and expert consultation (Appendix C). Three women's-health physicians, a nurse practitioner, and one epidemiologist with expertise in HPV reviewed the explanation page.

Due to the researcher's ongoing clinical collaboration with epidemiologists from the Cancer Research Center of Hawai`i (CRCH), there was an opportunity to obtain the expert assistance of a CRCH information technician in the development and design of a web site for delivery of the survey. The web page included a hyperlink to recruit participants for a separate clinical HPV study conducted by CRCH epidemiologists. An HPV expert epidemiologist from CRCH was accessible for advice and feedback on the survey questions as well as the answer page. This collaboration led to an arrangement to refer survey participants to the Cancer Information Service as a personalized resource for information about HPV and cervical cancer.

Web Design and Internet Procedure

A computer technician from the Cancer Research Center of Hawai`i (CRCH) designed the web page utilizing Dreamweaver (Macromedia) software. This included an "about us page" that provided an introduction and the credentials of the researcher (Appendix D). The web page was designed with separate links for; the consent form (Appendix A); the 37-item survey (Appendix A); a hyperlink to a page that addressed explanations for each survey item (Appendix C); two hyperlinks to credible educational

resources; and a hyperlink to an HPV clinic based study on Oahu conducted by the CRCH (Appendix D). The hyperlink to the clinic based study served as a recruitment tool for that study. All fields of the Internet survey were required in order to submit a completed survey. Survey participants were not able to access the survey until they accepted the consent form. Similarly, participants were not able to access the explanation page until the survey was completed. (www.hawaii.edu/hpv/cathy/index.html)

Educational Features

At the end of the explanation page, survey participants were directed to the website of the American Sexual Health Association (ASHA), a nationally recognized organization associated with the National Institute of Health (NIH), Centers for Disease Control, that provides health education regarding sexually transmitted diseases. An additional hyperlink connected participants to the Cancer Information Service (CIS) in Hawai`i, an agency that provides health education about various cancers, including cervical cancer. Participants were also invited to telephone the CIS information line with any questions about cervical cancer.

Ethical Considerations

Prior to conducting the survey, the researcher completed the required human subjects training certification and subsequently submitted an application to the University of Hawai`i Institutional Review Board (IRB), which granted an exemption (Appendix E). Permission was granted to obtain a confidential listserv of current email addresses of all undergraduate students at the University of Hawai`i at Manoa from the Office of the Registrar. Permission was also obtained from the University of Hawai`i School of Nursing and Dental Hygiene to allow the web-site design to include their logo

and to design the email so that the sender address was from the Department of Nursing, a credible source.

An informed-consent paragraph preceded the survey (Appendix A). Participants were informed that by reading the consent form and completing the survey, they were consenting to participate in research. They then clicked on an "accept" button, which directed them to the survey, or a "reject" button that did not connect to the survey. In the informed consent section, it was clearly stated that there was no obligation to complete the survey and that all responses to the survey would remain both anonymous and confidential. The informed consent form stated that all respondents must be 18 years of age or older, that the survey would take approximately ten minutes to complete, that the participant could withdraw from the study at any time, and that participating in the survey would not affect their status as a student. The consent form also addressed risks and benefits of the study, and indicated that the study may be published in the future.

Although there was a hyperlink from the initial email to the web page, the return email address was blinded from the survey response page, thereby establishing anonymity and confidentiality. The survey participants were able to send emails with questions or comments directly to the researcher's email address only via the separate hyperlinked page that provided explanations to the survey questions. Again, this was done to maintain survey anonymity.

Reliability and Validity

Although the primary purpose of this survey was to address the sample population's knowledge and beliefs about HPV and abnormal Pap smears, a purely descriptive inquiry, it was necessary to test the survey's psychometrics to determine the

validity and reliability of the fourteen items that comprised a measurement of knowledge about HPV and abnormal Pap smears (HPVAPK). The fourteen-item knowledge composite was established as the dependent variable for each analysis.

Face validity was obtained from a critique by a class of twelve survey-development students and again during the pilot test of ten health-care students. After completion of the survey, the students offered comments on the wording and clarity of the questions. Content validity was established by obtaining expert commentary from a professional nurse practitioner and physician colleagues and professors, and by comparison with published health-education materials from credible sources such as the American Social Health Association (ASHA) and the American Society for Colposcopy and Cervical Pathology (ASCCP). Criterion validity is based on comparison to a well-established standard. Although no "gold standard" to measure knowledge about HPV and abnormal Pap smears exists, five surveys of HPV knowledge were obtained directly from authors sited in the HPV knowledge literature to use for comparison. Construct validity represents the usefulness of a survey instrument after it is used multiple times (Litwin, 2003). It would be necessary to use the survey in a variety of populations in order to determine construct validity.

Internal-consistency reliability determines the homogeneity of an instrument. The knowledge composite (HPVAPK) had a Crohnbach's standardized alpha of 0.8495. Individual item reliability was assessed by deleting individual items and obtaining resultant alphas, each of which were lower than the composite alpha. Thus, each of the fourteen items maintained internal consistency reliability.

Sample Size and Power Calculations

An Internet site was utilized for an initial calculation of sample size requirements (http://www.statspages.net). Confidence intervals were first calculated based on a 95% confidence level, a population of 8,668, and a sample of 492. A 50% level of accuracy was used as the worst-case percentage. The resulting confidence interval was 4.3%. The required sample size was then calculated based on a confidence level of 95% and a confidence interval of 4.3% for a population of 8,668. The resulting sample size required was 490. Therefore, the sample size of 492 was considered adequate to establish meaningful power with a confidence interval of 4.3%.

Power calculations based on an approach developed by Cohen (1988, in Polit & Beck, 2004) were done for each analysis of variance (ANOVA) to determine the minimum number of participants required for each group within an analysis. In order to achieve a power of 0.80 at 0.05 significance level using ANOVA for a non-dichotomous independent variable , it is necessary to have a group size of 319, 53, or 22 respectively within the sample (Polit & Beck, 2004). This calculation uses an Eta squared of 0.01 (small effect), 0.06 (medium effect), or 0.14 (large effect). Only groups with adequate size were included in ANOVA calculations.

Power calculations were also done to establish the group size necessary for a test of differences between two means (t-test), where the average HPVAPK scores represent means for the performance of groups described by the identified independent variables. To achieve a power of 0.80 at 0.05 significance, for a small effect (0.20), a medium effect (0.50), or a large effect (0.80), the size of each group must be 392, 63, or 25 respectively (Polit & Beck, 2004). The effect size in this context refers to the magnitude of the

difference between two groups in terms of performance on HPVAPK measures of knowledge, represented by Eta squared. Only groups with adequate size were included in t-test calculations.

The Survey

The 37-item survey included fourteen items that addressed knowledge about HPV and abnormal Pap smears (HPVAPK); one item that addressed perceived knowledge about HPV; four items that addressed particular beliefs about HPV or abnormal Pap smears; four items that categorized behavioral risk; seven items that addressed direct or indirect experience with the topic, two items that addressed opinions about future HPV immunizations; and eight demographic items (Appendix A). The response choices for the knowledge items were "true/false" or "don't know." Other items required a multiple-choice response or a "yes/no/don't know" response. There was only one item that required a fill-in-the-blank response regarding the student's major field of study.

Knowledge Items

The knowledge items were as follows:

1. Routine medical screening for sexually transmitted infections usually includes a test for HPV (Human Papillomavirus).
2. HPV can cause genital warts.
3. Genital warts can cause cervical cancer.
4. You can tell if someone has been exposed to HPV by looking for warts.
5. There is a screening test that is commonly used to test males for HPV.
6. Most women with an abnormal Pap smear are able to have a completely normal pregnancy in the future.

7. "Low-grade" abnormal Pap smears are usually not harmful and often go away completely without treatment.

8. "High grade" abnormal Pap smears are treated by removing or destroying a small part of the cervix in order to prevent cervical cancer.

9. If a heterosexual woman has HPV, her partner should be seen by his health-care provider to be treated for it even if he has no signs of warts.

10. Condoms will help prevent women from having abnormal Pap smears.

11. Risk factors for the development of cervical cancer include persistent positive HPV.

12. Risk factors for the development of cervical cancer include smoking cigarettes.

13. Risk factors for the development of cervical cancer include a history of multiple sexual partners

14. HPV is *not* a very common virus.

Belief Items

Belief items were distinguished from knowledge items if the answer was controversial or not fully supported in the literature or in established clinical practice. The following belief items were included, requiring a "true/false/don't know" response:

1. Genital warts are not curable.

2. A family history of cervical cancer places a woman at higher risk for cervical cancer.

3. Abnormal Pap smears can be treated successfully with less invasive methods like vitamins and dietary supplements.

4. Risk factors for the development of cervical cancer include birth control pills.

Behavioral Risk Items

Among the four items that addressed risk, two items required a single multiple-choice response, and two items required a "yes/no/don't know" response.

1. Which of the following describes your sexual relationship?
   a. In a monogamous relationship
   b. Sexually involved with more than one person
   c. No sexual activity
   d. Frequent short-term relationships

2. Have you ever been told that you had a sexually transmitted infection? (yes/no/don't know)

3. Do you consider yourself at risk for being exposed to HPV? (yes/no/don't know)

4. Do you use condoms:
   a. Always
   b. Usually
   c. Sometimes
   d. Never
   e. Not applicable
   f. No sexual activity

Experience Items

Among the seven experience items, direct experience was differentiated from indirect experience. Direct experience was measured exclusively by item #21 (see Appendix A), which revealed a personal history of having an abnormal Pap smear. The remaining six experience items involved indirect experience with the subject—information obtained through a university course, an Internet search, participation in a local clinical research project that recruited students, talking with a health-care provider, or through knowing someone, such as a sexual partner, friend, or relative that had direct

experience with HPV or abnormal Pap smears. The experience items required a "yes/no/don't know" response:

1. Have you ever talked with a doctor or health-care provider about HPV?

2. Have you taken any university courses that include the subject of sexually transmitted infections?

3. Have you ever participated in the HPV study conducted by the Cancer Research Center of Hawai`i at the University of Hawai`i student health service, Kaiser Permanente Medical Center, The Queen's Medical Center, Kapiolani Medical Center or Leeward Community College student health service?

4. Do you have a friend or relative who has been worried about having an abnormal Pap smear or HPV?

5. Have you ever done an Internet search on the topic of HPV or abnormal Pap smears before answering this survey?

6. I have known at least one person with HPV (Human Papillomavirus).

7. **(Women only)** I have **never** had an abnormal Pap-smear result (direct experience).

Opinion Items

There were two items developed to ask participants' opinions about HPV immunizations, which are currently undergoing clinical trials and are expected to become available in the near future:

1. If a new vaccine to prevent HPV were available to you, would you take it?
   a. Yes
   b. Maybe
   c. Don't know
   d. Probably not
   e. No

2. At what age should people be immunized to prevent HPV?
   a. birth to age 4
   b. age 5–10
   c. age 11–15
   d. age 16–20
   e. age 21–25
   f. age 16–30
   g. age 31–35
   h. over 35

One question that was originally considered a belief question was recategorized as a unique measure of perceived knowledge: "Prior to reading this questionnaire, I did not know that a virus was in any way related to an abnormal Pap smear" (item #22). This item was most similar to those utilized in knowledge surveys published in the HPV knowledge literature.

Demographic Items

Finally, the eight demographic items included age, gender, education, ethnicity, citizenry, mother's and father's education (a measure of socioeconomic status), and major field of study at the university.

Data Management

The completed surveys were retrieved from a secure university email account. All identifying email addresses were blocked, guaranteeing that the survey responses were completely anonymous. Each survey was printed and downloaded into a Word document for data security. Each response, excluding repeat responses, was data-entered into SPSS (Statistical Product and Service Solutions, Version 10.0, SPSS, Inc.), a data management program for statistical analysis.

Frequencies were obtained on all survey items to assess data-entry errors, missing responses, and outlying responses (Appendix D). The data set was also scanned visually

for entry errors. Missing items were located from the original printed surveys and corrected. A master file was saved, as was a working file.

Frequencies of the demographic variables (age, gender, and ethnicity) were ascertained. The variables for ethnicity and major field of study were recoded in order to establish standard terminology for comparison between the sample population and the sampling frame. The sample demographics were compared to available demographic information from the University of Hawai`i Institutional Research Office enrollment reports to determine if the sample was reasonably representative of the sampling frame.

The variable for age was later recoded from individual ages to age groups to establish a meaningful comparison of HPV knowledge among younger and older age groups. Students who attend college directly after high school are likely to be between the ages of 18 and 22. Students who are above age 22 are more likely to have delayed university enrollment or have returned to the university. For this reason, the age categories were established as a group of 18–22 years and a group of 23 years or greater.

Sixteen ethnicity variables were later recoded into one ethnicity variable with five ethnic categories to provide adequate group size for analysis and to establish mutually exclusive ethnic categories for statistical analysis.

The survey questions were categorized into demographic items, knowledge items, belief and opinion items, experience items, and risk items. A fourteen-item knowledge composite (HPVAPK) was established by transforming and recoding each of the fourteen variables. Each item was answered by participants as "true/false/don't know." All items correctly answered "true" were recoded as 1=correct response, and 0=incorrect or all other ("don't know") response. All items correctly answered "false" were recoded as

1=correct response, 0=incorrect response or all other responses ("don't know"). The HPVAPK knowledge composite score was created by adding all of the correct responses together (transform-compute). This resulted in a score from 0 to 14 in which 0 represented no knowledge and 14 represented the highest knowledge level. Frequencies were run on the HPVAPK composite variable to determine scores for the sample population. In addition to the reporting of composite knowledge scores among the sample population, individual items were evaluated for frequency of correct or incorrect responses. One knowledge item that addressed risk factors allowed multiple answers among six possible multiple-choice responses. These were later recategorized as "true/false/don't know" responses to three individual risk-factor items during data analysis (item #25) (see Appendix B).

Belief items, although related to knowledge, were categorized separately from knowledge items if the explanation to the item was ambiguous or could not be substantiated in the literature or in clinical practice. Ambiguity may be present when the scientific literature includes hypotheses that remain controversial. Ambiguity is also present when value-laden terms are used, such as "curable" or "serious." There were four items categorized as beliefs about HPV and abnormal Pap smears. One of these included a question about risk factors that was originally categorized as a knowledge item; "risk factors for the development of cervical cancer include birth control pills" (item # 25). This item was recategorized as a belief item since the answer remains controversial within the literature and within clinical practice. Frequencies for individual belief items were obtained.

A seven-item composite score for experience and a four-item composite score for personal behavioral risk, both independent variables, were established. The experience composite included questions regarding exposure to information about HPV either academically, from prior Internet searches, or from direct (personal) or indirect experience with abnormal Pap smears or HPV. Personal experience with having an abnormal Pap smear was categorized as a separate item since it was a unique measure of direct experience as opposed to indirect experience. The indirect experience items (20, 32, 33, 34, 35, 37) all required a yes/no response. These were recoded yes=1, no=0. Item # 21 was a unique measure of direct experience of having an abnormal Pap smear. This item was recoded into a new variable in order to reveal participants who did have a history of having an abnormal Pap smear, where false=99, and all else=0.

Table 1. Direct Experience (Survey Question #21)

I have never had an abnormal Pap smear
a. True
b. False
c. Don't know
d. Never had a Pap smear done

Summation of items (transform-compute) 20, 21, 32, 33, 34, 35, and 37 resulted in a new composite variable for total experience. The next step was recoding into the same variable: 0=0, 1–6=2, indirect experience, and >99=1, direct experience. This created three mutually exclusive categories: no experience, indirect experience, and direct experience. Recoding into the same variable enabled the new composite to discriminate between those with no experience, those with indirect experience, and those with direct

experience, accounting for the overlap of those with direct experience who also had indirect experience. Frequencies were obtained for the new composite experience variable and were compared to frequencies prior to recoding.

The risk composite involved parameters of multiple sexual partners, absence of condom use, history of previous sexually transmitted infection, and self-perception of increased risk. Items were recoded and summarized to create a new risk variable. For item #9, which characterizes sexual relationship, responses a and c were recoded as low risk; b and d were recoded as at risk.

Table 2. Relationship Risk (Survey Question #9)

Which of the following describes your sexual relationship:
a. In a monogamous relationship
b. Sexually involved with more than one person
c. No sexual activity
d. Frequent short-term relationships

For item #31, which categorizes behavioral risk according to condom use, responses a, b, e, and f were categorized as "low risk," whereas response c and d were categorized as "at risk." The remaining items (#29 and #30) required a "yes/no" response and were recoded to No=0, low risk, and Yes=1, at risk.

Table 3. Condom Use (Survey Question #31)

Do you use condoms:
a. Always
b. Usually
c. Sometimes
d. Never
e. Not applicable
f. No sexual activity

The four recoded risk items were summarized (transform-compute) into a new risk variable. In order to rank and label risk status, the composite risk variable was recoded into the same variable where 0=low risk, 1–2=1, at risk, and 3–4=2, high risk. Thus, a positive response to one or two out of four risk responses was categorized as at risk; a positive response to three or four out of four risk responses was categorized as high risk. Frequencies were obtained for the new risk composite.

In summary, there were five independent variables and one dependent variable addressed in this study. The five independent variables were age, gender, ethnicity, behavioral risk status, and experience status. Behavioral risk status and experience status were based on the creation of two composites of multiple survey items. The dependent variable was a measurement of knowledge about HPV and abnormal Pap smears, referred to as the HPVAPK.

Statistical Approach for Each Research Question

Research Question 1

> What is the level of knowledge about HPV and abnormal Pap smears as measured by the Human Papillomavirus and Abnormal Pap smear Knowledge (HPVAPK) composite among the sample population?

To answer this question, descriptive statistics of knowledge composite scores were reported. The number and percentage of correct responses to individual items were also obtained to determine which items were more frequently correct. Frequencies were also obtained for item #22; a measure of self-perceived knowledge about HPV and abnormal Pap smears.

Research Question 2

What are the predominant beliefs and opinions regarding particular HPV related issues presented in this survey?

This question was addressed by reporting of frequencies and percentages for those items categorized as belief or opinion items.

Research Question 3

Which questions about HPV and abnormal Pap smears have the highest frequency of an uncertain response?

This question was answered by reporting frequencies and percentages of "don't know" responses to each of those items categorized as knowledge items.

Research Question 4

Are there gender, age, or ethnic differences in HPVAPK scores among the study participants?

Gender

Gender differences were analyzed by a t-test in which gender was the independent variable and the HPVAPK score was the dependent variable. Individual items were inspected for number and percentage of correct answers and uncertain ("don't know") answers according to gender.

Age

Age differences were analyzed by a t-test in which a two-age-group variable represented the independent variable and HPVAPK scores represented the dependent variable.

Ethnicity

A recoded ethnicity variable condensed ethnic groups with very small numbers into larger groups for the purpose of establishing adequate power. It was also necessary

to separate primary self-reported ethnicity with multiple or mixed ethnicity in order to establish categories that were mutually exclusive and therefore amenable to ANOVA analysis. The resulting five ethnic categories represented an independent variable, ethnicity, which was entered into an ANOVA in which the HPVAPK scores were the dependent variable.

Research Question 5

Do participants categorized as having behaviors at higher risk of HPV infection differ in HPVAPK scores when compared to participants with low risk behaviors?

A risk composite was created that categorized participants into three groups (low-risk, at-risk, or high-risk) depending on responses to four items that identified risk. Frequencies and percentage of risk status were reported according to gender. This question was addressed by two-way ANOVA, in which the three risk categories represented the independent variable and the HPVAPK scores represented the dependent variable. Gender was included as the covariate. Next, multiple regression of the individual risk items and the HPVAPK scores was evaluated specifically for females to further inspect which of the four risk items were most predictive of risk status.

Research Question 6

Do participants who have direct experience, indirect experience, or no experience with HPV or abnormal Pap smears differ in their knowledge about HPV and abnormal Pap smears as measured by the HPVAPK?

The six indirect experience items and the one direct experience item were recoded and transformed into an experience composite that discriminated between direct experience, indirect experience, and no experience. Frequencies and percentages of experience status were obtained. A two-way ANOVA was done with the three experience categories as the independent variable and the HPVAPK as the dependent variable. Gender differences

were expected since having direct experience with an abnormal Pap smear is gender specific. Therefore, gender was included as a covariate to determine if the expected gender differences significantly influenced the results. Individual item responses were also compared.

Research Question 7

Are there age or ethnic differences in direct experience of having a history of an abnormal Pap smear?

Cross-tabulation of the two age categories and the direct experience variable was calculated among females to observe the frequency of direct experience in having an abnormal Pap smear among the age groups. A chi square analysis was obtained to determine the existence of a statistically significant relationship between age group and direct experience of having an abnormal Pap smear.

Cross-tabulation of the recoded ethnicity variable and the direct experience variable was obtained for females to observe the frequency of direct experience in having an abnormal Pap smear among the five ethnic categories. This was followed by a Chi square analysis to determine the existence of a statistically significant relationship between ethnicity and direct experience of having an abnormal Pap smear.

CHAPTER 4

RESULTS

This chapter describes the results of the study. The first section includes a demographic description of the sample population. The next section describes results of each of the research questions. The Human Papilloma Virus and Abnormal Pap-Smear Knowledge composite (HPVAPK) represents the dependent variable in all t-tests and ANOVA analyses. The independent variables studied are age, gender, ethnicity, behavioral risk status, and experience. A comparison of the responses to individual items that measure knowledge and beliefs about HPV and abnormal Pap smears are also shown.

The Sample

There were 494 email responses to the survey. Among these, only two indicated that they were second responses, and these were deleted from the data (n=492). The resulting sample consisted of 5.4 % of the sampling frame. The sample itself is of interest as it contains variability in the demographic features such as age, gender, and ethnicity, and in the independent variables (experience and risk status). The sample (n=492) is large enough to achieve adequate power for a meaningful statistical analysis. The sample is not assumed to be random, and conclusions are not intended to describe the entire population of the University of Hawai`i. However, the sample does appear to reflect the demographic features of the university's undergraduate population. The Hawai`i Institutional Research Office's annual enrollment reports provide demographic information about the sampling frame. The following comparison reveals modest differences in gender, ethnicity, and major fields of study. There was a higher proportion

of females to males in the sample (75.8%/24.2%) than in the sampling frame (56%/44%). The sample population included more social-science students and fewer arts-and-science students than the sampling frame. The following demographic comparisons were made between the sample and the sampling frame based on the 2003 annual report detailing demographic characteristics of the undergraduate population at University of Hawai`i at Manoa (Table 4, Table 5, Table 6). The mean age for the 2003 University of Hawai`i at Manoa enrolled undergraduates was 22.4 years and the mean age for the sample population was 22.7.

Table 4. Comparison of Sample to UH Undergraduate Population 2003*

University of Hawai`i at Manoa 2003 enrollment	Population number	Population percent	Sample number	Sample percent
Registered students	13,292	N/A	N/A	N/A
Current e-mail accounts	8,668	N/A	492	5.6
Females	7,284	56.0	373	75.8
Males	5,869	44.0	119	24.2

Table 5. Comparison of Sample Ethnicity to UH Undergraduate Population 2003*

ETHNICITY 2003 Enrollment	Population percent	Sample percent	Percent difference
Asian	47.0	48.8	1.8
Caucasian	19.6	18.9	0.7
Filipino	7.5	12.2	4.7
Hawaiian	8.6	11.4	2.8
Hispanic	1.8	3.7	1.9
African American	0.9	1.4	0.5

Table 6. Major Field of Study*

University of Hawai`i at Manoa Major Fields of Study: 2003	Population percent	Sample percent	Percent difference
Arts and Sciences	33.5	4.5	29.0
Social Sciences	12.4	26.4	14.0
Business	6.7	14.6	7.9
Nursing and Dental Hygiene	2.7	5.5	2.8
Education	2.8	5.1	2.3
Natural sciences	12.2	10.0	2.2
Arts and Humanities	7.8	6.5	1.3
Computer and ICS	4.4	5.5	1.1
Tropical Agriculture and Family Resources	3.7	4.7	1.0
Travel	2.6	1.8	0.8
Language arts	3.8	3.5	0.3
Engineering	5.4	5.5	0.1
Hawaiian and Asian Studies	1.0	1.0	0

*Data from 2003 Enrollment reports, University of Hawai`i at Manoa, Institutional Research Office File Reference: Management and Planning Support Folder

Sample Demographics

Descriptive statistics of all demographic variables were obtained. The age range of the sample was 18 to 49, with a mean age of 22.7, a median age of 21, and mode of 21. Eighty-eight percent (88%) of the sample was under age 27. Seventy-nine percent (78.7%) were under age 24. The standard deviation of the sample was 4.55, with skewness of 2.715 and kurtosis of 9.083. This approximates a normal distribution that is skewed toward younger ages, as might be expected in a university population (Figure 3).

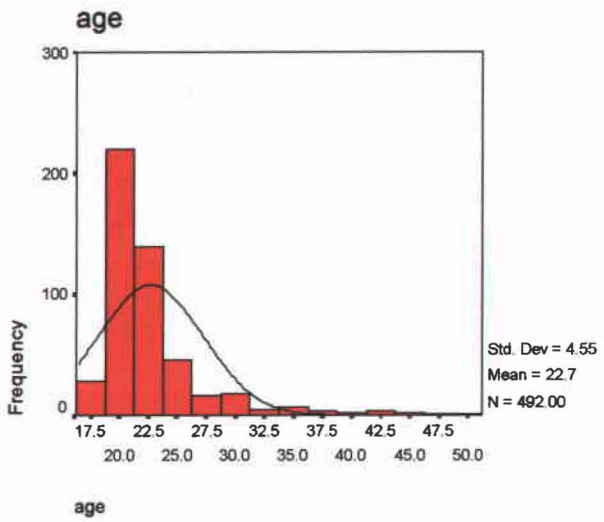


Figure 3. Sample Age Distribution

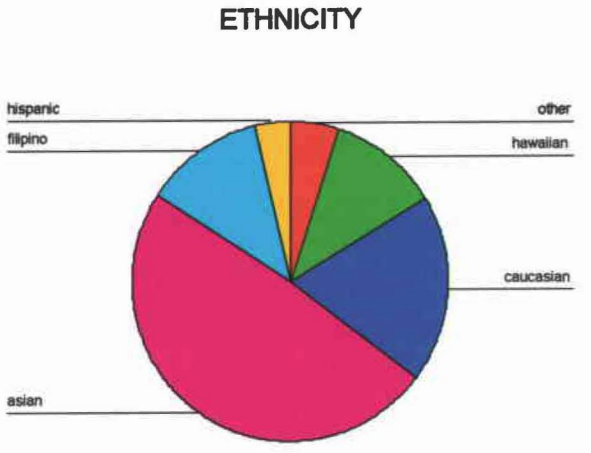
A grouped categorical variable was created with two age categories for evaluation of group differences where 1=18–22, 2= >22. The creation of three age groupings was also considered, but these groupings lacked adequate group size for a meaningful comparison for power analysis, based on an assumption of a power of 0.80 and significance of 0.05. A power of 0.80 is commonly assumed in social-science research (Munro, 2001). The minimum group size necessary to detect a small effect in ANOVA at this power would be 319; a moderate effect size would require at least 62 participants (Polit & Beck, 2004). There were 51 participants over the age of 27. Use of three groups would only have allowed for detection of a large effect size. Therefore, the two-age-group variable was chosen for use in this analysis.

Gender demographics included 373 females and 119 males representing 75.8% and 24.1% of the sample respectively. The mean education level was fifteen years (15.3, Standard deviation=2.11). Thirteen percent (13.2%) of participants indicated that they had completed one year of college or less. Thirty-one percent (30.5%) had completed two

years of college or less. Fifty-three percent (52.8%) had completed three years of college, and seventy-five (75.4%) indicated completion of four years of college or less. An interesting finding was that twenty-five percent (24.6%) of the sample indicated that they had more than four years of college despite the fact that the listserv included only undergraduate students.

Parental education represents a measure of socio-economic status. The education level of mothers of students was moderately high: forty-two percent (41.6%) were college educated and fourteen percent (13.8%) had completed a professional degree beyond college. Thirty-eight percent (37.6%) of the sample indicated that their mother had a high-school education or less. Similarly, fifty-five percent (54.6%) of fathers were college educated or had completed professional degrees beyond college. Thirty percent (30.4%) of the sample indicated that their father had a high-school education or less. Eleven percent (10.8%) of fathers had completed a trade-school program.

The survey allowed participants to indicate more than one ethnicity. Therefore, the raw ethnicity data includes all self-identified ethnicities. Ethnic categories were recoded to establish mutually exclusive ethnic categories, a requirement for analysis of variance. Ethnic categories with frequencies of six or fewer were excluded from the analysis of variance. The excluded categories included African American, Native American, Other Pacific Islander, Other, and Mixed. The excluded categories are represented by "other" in Figure 4. There were thirty-one foreign students, which represented six percent (6.3%) of the sample.



Asian=48.8%, Caucasian=18.9%, Filipino=12.2%
Hawaiian=11.4%, Hispanic=1.8%

Figure 4. Sample Ethnicity

Statistical Analysis of Research Questions

This section addresses the results of each of the research question.

Research Question 1

What is the level of knowledge about HPV and abnormal Pap smears as measured by the Human Papillomavirus and Abnormal Pap smear Knowledge (HPVAPK) composite?

The HPVAPK comprised 14 questions. Correct responses were reported as a composite score ranging from 0–14. The resulting distribution of HPVAPK scores was as follows: 14% of the sample had no correct answers, 20.5% of the sample answered one item correctly, 55.7% of the sample answered five items or fewer correctly, and 97% of the sample answered ten items or fewer correctly. No one answered all fourteen items correctly. The mean score for the HPVAPK was 4.8 correct answers, with a standard

deviation of 3.2, skewness of 0.088 and kurtosis of -0.983. This represents a normal distribution (Figure 5).

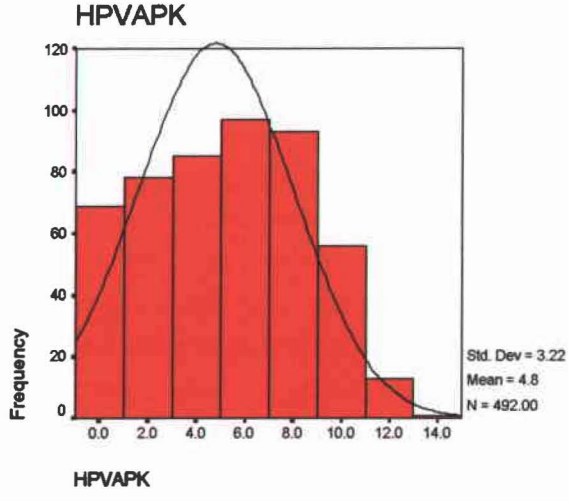


Figure 5. Distribution of HPVAPK Scores

Individual item analysis of correct responses to HPVAPK is presented in Table 7, including the number and percent of correct responses for the entire sample.

Table 7. HPVAPK Correct Responses by Item

Item	Number	Percent
Risk factors for cervical cancer include persistent positive HPV results (true)	314	63.8
Risk factors for cervical cancer include history of multiple sexual partners (true)	267	54.3
HPV is not a very common virus (false)	265	53.9
Most women with an abnormal Pap smear are able to have a completely normal pregnancy in the future (true)	232	47.2
You can tell if someone has been exposed to HPV by looking for warts (false)	231	47.0
HPV can cause genital warts (true)	188	38.2
Risk factors for cervical cancer include smoking cigarettes (true)	184	37.4
Routine medical screening for STD usually includes an HPV test (false)	131	26.6
Condoms will help prevent women from having abnormal Pap smears (true)	125	25.6
High-grade abnormal Pap smears are treated by removing a small part of the cervix to prevent cervical cancer (true)	122	24.8
Low-grade abnormal Pap smears are usually not harmful and often go away completely without treatment (true)	106	21.5
There is a screening test that is commonly used to test males for HPV (false)	84	17.1
Genital warts can cause cervical cancer (false)	82	16.7
If a heterosexual woman has HPV, her sexual partner should be seen by his health-care provider to be treated for it even if he has no sign of warts (false)	16	3.3

One question was asked in order to compare HPV knowledge as measured in this study with other published studies. (The question was "Prior to reading this questionnaire, I did not know that a virus was in any way related to abnormal Pap smears.") Forty-two percent (41.9%) of the sample indicated they did not know that HPV was related to abnormal Pap smears. Eight percent (7.9%) gave an uncertain ("don't know") response to this item. A t-test was done to examine the relationship between participants' self-perceived measure of knowledge (as measured by this item) and their actual knowledge (as measured by the HPVAPK composite items). The result showed a low HPVAPK score (mean=3.5 correct out of 14) among those who said that they did not know that a virus was related to abnormal Pap smears. Those who reported having prior knowledge had a higher mean HPVAPK score (6.2) ($p<.0000$, $t=-9.96$). Thus, the item measuring self-perceived knowledge discriminates between higher and lower levels of knowledge, giving support to the validity of the HPVAPK as a measure of knowledge.

Research Question 2

What are the predominant beliefs and opinions regarding the particular HPV-related issues presented in this survey?

Seventy-six percent (76.2 %) of the sample believed that a family history of cervical cancer increases a woman's risk of cervical cancer. Although family history may have some predisposing influence, it is not a primary risk factor for cervical cancer. This may reflect a broad conception of cancer as a hereditary disease. Forty-nine percent (49%) of the sample believed that genital warts are an incurable disease. This is a very revealing value statement. The concept of "cure" carries profound psychological consequences. Interestingly, nineteen percent (19.3%) thought that vitamins or dietary supplements could effectively treat cervical disease labeled as having an abnormal Pap

smear. This item was limited, however, by the lack of differentiation between low-grade and high-grade lesions detected by Pap smear.

Although some evidence does exist that birth-control pills or oral contraception may be associated with the development of cervical cancer in the presence of persistent HPV (Schiffman & Castle, 2003), only sixteen percent (16.1%) of the sample believed that birth control pills were a risk factor. This is consistent with current clinical guidelines, which do not recommend cessation of oral contraception among women with abnormal Pap smears.

Participants were asked their opinion about whether they would be likely to take a vaccine to prevent HPV if it were available, and also at what age they thought people should be immunized to prevent sexually transmitted viruses. A large percentage of the sample indicated willingness to be immunized. Approximately seventy-nine percent (78.6%) said that they would or might take such a vaccine. Only nine percent (8.6%) indicated a negative response (that they would not or probably would not take an HPV vaccine if it were available). Only thirteen percent (12.8%) indicated that they did not know if they would take such a vaccine. A majority of the sample (75.7%) thought the vaccine should be given during adolescence (ages 11–20). Twenty percent (19.7%) of the participants thought the vaccine should be given in childhood (ages 0–10). Only five percent (4.7%) thought the vaccine should be given in adulthood (ages 21 to over 35).

Research Question 3

Which questions about HPV and abnormal Pap smears have the highest frequency of an uncertain response?

Among the fourteen HPVAPK items, the uncertain response "don't know" was considered an admission of lack of knowledge or uncertainty. By having the option of a

"don't know" response among otherwise dichotomous variables, the likelihood of a random guess in response to the item is somewhat decreased. This admission of lack of knowledge represents a unique measure of self-perception regardless of the HPVAPK measurement. Table 8 shows the frequency of "don't know" responses to each of the HPVAPK items. The item labeled "risk factors" includes three risk factors: history of multiple partners, smoking cigarettes, and persistent positive HPV results.

More than fifty percent (50%) of participants indicated that they did not know the answer to five of the fourteen items. More than forty percent (40%) of participants indicated that they did not know the answer to ten of the fourteen items. This result is comparable to item # 22, "Prior to reading this questionnaire, I did not know that a virus was in any way related to abnormal Pap smears," to which forty-two percent (41.9%) responded in the affirmative, lending additional support to the validity of the HPVAPK composite scale.

Table 8. Percent Uncertain (Don't Know) Responses to HPVAPK Items

HPVAPK items	Percent uncertain responses
High-grade abnormal Pap smears are treated by removing a small part of the cervix to prevent cervical cancer	67.5
There is a screening test that is commonly used to test males for HPV	66.5
Low-grade abnormal Pap smears are usually not harmful and often go away completely without treatment	55.3
HPV can cause genital warts	53.3
You can tell if someone has been exposed to HPV by looking for warts	46.7
Most women with an abnormal Pap smear are able to have a completely normal pregnancy in the future	44.1
Genital warts can cause cervical cancer	42.1
Routine medical screening for STD usually includes HPV test	41.9
HPV is not a very common virus	40.2
Condoms will help prevent women from having abnormal Pap smears	36.0
*Risk factors for cervical cancer include persistent positive HPV results	34.6
*Risk factors for cervical cancer include smoking cigarettes	34.6
*Risk factors for cervical cancer include history of multiple sexual partners	34.6
If a heterosexual woman has HPV, her sexual partner should be seen by his health-care provider to be treated for it even if he has no sign of warts	20.9

* from a single multiple-choice item with 6 possible responses, including "don't know"

Research Question 4

Are there gender, age, or ethnicity differences in HPVAPK scores among the study participants?

Gender

The independent t-test revealed a significant difference between the mean scores of females and males (p=000, t=4.6), with a mean difference of 1.5 (CI 0.88 – 2.2). Females (N=373) scored higher on the HPVAPK than males (N=119), with an average of 5.1 (36.7%) correct answers, as opposed to 3.6 (25.7%) correct answers for males. Although the difference between male and female mean scores achieved significance, the magnitude of the difference was small (Eta squared=0.041). The individual item analysis according to gender differences was quite revealing, however, as is shown in Tables 9 and 10.

Table 9. Percent Correct Responses to HPVAPK Items, by Gender

HPVAPK item	Correct Responses		
	Percent females	Percent males	Percent total
Risk factors for cervical cancer include persistent positive HPV results	67.6	52.1	63.8
Risk factors for cervical cancer include history of multiple sexual partners	57.6	43.7	54.3
HPV is not a very common virus	57.1	43.7	53.9
Most women with an abnormal Pap smear are able to have a completely normal pregnancy in the future	52.5	30.3	47.2
You can tell if someone has been exposed to HPV by looking for warts	49.9	37.8	47.0
HPV can cause genital warts	41.8	26.9	38.2
Risk factors for cervical cancer include smoking cigarettes	38.9	32.8	37.4
Routine medical screening for STD usually includes an HPV test	29.5	17.6	26.6
Condoms will help prevent women from having abnormal Pap smears	26.8	21.8	25.6
High-grade abnormal Pap smears are treated by removing a small part of the cervix to prevent cervical cancer	27.1	17.6	24.8
Low-grade abnormal Pap smears are usually not harmful and often go away completely without treatment	25.2	10.1	21.5
There is a screening test that is commonly used to test males for HPV	18.5	12.6	17.1
Genital warts can cause cervical cancer	18.8	10.1	16.7
If a heterosexual woman has HPV, her sexual partner should be seen by his health-care provider to be treated for it even if he has no sign of warts	2.9	4.2	3.3

Table 10. Percent Uncertain (Don't Know) Responses to HPVAPK Items, by Gender

HPVAPK items	"Don't Know" Responses		
	Percent females	Percent males	Percent total
High-grade abnormal Pap smears are treated by removing a small part of the cervix to prevent cervical cancer	64.9	75.6	67.5
There is a screening test that is commonly used to test males for HPV	64.3	73.1	66.5
Low-grade abnormal Pap smears are usually not harmful and often go away completely without treatment	50.4	70.6	55.3
HPV can cause genital warts	48.8	67.2	53.3
You can tell if someone has been exposed to HPV by looking for warts	42.4	60.5	46.7
Most women with an abnormal Pap smear are able to have a completely normal pregnancy in the future	37.3	65.5	44.1
Genital warts can cause cervical cancer	38.6	52.9	42.1
Routine medical screening for STD usually includes HPV test	37.0	57.1	41.9
HPV is not a very common virus	37.0	50.4	40.2
Condoms will help prevent women from having abnormal Pap smears	31.9	48.7	36.0
*Risk factors for cervical cancer include persistent positive HPV results	31.1	45.4	34.6
*Risk factors for cervical cancer include smoking cigarettes	31.1	45.4	34.6
*Risk factors for cervical cancer include history of multiple sexual partners	31.1	45.4	34.6
If a heterosexual woman has HPV, her sexual partner should be seen by his health-care provider to be treated for it even if he has no sign of warts	19.3	26.1	20.9

* one multiple-choice item with 6 possible responses

Age

The independent t-test was used to determine HPVAPK score differences between the two age groups. Although there were significant differences in mean HPVAPK scores between the two age groups (t=-2.28, p=0.023, CI= -1.32– -9.77), the magnitude of the difference was small (Eta squared=0.010). The average score for the 18- to 22-year-olds (n=337) was 4.5 (32.5%) correct, whereas the average score for the 23-and-above age group (n=155) was 5.3 (37.6%) correct.

Ethnicity

The HPVAPK scores among the five mutually exclusive ethnic categories were evaluated by One-way ANOVA. Although the result was significant (p=0.000, F=5.839), indicating a general difference in HPVAPK scores between groups, the Post Hoc Bonferroni analysis revealed that some of the HPVAPK score differences between groups were significant and some were nonsignificant. There were significant differences in HPVAPK scores between respondents of Asian and Caucasian ethnicity, Hawaiian and Caucasian ethnicity, and Filipino and Caucasian ethnicity, but there were no significant differences in scores between respondents of Hawaiian, Asian, and Filipino ethnicity. Hispanic ethnicity showed no significant score differences compared to any other group, possibly due to small group size.

The mean HPVAPK score for respondents of Hawaiian ethnicity was 4.2 correct responses (n=56, standard deviation [s.d.] of 3.2); for Caucasian ethnicity, 6.2 correct responses (n=93, s.d.=3.3); for Asian ethnicity, 4.3 correct responses (n=240, s.d.=3.1); for Filipino ethnicity, 4.5 correct responses (n=60, s.d.=3.2); and for Hispanic ethnicity, 5.4 correct responses (n=18, s.d.=3.6).

Research Question 5

Do participants categorized as having behaviors at high risk for HPV infection differ in HPVAPK scores when compared to participants with low-risk behaviors?

Behavioral risk for exposure to HPV was represented as a risk composite based on responses to four items: rarely or sometimes using condoms, prior history of sexually transmitted infection, sexual relationship characterized as involving multiple partners or frequent short-term relationships, or self-perceived risk of HPV exposure. The absence of a positive response to any of the four risk items was labeled "low risk." A positive response to one or two of any of the risk items was labeled "at risk." A positive response to three or four of any of the risk items was categorized as "high risk." Individual risk item responses are reported in Table 11.

Table 11. Responses to Individual Risk Items, by Gender

RISK	% Females	% Males	% Total
History of STD	16.9	4.2	13.8
Self-identified risk	28.4	16.0	25.4
Relationship risk	9.1	10.1	9.3
Lack of condom use	43.5	23.6	38.6

Individual item analysis of the risk composite revealed that a small percentage of the sample (8.5%) reported high-risk behavior, as indicated by positive responses to all four items. The at-risk category, defined by a positive response to one or two of the risk questions, represented a larger percentage of the sample (46.3%). The low-risk category was represented by forty-five percent (45.1%) of the sample. Ninety-one percent (90.7%) of the sample reported either a monogamous relationship, no sexual activity, or not applicable. Females reported prior history of a sexually transmitted infection more often

than males, although only fourteen percent (13.8%) of the total sample reported such history. This figure is lower than the reporting of a history of an abnormal Pap smear in the sample (24.9% of females). Twenty-five percent (25.4%) of the sample admitted to a self-perceived risk of exposure to HPV, very similar to the reporting of a history of an abnormal Pap smear in the sample (24.9% of females). Sixty-two percent (62%) of the sample reported either that they used condoms always or usually, that condom use was not applicable, or that there was no sexual activity.

Two-way ANOVA was utilized to examine differences between the three risk categories in terms of the dependent variable (HPVAPK scores), including gender as a covariate. There were significant differences between the three risk groups ($p=0.000$, $F=35.501$). The Bonferroni post hoc test confirms that the largest differences in HPVAPK scores were between the high-risk and low-risk groups.The magnitude of the difference between groups as indicated by the Eta squared was 0.127, a moderate effect size. Gender did have an interaction with the risk variable, but the magnitude of the difference was small ($p=0.002$, $F=9.24$, Eta square=0.019, adjusted r squared=0.138).

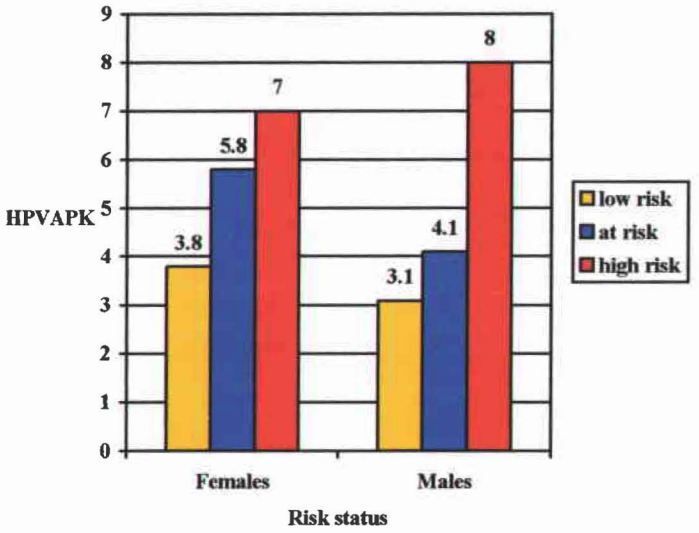


Figure 6. Behavioral Risk and HPVAPK Scores, by Gender

A point of interest is that the highest-risk group also had the highest HPVAPK scores. The low-risk group answered an average of twenty-six percent (25.7%) of the HPVAPK items correctly; the at-risk group answered an average of 39% of the HPVAPK items correctly; and the high-risk group answered an average of 50.7% of the HPVAPK items correctly. Although differences in scores for at-risk, low-risk, and high-risk categories were minimally affected by gender, it was clear that risk status was gender dependent. There were more high-risk females (n=38, 10%) than high-risk males (n=4, 3%), and more at-risk females (n=190, 51%) than at-risk males (n=38, 31%). A higher percentage (65%) of males were low risk than females (39%).

In order to better understand gender differences in reported behavioral risk, multiple regression was done to determine which of the risk variables explained these differences. Multiple regression of the four risk items (relationship, condom use, history of STD, and self-perceived risk) was evaluated using the dependent variable (HPVAPK

scores) among females. The results indicated that a history of sexually transmitted infection had the greatest influence on knowledge (HPVAPK scores), ($B=2.2$, $p<0.05$). Self-perceived risk was also predictive of knowledge ($B=1.18$, $p<0.05$). Relationship status and condom use were not significantly associated with knowledge. The lack of a significant influence from relationship risk and condom-use risk may also explain why so few participants were categorized as having high behavioral risk (n=42, 8.5 %) for HPV infection.

Research Question 6

Do participants who have direct experience, indirect experience, or no experience with HPV or abnormal Pap smears differ in their knowledge about HPV and abnormal Pap smears as measured by the HPVAPK?

After recoding to establish a combined experience variable that was able to discriminate between no experience, indirect experience, and direct experience, the three mutually exclusive categories were analyzed for group differences in the HPVAPK scores by a Two-way ANOVA. Gender differences were examined as a covariate in this analysis, since only females have direct experience with having an abnormal Pap smear.

Twenty-five percent (24.9%) of the females in the sample had direct experience, as measured by having a personal history of an abnormal Pap smear. About thirty-five percent (34.8%) of both females and males had indirect experience with the subject, either by knowing someone with HPV or an abnormal Pap smear, by talking with a health-care professional about the topic, by taking a university course that included the topic, by doing an Internet search about the topic prior to participation in the survey, or by participating in a local HPV clinical trial, thereby gaining experience with the topic

and possibly increased knowledge (Table 12). Forty-six percent (45.5%) of the sample had neither direct nor indirect experience with the topic.

Table 12. Responses to Experience Items, by Gender

Experience items	Females		Males	
	% yes	% no	% yes	% no
HPV discussed in course?	26.8	73.2	27.7	72.3
Worried friend with abnormal Pap smear or HPV ?	25.2	74.8	15.1	84.9
Talked to MD/NP?	24.4	75.6	0.8	99.2
Know anyone with HPV?	19.0	60.6	7.6	63.9
Prior web search ?	9.9	82.3	5.0	80.7
Participant in clinical study?	7.0	93.0	0	100
History of abnormal Pap smear? (females only, direct)	24.9	n/a	n/a	n/a

Two-way ANOVA showed that the HPVAPK scores among the three groups (no experience, direct experience, and indirect experience) differed significantly ($p=0.000$, $F=72.862$) and that the magnitude of the difference was large (Eta squared=0.23). The Bonferroni Post Hoc analysis confirms that the greatest differences in scores are between those with direct experience and those with no experience ($p<.0001$). The gender covariate had a minor interaction with experience but did not alter the significance of the findings ($p=0.015$, $F=6$, adjusted r squared=0.234).

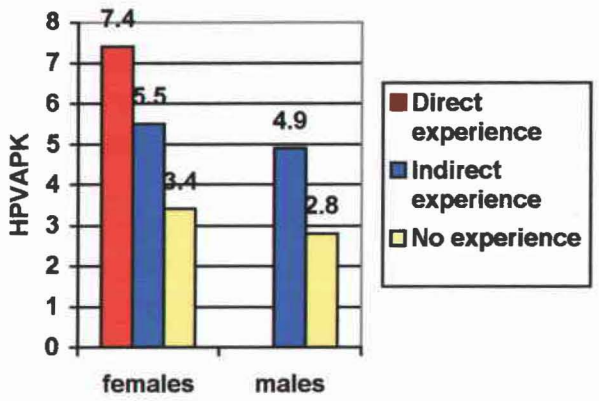


Figure 7. Experience and HPVAPK Scores

A closer inspection of the individual HPVAPK items that were answered correctly by participants with no experience, direct experience, or indirect experience provides further descriptive information about HPV and abnormal Pap-smear knowledge within this sample population (Table 13).

Table 13. Percent Correct Responses to HPVAPK, by Experience and Gender

HPVAPK items	Direct experience	Indirect experience		No experience	
	% females	% females	% males	% females	% males
HPV is not a very common virus	79	57	51.2	40	38.9
Most women with an abnormal Pap smear are able to have a completely normal pregnancy in the future	78	51	46.5	30	20.8
Risk factors for cervical cancer include persistent positive HPV results	71	75	76.7	48	38.9
Risk factors for cervical cancer include history of multiple sexual partners	71	61	55.8	42	36.1
You can tell if someone has been exposed to HPV by looking for warts	62	58	48.8	32	31.9
Risk factors for cervical cancer include smoking cigarettes	58	44	51.2	24	23.6
HPV can cause genital warts	56	46	30.2	25	23.6
High-grade abnormal Pap smears are treated by removing a small part of the cervix to prevent cervical cancer	56	22	23.3	14	15.3
Low-grade abnormal Pap smears are usually not harmful and often go away completely without treatment	49	22	18.6	9.0	5.6
Routine medical screening for STD usually includes HPV test	37	33	23.3	17	13.9
There is a screening test that is commonly used to test males for HPV	36	16	23.3	10	6.9
Condoms will help prevent women from having abnormal Pap smears	36	28	25.6	19	20.8
Genital warts can cause cervical cancer	21	19	16.3	13	5.6
If a heterosexual woman has HPV, her sexual partner should be seen by his health-care provider to be treated for it even if he has no sign of warts	4	5	7.0	2	2.8

A description of the uncertain ("don't know") responses among females with direct experience of having an abnormal Pap smear is perhaps most revealing about the knowledge and beliefs of this subset within the sample. Self-admission of what participants did not know reveals particular areas of uncertainty even among those with comparatively higher HPVAPK scores. The following table shows what participants with abnormal Pap smears thought they did not know.

Table 14. Knowledge and Beliefs: Percent Uncertain Responses of Women with Abnormal Pap Smears

Knowledge and Beliefs	Percent uncertain ("don't know") response	
	Women with abnormal Pap smears	Sample total
Abnormal Pap smears can be treated successfully with vitamins and dietary supplements	88.0	68
There is a screening test that is commonly used to test males for HPV	51.5	67
High-grade abnormal Pap smears are treated by removing a small part of the cervix to prevent cervical cancer	38.1	56
HPV can cause genital warts	35.1	55
Low-grade abnormal Pap smears are usually not harmful and often go away completely without treatment	33.0	53
You can tell if someone has been exposed to HPV by looking for warts	27.8	47
Condoms will help prevent women from having abnormal Pap smears	22.7	44
Genital warts can cause cervical cancer	23.7	42
Routine medical screening for STD usually includes an HPV test	20.6	42
Risk factors for cervical cancer include: persistent positive HPV, smoking cigarettes, history of multiple sexual partners	16.5	41
Genital warts are not curable	16.5	40
If a heterosexual woman has HPV, her sexual partner should be seen by his health-care provider to be treated for it even if he has no sign of warts	16.5	36
Family history of cervical cancer increases a woman's risk of cervical cancer	14.5	35
HPV is not a very common virus	14.4	23
Most women with an abnormal Pap smear are able to have a completely normal pregnancy in the future	13.4	21
I did not know that a virus was related to abnormal Pap smears	3.1	19

Research Question 7

Are there age or ethnic differences in direct experience of having a history of an abnormal Pap smear?

There were 93 females with a history of an abnormal Pap smear, representing 24.9% of females (n=373) in the sample. There were 80 females that indicated never having had a Pap smear done (21.4% of females).

Age

Comparison of two age groups reveals that sixteen percent (16%) of the younger group (ages 18–22) had experienced an abnormal Pap smear, whereas forty-six percent (46%) of the older age group (ages >22) had experienced an abnormal Pap smear. Further inspection of the older age group revealed that forty-one percent (41%) of females aged 23–27 (n=70) and fifty-five percent (55%) of females aged 27 and older (n=38) had a history of an abnormal Pap smear.

The Pearson's Chi square of 37.06 (p=0.000) indicates that there is a significant relationship between age and having an abnormal Pap smear. In this analysis, a Phi of 0.315 is closer to 0 than to 1, indicating a weak association. Overall, there is a significant but weak association between the age group and the experience of an abnormal Pap smear. The weakness of the association may be explained by the smaller number of women in the older age group in this sample.

Ethnicity

The frequency of having an abnormal Pap smear reported among females for each of the ethnic categories is shown in Table 15. The Pearson's Chi square result was 9.23 (p=100). The differences between the actual and expected counts for females with direct experience in having an abnormal Pap smear were similar among many of the ethnicities,

indicating independence or lack of association between the two categorical variables (ethnicity and direct experience with having an abnormal Pap smear). The Chi square analysis did not achieve statistical significance. In summary, there were no significant differences by ethnicity in having an abnormal Pap smear within the sample population.

Table 15. Number and Percent of Abnormal Pap Smears Within Ethnic Groups

Ethnicity	Number	Percent of ethnic group
Caucasian	23	37%
Hispanic	5	28%
Filipina	10	22%
Asian	38	21%
Hawaiian	10	20%

Summary of Results

Statistical analysis of the research questions showed that in general, people scored low on the HPVAPK measurement of knowledge about HPV and abnormal Pap smears. There was a high percentage of uncertain ("don't know") responses to many of the questions. Those with experience had more knowledge about HPV and abnormal Pap smears. Females with direct experience of an abnormal Pap smear were most knowledgeable, although they continued to express a lack of self-perceived knowledge about many of the items. Females in the older age group were slightly more knowledgeable, but also had more direct experience in having an abnormal Pap smear than the younger age group. Caucasians scored slightly higher than Asians, Hawaiians, and Filipinos, despite a lack of significant experiential difference among ethnicities.

Those with a higher risk of HPV exposure knew more than those at lower risk. Individual item analysis of HPVAPK responses and belief-item responses reveals the underlying issues that were known or believed.

CHAPTER 5

DISCUSSION AND CONCLUSIONS

Overview

This section discusses the findings from this study, the relevance of the conceptual model of uncertainty in illness, and the broader issues highlighted by this study. The study findings are categorized by the seven separate issues regarding HPV knowledge and beliefs that were addressed by the survey: HPV basics; the relationship between HPV-induced warts and cervical cancer; HPV in males; HPV and pregnancy; risk factors for cervical cancer; awareness of low-grade and high-grade cervical lesions; and HPV and cervical cancer prevention. Next, differences in knowledge among subpopulations within the sample are discussed. Study limitations, the broader context of HPV knowledge, application of the theoretical model of uncertainty and introduction of the concept of a paradigm shift are elucidated. Application of research to practice and suggestions for further research follow.

Discussion of Findings in This Study

This study showed that the sample population of university students had a low level of knowledge about HPV and abnormal Pap smears. Experience appears to have been the best teacher: females with a history of an abnormal Pap smear, females in the older age group, and females at highest behavioral risk of acquiring HPV knew more than males, the younger age group, people without HPV-related experience, and people with low-risk behaviors. The older age group also had a higher incidence of abnormal Pap

smear experience than the younger of the two groups. Higher knowledge among a higher-risk group may also be a function of experience.

The knowledge composite created for this study (HPVAPK) highlighted issues of basic HPV awareness, as well as more detailed issues that women are confronted with when they have an abnormal Pap smear and are trying to understand their condition. Perhaps the most notable aspect of this study is not only that it reveals a low level of knowledge about HPV and abnormal Pap smears, as has been shown by several other studies (Dell et al., 2000; Gerhardt et al., 2000; Holcomb et al., 2004; Lambert, 2001; Pitts & Clarke, 2002; Waller et al., 2003; Yacobi et al., 1999), but that it reveals a complexity associated with the issue of HPV and the diagnosis of an abnormal Pap smear that obscures understanding of the issues, even among women who have experience with both. This complexity may thwart health-care providers' efforts to convey adequate information during disclosure of an abnormal Pap smear. Furthermore, the lack of public knowledge about HPV serves to perpetuate the knowledge void that women face when they discover that they have an abnormal Pap smear.

Information-seeking is a form of adaptive behavior that helps people to cope with a medical condition or diagnosis (Mishel, 1981). When a health condition is complicated to explain, full of ambiguity, and unpredictable in terms of prognosis, uncertainty predominates and negative psychological consequences are more likely to ensue. In the present study, women with a history of an abnormal Pap smear or a history of an STD were comparatively more knowledgeable about HPV and abnormal Pap smears, as one would expect, indicating that information-seeking and learning did occur as a result of personal experience. However, there was evidence that self-perceived ignorance about

the underlying issues prevailed. Perhaps most revealing about knowledge and beliefs about HPV and abnormal Pap smears are responses to the individual knowledge and belief questions.

HPV Basics

Roughly half of the sample did not know that HPV is a common virus. Indeed, half of the sample indicated that they had no experience at all with the topic of HPV. Several studies do show an awareness of sexually transmitted diseases in general, particularly HIV, and that high-school health-education classes are a major source of STD education (Baer et al, 2000; Dell et al., 2000). Although health education, which usually includes the topic of sexually transmitted infections and contraception, is now a part of the curriculum for most high schools, one must conclude that adequate information about STDs and particularly HPV is lacking even at this level. Other public resources for health education include the Internet, health-care providers, family, friends, popular magazines, and television. Waller notes that the usual public media resources do not appear to be addressing this issue (Waller et al., 2003).

HPV, Warts, and Cancer

The present study shows that women confused the issue of warts and cervical cancer. This is not surprising. Some form of HPV is involved in each, although low-risk HPV subtypes are usually associated with external warts and high-risk HPV subtypes are associated with cervical disease. A discussion of high-risk and low-risk HPV and high-grade and low-grade cervical lesions may be quite complex and confusing. While roughly half of the sample knew that HPV was associated with abnormal Pap smears, and one-third also knew that HPV was identified with genital warts, the distinction between the

HPV that causes warts and the HPV that causes cervical cancer was known by very few. Indeed, only sixteen percent (16%) of the sample knew that external genital warts do not usually cause cancer.

This distinction is also one that causes significant fear and concern among women with external genital warts, who may believe that cervical cancer is impending. Maissi et al. (2004) measured anxiety, concern, and distress among women with abnormal Pap smears with positive HPV testing (n=536) and found that younger age, a higher perceived risk of cervical cancer, and a lack of understanding about the meaning of test results were associated with the highest levels of anxiety. Multiple studies have shown that having an abnormal Pap smear as a consequence of HPV causes anxiety, concern, and distress (Maissi et al., 2004; Clarke et al., 1996).

The common misconception that genital warts are "incurable" is also laden with psychological ramifications. This study showed that forty-nine percent (49%) of the sample believe that HPV is an incurable disease. The choice of wording or message framing in disclosure of an abnormal Pap smear is particularly important. The word "incurable" is likely to be associated with a greater perception of threat. Most researchers agree that a majority of HPV infections resolve spontaneously, and indeed, low-grade cervical lesions frequently resolve without treatment (ZurHausen, 2002; DHHS, 1999). It is entirely possible to effectively treat precancerous disease, thereby preventing cervical cancer (Waller et al., 2003; Linnehan & Groce, 2000). External genital warts are also responsive to treatment modalities. For women who confuse external genital warts with asymptomatic cervical cancer, the term "incurable" is particularly misleading and can

lead to feelings of hopelessness and anxiety. Under these circumstances, the perception of impending cervical cancer appears far more dire and more complex than is necessary.

Unfortunately, well-meaning teachers, health educators, health-care providers, and materials written for the purpose of public-health education perpetuate some of the messages that explain HPV as one disease. For example, Krames, a well-respected producer of patient education materials, produces a pamphlet entitled "Abnormal Pap Test Results" (updated 2001). In this pamphlet, abnormal Pap smears and external genital warts are covered in a single, brief paragraph: "Abnormal Pap test results are often linked to the human Papillomavirus (HPV). This is a sexually transmitted virus that is the cause of genital warts (condyloma)." It may be far too complicated to explain the details about the differences between HPV subtypes or the physiologic behavior of viruses to the general public or to individuals alarmed by recently disclosed personal news of HPV exposure, but by generalizing information about HPV, multiple issues become obscured. Greater clarity would be achieved by presenting information about condyloma, or external genital warts caused by low-risk HPV subtypes, *separately* from information about precancerous cervical disease that is associated with high-risk HPV and by reinforcing to patients that these two diseases behave differently. Additionally, health educators and providers should avoid value-laden terms such as "incurable" that can easily cause alarm and misinterpretation.

Furthermore, reporting of prevalence and incidence statistics in public health and research would also be more consistent if external genital warts were reported separately from cervical HPV, and if laboratories were required to report annual incidence of low-grade and high-grade abnormal Pap smears.

Fertility

Almost half of the sample (47%) felt that the ability to have a normal pregnancy in the future would not be harmed by HPV. Interestingly, males (65%) indicated that they did not know if HPV could have an effect on a future pregnancy, whereas females (37% "don't know") were more certain about their answers to this question. With other sexually transmitted infections, such as Chlamydia or Gonorrhea, fertility may be affected due to scarring of the fallopian tubes. At this time, there is no evidence that HPV has a significant effect on fertility unless very large areas of the cervix are removed if treatment of cervical lesions is necessary. Although large exophytic warts during pregnancy may require removal to minimize obstruction during birth and minimize direct HPV exposure to the newborn during delivery, even high-grade cervical lesions short of frank cervical cancer are usually managed after completion of the pregnancy, and an unaffected vaginal delivery is usually expected. There is a rare long-term complication (respiratory papillomatosis) of HPV birth exposure in some children. However, the current management guidelines for HPV in pregnancy include treatment of large exophytic condyloma but do not recommend avoidance of vaginal delivery (Bergeron, 1989).

HPV In Males

Men may be very much affected by their partner's experiences in dealing with an abnormal Pap smear but frequently remain uninformed about the underlying issues, or even marginalized as vectors of a sexually transmitted disease. Aside from the observation that males had lower scores (26%, compared to 37% for females) on the measure of knowledge used in this study, the qualitative aspects of knowledge, beliefs,

and opinions among males in this sample are of interest. Males also had more "don't know" responses overall than females. This may be due to a self-perceived lack of knowledge, but it might also represent gender differences in how people respond to Internet surveys.

A very high percentage of the sample (73%) believed that even asymptomatic male partners of HPV-affected women should see a health-care provider. In fact, most people appeared more certain that they knew the answer to this question. Actually, there is no current standard of care to screen males for HPV aside from genital inspection for visible exophytic warts. In a study of HPV in males, Rosenblatt et al. (2004) concluded that most HPV infections in males resolved spontaneously and that methods to detect HPV in males—such as HPV DNA testing, penoscopy, or penile biopsy—among male partners of women with abnormal Pap smears is not warranted in the absence of visible lesions.

Perhaps the belief that male partners should see a health-care provider reflects more of a need or desire among males and female partners of males for males to have equal access to health care. Even if HPV is very prevalent among both genders (Rosenblatt et al., 2004; Dilner, Meijer, vonKrogh, & Horenblas, 2000) and the majority of HPV infections resolve spontaneously (Dilner et al., 2000), both males and females may feel an ethical responsibility to know their HPV status, or a desire for males to at least obtain information directly from a health-care provider about their own risks. Unfortunately, it is not yet feasible to provide meaningful HPV detection by screening or to predict patterns of infectivity in males. At this stage of health-care research, males are primarily viewed as temporary carriers of infection (Castellsaque, Bosch, & Munoz,

2002) unless there are visible genital warts caused by low-risk HPV types, or, very rarely, if there is visible evidence of high-risk-type HPV-associated penile intraepithelial neoplasia (PIN). Although PIN lesions do occur, high-grade PIN and penile cancer is extremely rare, despite an increase in HPV prevalence (Dilner et al., 2000; Rosenblatt et al., 2004).

As scientific knowledge about the natural history of HPV in males becomes clearer, there may be an opportunity to develop a better screening strategy for males. Additionally, if males are willing to be immunized against HPV when a vaccine becomes available, as was indicated by seventy-nine percent (79%) of males in this study, such health-care services for males will be in greater demand.

Risk Factors

A majority (76%) of the sample believed that family history was a major risk factor for cervical cancer. This may be due to the general public belief that cancers are hereditary, when in fact only about five percent of all cancers are hereditary (ACS, 2000). Public education strategies have effectively conveyed the message that some cancers, such as breast and colon cancer, are associated with family history, warning family members of people with cancer to be aware of their own need for early detection. In a virally induced mechanism of carcinogenesis, family history is not a major contributor, however. Public-education messages that address viral-associated cancers should be conveyed without detracting from the current, successful public-health strategy that delivers a message of early detection for hereditary cancers.

Although slightly more than half of the sample indicated that persistent HPV was a risk factor for cervical cancer, this may have been a leading question. Thirty five

percent (35%) indicated that they did not know anything about the risk factors for cervical cancer. The risk factors for cervical cancer include persistent high-risk HPV, early sexual initiation, multiple lifetime sexual partners, smoking cigarettes, and possibly hormonal factors such as high parity or use of hormonal contraceptives, although the latter remains controversial (Moscicki et al., 2001; Waller et al., 2003; Schiffman & Castle, 2003).

The public may be aware of the risk of lung cancer from smoking cigarettes, but the increased risk of bladder and cervical cancer due to tobacco is less well known (Marteau, Hankins, & Collins, 2002). Indeed, tobacco by-products have been isolated in cervical secretions among smokers, and smoking is a well-established cofactor for cervical cancer, particularly in the U.S. (Haverkos, Soon, Steckley, & Pickworth, 2003; Au, Sierra-Torres, & Tyring, 2003). A low percentage (37%) of this sample associated smoking cigarettes with cervical cancer.

Long-term use of oral contraceptives has been associated with the development of cervical cancer among women with persistent high-risk HPV and abnormal Pap smears (Moreno et al., 2002; Schiffman & Castle, 2003). However, the evidence has not been specific enough or conclusive enough to establish changes in clinical practice regarding the prescription of oral contraceptives among women with abnormal Pap smears. Most practitioners maintain that the risks of unintended pregnancy outweigh the potential risk that cervical disease might progress as a result of the influence of oral contraception. In the present study, the sample expressed the predominant belief that oral contraceptives are not a risk factor in the development of cervical cancer.

Prevention

The issue of prevention can provide a means for people at risk of infection to feel some sense of control over the possibility of impending HPV infection or impending cervical cancer. Condoms are associated with the concept of safe sex. Although condoms do not protect against external genital warts due to lack of an external barrier, they are likely to protect against cervical infection (Dailard, 2003; Dilner et al., 2000; Gerhardt et al., 2000; Hildesheim et al., 2001; Rosenblatt et al., 2004; Waller, McCaffery, Forrest, et al., 2004). A large percentage of the sample population (71%) in this study did not recognize the potentially protective role of condoms in the prevention of cervical disease.

There was generally a favorable response to the idea of HPV immunization. A majority expressed willingness to obtain an immunization if it becomes available. Most indicated that HPV immunizations should be offered during adolescence, presumably before the onset of sexual activity. Indeed, if reports of HPV incidence in 50% of women within the first two years of sexual activity are accurate (Bekkers et al., 2004), a preventive vaccine should be offered before the onset of sexual activity. Clinical trials are currently underway for both a preventive HPV vaccine as well as a therapeutic vaccine (Schiffman & Castle, 2003). Preliminary results of the preventive vaccine are very promising.

Although the use of nutriceuticals in this country is very popular, a fairly small number of people in this sample (19%) shared the belief that dietary supplements or vitamins could treat cervical disease. Epidemiologists have reported that dietary micronutrients, including folic acid, may have beneficial preventive effects against the development of various cancers, including cervical cancer (Goodman et al., 1998;

Hernandez, McDuffie, Wilkens, Kamemoto, & Goodman, 2003). Carotinoids have been suggested as micronutrients that might help to prevent cervical cancer by enhancing communication between healthy and pre-neoplastic cells, thereby reducing the occurrence of genetic instability (King, 2000). Although several studies have addressed assessment of micronutrients and prevention of cervical cancer, few have revealed adequate evidence for the establishment of practice standards. It is therefore not a current clinical standard to recommend dietary supplements to prevent cervical cancer, although further research may be more promising. Yet, it is appropriate for health-care providers to recommend good nutrition and healthy lifestyle habits to support resistance to disease.

Low-grade and High-grade Lesions

Not surprisingly, females with a history of an abnormal Pap smear scored higher on the two questions that addressed cervical lesions. However, even among these experienced females, one-third indicated they did not know the answer to these questions. The distinctions between a low-grade lesion and a high-grade lesion and the distinction between low-risk HPV and high-risk HPV involve a fairly complex knowledge that may need reinforcement over time, even for women with abnormal Pap smears. Additionally, it may not be clear to female patients with abnormal Pap smears that low-grade lesions frequently resolve spontaneously without treatment (Dailard, 2003; Schiffman & Castle, 2003; Wright et al., 2003). It has been suggested by some (Schiffman & Castle, 2003) that low-grade lesions should not be categorized as truly precancerous. It is reasonable, therefore, to provide reassuring statistics to patients with low-grade lesions that they are not likely to develop cervical cancer—with the caveats that careful monitoring for change

to higher-grade lesions will remain important to their health, and that treatment may become necessary if the low-grade abnormality persists.

High-grade lesions, confirmed by colposcopy and biopsy as cervical intraepithelial neoplasia grade two or three (CIN II-III), have a greater chance of progression to cervical cancer (Wright et al., 2003) and therefore do require excision, usually by LEEP (loop electrical excision procedure) or cone biopsy. High-grade lesions are classified as precancerous. However, the prognosis for complete prevention of cervical cancer is excellent.

Understanding of the terms *low-grade lesions* and *high-grade lesions* may be important during and after disclosure of an abnormal Pap smear, but the concepts may be too complex or too detailed to expect from a population inexperienced with this problem. However, it is important for the general public to understand the difference between having an abnormal Pap smear and having cervical cancer, a distinction that is frequently misunderstood.

Age Differences and Knowledge

The older age group (>23) knew more about HPV as well as abnormal Pap smears than the younger age group (ages 18–23). Other studies found that knowledge about HPV is higher among older age groups, as is the incidence of cervical dysplasia (Gerhardt et al., 2000; Holcomb et al., 2004; Rosenblatt et al., 2004; Waller et al., 2004). However, incident HPV infection is higher among lower age groups, which have a reported lower awareness about HPV (Moscicki et al., 2001; Waller et al., 2003). Incident infection in younger women has been estimated to be as high as 50% within the first two years after

sexual debut. Although estimates vary widely, prevalence of HPV has been reported as 19–46% of young women aged 18–24 (Bekkers et al., 2004; Waller et al., 2004).

In the present study, it is likely that experience also influenced the trend of greater knowledge among the older age group. Indeed, there were more females (46%) with abnormal Pap smears among the older age group than the younger age group (16%) in this study.

Experience Teaches

This study confirmed, as expected, that people with direct experience in having an abnormal Pap smear were more knowledgeable about HPV than those without such experience. Furthermore, females with direct experience indicated less frequently that they did not know the answer to several of the questions. However, even women with experience were not well informed about risks for cervical cancer, issues of partner screening or partner management, the protective usefulness of condoms, or the distinction between external warts and cervical cancer risk.

Females with direct experience are a subset of this study sample (n=93) that can be viewed as a patient population. Women who experience having an abnormal Pap smear are abruptly confronted with an issue that requires further learning and understanding. The critical experience of having an abnormal Pap smear is a stimulus for learning about the issue, whether that learning is from a health-care provider, a friend, a book, or the Internet. According to the theory of uncertainty in illness (Mishel, 1981), the woman who is first alerted to an impending threat of illness requires information in order to adapt and cope adequately. The theory stipulates that if she does not acquire adequate information that is understandable to her, then her ability to cope will be delayed or

thwarted. This points to the critical role of providing lucid, uncomplicated, unambiguous information both to patients and to the general public.

Gender Differences

This study agrees with previous reports that females are more knowledgeable than males about HPV and abnormal Pap smears (Baer et al., 2000; Dell et al., 2000; Holcomb et al., 2004). Although only females have direct experience in having an abnormal Pap smear, this difference in knowledge may also be partially explained by the fact that females have better access to health-care screening tests and simultaneous health education than males. Partners of women with abnormal Pap smears may have a similar but indirect learning opportunity during or after disclosure of a woman's abnormal Pap smear. This may depend upon how involved the partner is, or how involved the woman wants the partner to be in understanding her condition. In this sample there were 93 women that reported a history of an abnormal Pap smear. There were only 18 males in this study (15% of the males who responded) who reported knowing a friend who had had an abnormal Pap smear or HPV. There were 43 males (36% of males) that reported some form of indirect experience. One study that addressed disclosure between partners of HPV diagnosis showed that fifty percent (50%) of female patients said they planned to inform future partners of their HPV exposure, but only thirty percent (30%) actually did inform new partners prior to sexual relations (Keller, Von, Pankratz, & Hermsen, 2000) Thus, the quality of indirect experience of male partners is partly dependent on the decisions and attitudes of women with abnormal Pap smears regarding communication with partners.

Behavioral Risk

Multiple sexual partners, lack of condom use, self-perceived risk, and prior history of a sexually transmitted infection characterize risk for HPV exposure in this study. Surprisingly few people in this sample were in the high-risk behavior category; other studies have suggested that college student of this age group have higher-risk behaviors (Holcomb et al., 2004; Ramirez, Ramos, Clayton, Kanowitz, & Moscicki, 1997; Yacobi et al., 1999). There were more females than males in the high-risk category, and those at higher risk scored better on the measure of HPV and abnormal Pap-smear knowledge than those at low or intermediate risk. Further inspection of this finding showed that among females, a prior history of an STD, which was associated with a self-perceived risk of exposure to HPV, predicted higher risk categorization as well as higher scores on measurement of knowledge.

Those who did meet criteria for the high-risk category may have been more knowledgeable due to experience, but if so, there did not appear to be a change in behavior or reduction of risk-taking behavior as a result of knowledge, since the highest-risk and most knowledgeable group had three to four of the possible risk factors.

Cultural Differences

The suggestion of cultural differences between Caucasians and all other ethnic groups in the analysis bears further investigation. Perhaps there are cultural differences that favor access to health care or that perpetuate the ethnic disparities that result in knowledge differences. Perhaps the issue of shame is experienced differently among Hawaiian, Asian, or Filipino women compared to Caucasian women. It would be useful to explore possible differences in patient-provider communication dynamics. Although

this study suggests a general lack of public information about HPV, there may also be ethnic or cultural differences in use of the popular media.

Limitations of This Study

Although this sample had adequate size for a meaningful analysis (n=492), it was not a random sample and therefore conclusions can not be generalized to the sampling frame or to the general population. Although the sample population was somewhat representative of the sampling frame of University of Hawai`i undergraduate students with a university e-mail account, some sampling bias did occur. Those who are familiar with survey methods, those who are interested in the topic of HPV or abnormal Pap smears, or those who are interested in social issues in general may have been more motivated to participate in the survey. Indeed, students who majored in social sciences were overrepresented in the sample.

The fact that twenty-five percent (25%) of females in the sample had a history of an abnormal Pap smear also suggests that those with a personal motive may be more likely to participate in the survey. The national rate of abnormal Pap smears is approximately 7% (Wright et al., 2002). Other survey studies also report a sample bias in that people interested in the topic are more likely to complete a survey, whether in person, by telephone, by mail, or by the Internet (Anderson & Kanuka, 2003).

The HPVAPK developed for this study seeks to measure both broad and specific areas of knowledge about both HPV and abnormal Pap smears. Psychometric properties of the measurement were found to be very good. However, repeated application of this instrument on other populations is required to further establish validity and reliability. Additionally, some questions could be modified for clarity.

This study revealed significant ethnic differences in knowledge about HPV and abnormal Pap smears despite a fairly complex scheme to isolate ethnic categories. The issue of measuring ethnicity was complicated in this study, as it is in most studies that include mixed ethnicity. The survey allowed for multiple responses to self-identified ethnicity, thereby obtaining the most complete information for the database. However, most statistical applications require the establishment of mutually exclusive categories. In order to create such categories, a fairly complex scheme was devised. Ethnicity is primarily a label for measurement of cultural differences, cultural biases, and predispositions, whether genetic or familial. Therefore, a good measure of cultural differences includes participant reports of their ethnicity as well as the ethnic culture that they most identify with. In this population, most Hawaiians were of mixed ethnicity and all Native Americans were also Caucasian. Many in the Asian category reported a mixed Asian ethnicity such as Japanese-Chinese or Chinese-Korean. The selection scheme was devised in order to isolate Hawaiian ethnicity from all others and to sift through all part-Caucasian mixed ethnicities to identify their non-Caucasian cultural component. Japanese, Chinese, Korean, and other Asian ethnicities were combined together to produce an Asian conglomerate, despite the existence of cultural differences among the separate Asian ethnicities. It was possible to maintain Filipino and Hispanic as separate ethnic identities for statistical analysis due to adequate group numbers. Several ethnic identities were not represented in this sample because of small numbers too limited for meaningful statistical analysis.

Measurement of risk in this study involved a risk composite of four items. Low risk was indicated by a negative response to all four of the risk items; intermediate risk

status ("at risk") was a response to one or two of the risk items; and high risk was indicated by a positive response to three or four of the risk items. However, this may have been a temporally ambiguous question. A participant with a prior history of multiple relationships or frequent short-term sexual relationships who is currently in a long-term monogamous relationship or not currently sexually active would be considered at low current risk. However, prior risk could influence current knowledge. An additional caveat is that there may be gender differences in disclosure of personal information even within an anonymous Internet format. Despite these limitations, the differences in knowledge scores among the three groups were significant and revealed that risk and knowledge scores were positively related, primarily due to experience.

Limitations of Internet Surveys

The use of the Internet for conducting survey research is remarkably convenient and economical. However, despite the advantages of this method of surveying, one must acknowledge the limitations of Internet surveys as well as surveys in general. The Internet provides a unique environment for conducting surveys in that participants are entirely anonymous. A face-to-face interview or voice-to-voice telephone interview is not anonymous, and subtly influences participant responses. Mail surveys are more anonymous, but require more time and effort on the part of the participant to complete the survey and mail it back. Mail surveys are also more likely to have missing data than Internet surveys because Internet surveys can be programmed to require responses to all items. This survey was programmed in such a way that all items required a response and the incentive to complete the survey was the promise of access to an explanation page as well as other educational materials only after completion of the survey. Anonymity

provides a safe environment to reveal personal and private information. However, anonymity does not prevent deliberately erroneous responses or the assumption of an imaginary persona. One must also acknowledge undetectable and uncorrected keypunch errors in Internet survey responses.

Theoretical Model and Broader Issues

Uncertain Knowledge of a Certain Virus

Despite the fact that 3.5 million (7%) U.S. women have abnormal Pap smears every year that require further evaluation (Wright et al., 2002), there is an inordinately low level of knowledge about the cause of abnormal Pap smears and issues that surround having an abnormal Pap smear both among patients with abnormal Pap smears and among the general public. This survey showed that there was a low level of knowledge about HPV and abnormal Pap smears in an educated, reproductive aged population in Hawai`i, and that although women with a history of an abnormal Pap smear were more knowledgeable than those without experience, even those women with abnormal Pap smears had a low level of knowledge about particular issues related to HPV and abnormal Pap smears. Knowledge is vital as a moderator of stress and adaptation among women who experience the uncertainty of cervical disease.

The incidence of cervical cancer in the U.S. has decreased by approximately 50% in the past 30 years (ACS, 2003). Cervical cancer is very preventable as a direct result of early detection by Pap smear screening and treatment as necessary. In fact, the Pap smear is sensitive enough to detect low-grade cervical cytologic changes so benign that they frequently (40–60% of the time) resolve spontaneously (Unger & Duarte-Franco, 2001). The high incidence of abnormal Pap-smear detection and low level of knowledge about

issues surrounding abnormal Pap smears seem incongruent, forcing one to ask why this is so.

Complexity, ambiguity, and incongruence surround the experience of an abnormal Pap smear, obscuring knowledge and exacerbating uncertainty among women with abnormal Pap smears. There is a cognitive dissonance that occurs, particularly with low grade lesions, when a patient is informed that there is potential for cervical cancer to arise due to a sexually transmitted infection and that an uncomfortable procedure should be done for further evaluation (colposcopy)—but afterward, it is entirely safe to wait and see what happens in three to six months because it might just go away. This is not the medical advice one normally associates with the words "cancer" or "sexually transmitted infection."

In the present study, forty-two percent (42%) indicated that they did not know that HPV and abnormal Pap smears were in any way related. HPV has irrefutably been shown to be carcinogenic. In fact, the molecular basis of HPV-induced cervical cancer has been clearly elucidated. HPV is able to penetrate to the basal layers of the cervix and take control of the cell replication process (ZurHausen, 2002). HPV high-risk subtypes such as HPV-16 or HPV-18 are associated with more than ninety-eight (98%) of cervical cancers worldwide (Schiffman & Castle, 2003). HPV incident infection has been estimated to be as high as fifty percent (50%) within the first two years after the onset of sexual activity in young women (Bekkers et al., 2004). Despite this high incidence, most HPV infections occur asymptomatically and resolve spontaneously. A relatively small number of HPV infections actually persist; only persistent HPV infections with high-risk HPV subtypes result in cervical disease (Schiffman & Castle, 2003; ZurHausen, 2002). Although HPV

is undeniably involved in the development of cervical cancer and persistent HPV is the cause of most precancerous cervical lesions detected by Pap smears, protective factors may limit the ability of HPV to cause cervical disease. The circumstances, or cofactors, that determine whether HPV resolves spontaneously or not have not been fully elucidated scientifically. Patterns of infectivity, incubation, latency, cofactors, and predictors of HPV persistence are areas of current scientific research.

Lack of knowledge contributes to the uncertainty that women experience when they discover that they have an abnormal Pap smear. Multiple studies have documented the negative psychosocial effects of having an abnormal Pap smear (Lauver et al., 1999; Linnehan & Groce, 2000; Maissi et al., 2004; Rajaram et al., 1997). In a qualitative study in which patients with HPV were asked to give advice to others with the same condition (Taylor, Keller, & Eagan, 1997), study participants warned others to expect ambiguous, inconsistent information when talking with health-care providers. It is not clear whether this complexity and uncertainty surround the abnormal Pap smear itself, or whether HPV and the stigma associated with a sexually transmitted virus cloud the issue. Furthermore, one must ask: If there is an inordinate lack of knowledge about HPV and abnormal Pap smears, where do women usually obtain information about such health issues, and why is that information deficient?

The Paradigm Shift

A paradigm shift is occurring among health-care practitioners due to scientific advances in the understanding of the etiology of cervical cancer that directly impacts the disclosure of information about abnormal Pap smears and, therefore, knowledge about the surrounding issues. In the past, disclosure of an abnormal Pap smear did not usually

address etiology and did not involve discussion of sexually transmitted infection. Now that HPV has been implicated, providers have an important piece of information to share about etiology, but that information must be extracted from the context of unanswered questions about infectivity, latency, persistence, spontaneous resolution, and cofactors. There is a technological gap in information that increases uncertainty both for patients and health-care providers. In this study, the individual survey questions addressing partner screening and management, the difference between external genital warts and cervical disease, preventive measures, the nature of low-grade lesions, and smoking as a risk factor for cervical cancer were not well known, even among women with a history of an abnormal Pap smear.

Solid evidence about the nature of HPV represents a significant change in information about the etiology of cervical cancer. This has an impact not only on new frontiers in prevention of disease through immunization and early detection, but also on disclosure of disease by providers, support systems for patients, and educational efforts to improve patients' ability to comprehend their health status. This information is central to the paradigm shift that may initially increase the ambiguity and complexity of information about abnormal Pap smears. Ultimately, as further scientific advances are made, better information will become available to explain the natural history of HPV in both genders; determinants of HPV persistence; and cofactors in the development of cervical cancer. However, consensus on lucid informational messages that can be used during this transition period is needed to guide health-care providers through this paradigm shift.

A debate even exists over whether to disclose HPV etiology to patients with abnormal Pap smears or not. McCaffery et al. (2003) conducted a study of psychological consequences of HPV disclosure to patients with abnormal Pap smears among British, African-Caribbean, and Indo-Asian subcultures in England. She found that when HPV was disclosed as the etiological agent for cervical cancer, Indo-Asian women in particular were more likely to express blame, distrust, and stigmatization. While a woman who is informed of an abnormal Pap smear may be supported by her partner or her family, HPV disclosure may actually result in stigmatization and lack of support from her partner or her family.

The U.S. Department of Health and Human Services' consensus panel that convened in 1999 to address HPV discussed, among several other issues, the complexity of educational messages regarding HPV. The panel acknowledged that while patient disclosure of the most recent scientific findings that link cervical cancer with HPV was the most effective and most ethical policy, the stigmatization associated with STDs might undermine the utilization of Pap smear screening programs or might lead providers to think that women at low risk for STDs do not need Pap smears; "therefore, it may be counterproductive to promote messages that increase anxiety in the absence of effective strategies to reduce risk for infection" (DHHS, 1999, p.19). The consensus panel acknowledged that messages should be carefully construed to deal with these complexities.

Theoretical Relevance: Antecedents of Uncertainty

The midrange theory of uncertainty in illness developed by M. Mishel well describes the situation of the experience of uncertainty in having an abnormal Pap smear.

In 1988, Mishel tested the antecedent conditions of stimuli frame and structure providers on uncertainty and found that a lack of symptom awareness, a lack of event familiarity, and a perception of incongruence increased the experience of uncertainty (Figure 8). The existence of adequate structure providers (including a system of social support, a higher educational level among patients, and authority credibility) not only decreased the perception of uncertainty but also positively influenced the stimuli frame, presumably by teaching patients about their medical condition.

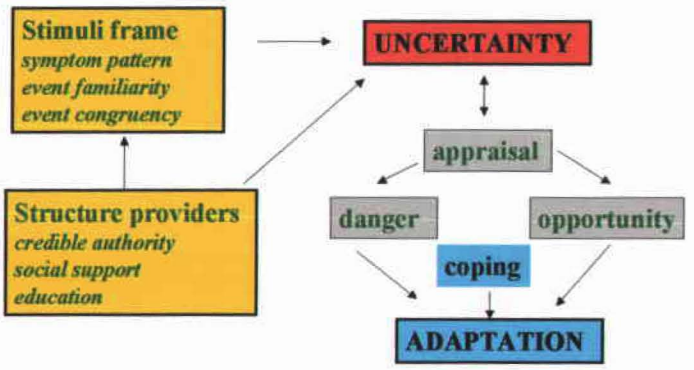


Figure 8: Antecedents of Uncertainty (Mishel, 1988)

Credible Authority

Within the model of uncertainty, the credibility of those who provide information and the process of education itself are inversely associated with uncertainty. If health-care providers can give credible, consistent information and remain accessible to patients for further informative opportunities after initial disclosure, then there will be a lesser

degree of uncertainty experienced by patients. Inconsistent health-care provider messages are likely to detract from authority credibility. The present study has focused on the education and informational deficits among patients and the general public regarding HPV and abnormal Pap smears. It should be mentioned, however, that health-care providers must also contend with a complexity and ambiguity of issues during disclosure of an abnormal Pap smear. Providers may be able to provide adequate, clear information about diagnostic and treatment procedures, as well as prognostic indicators, but information that addresses issues aside from the management of an abnormal Pap smear and the clinical prevention of cervical cancer is inconsistent and ambiguous. Important issues relevant to the discussion of HPV, such as infectivity, persistence, latency, and prevention, are only partially explainable due to this information gap.

Social Support

This study addressed a lack of public awareness about HPV and abnormal Pap smears. Public awareness may or may not influence risk-taking behavior. However, public awareness can influence people who develop abnormal Pap smears to have a realistic perspective of the meaning of an abnormal Pap smear, or at least to find resources for public support in terms of information and discussion. Within the theoretical framework of uncertainty (Mishel, 1988), public information and media discourse represents social support, an avenue for obtaining information and support outside of the health-care milieu. Social support can take the form of public forums, media coverage, talk-show debate, women's magazines, and support groups. If there is a general public lack of knowledge, the issues will not be addressed or debated in public venues.

Social support can also take the form of patient-provider communication and partner or family support. A newer form of support includes Internet chat groups. There are several groups that provide support to patients with abnormal Pap smears, some of which do provide helpful peer information and advice, and some of which—although well intentioned—unfortunately promulgate misinformation.

Education

In the model of uncertainty, education refers to the patient's general level of education. Those with higher education appear able to understand explanations about a medical condition more rapidly than those without formal education. Therefore, those with lower education appear to experience more uncertainty than those with more formal education. However, in this context, education may represent intelligence, or worldly experience, or maturity. The present study includes only university students; therefore according to the uncertainty in illness model, the sample presumably has less uncertainty than those who are less educated.

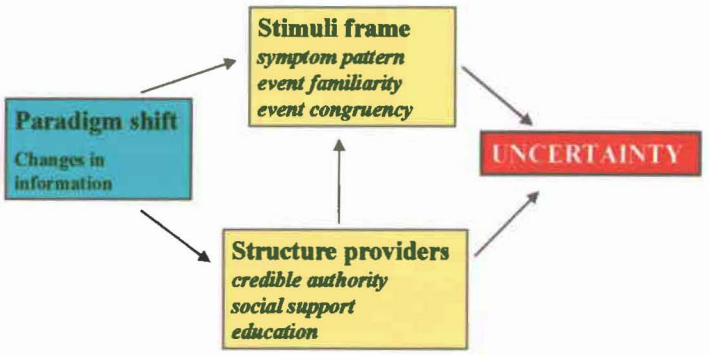


Figure 9. A Paradigm Shift and Antecedents of Uncertainty

Paradigm Shift

It appears to the author of this dissertation that an additional antecedent condition may contribute to uncertainty (Figure 9). A paradigm shift due to new medical or technological information creates an advance in understanding of disease but may be accompanied by an information gap that affects the concept of a disease among patients, health-care providers, and the public. This appears to be the case regarding information about HPV and abnormal Pap smears. It may also be applicable to multiple other health issues. For example, for over a decade, epidemiological evidence supported the use of hormone replacement therapy during menopause for the prevention of osteoporosis, heart disease, and the prevention of Alzheimer's disease. New evidence from the Women's Health Initiative, a large clinical trial, resulted in a paradigm shift in the practice of women's health care (McDonough, 2003). Health-care providers have reversed their messages about cardiac protection from hormone replacement therapy, are concerned about a potential although small increased risk of breast cancer, and are waiting for more information to replace the void that was left from this scientific news. Meanwhile, women who are either demanding refills for their hormone prescriptions or are newly concerned about the risk of breast cancer and heart disease are faced with an uncertain management of their postmenopausal years. All are waiting for more information. Meanwhile, authority credibility has suffered, and both health-care providers and patients face a looming uncertainty.

Application of Research to Practice

Two separate applications are apparent from this survey: one that targets patient education and one that targets public education. There is a need to further investigate the

content of existing patient education materials about HPV and abnormal Pap smears, and there is a corresponding need to develop focused, uncomplicated messages for use during and after disclosure of an abnormal Pap smear that clarifies the following topics:

1. Differentiation between external genital warts and high-risk cervical HPV, addressing them as two distinct entities;
2. Explanation of the difference between low-grade and high-grade lesions, placing the risk of cervical cancer in perspective;
3. Provision of information about the incidence and usual inconsequence of HPV, placing risk of cancer in perspective;
4. Admission of what is yet unknown about HPV and infectivity;
5. Suggestions for preventive measures and healthy lifestyle modalities to decrease cervical cancer risk;
6. Addressing of the issue of blame and attempts to diffuse it;
7. Avoidance of the use of misleading terms such as "incurable";
8. Reduction of the complexity of terminology, or introduction of a less confusing lexicon to describe high-grade lesion, low-grade lesion, high-risk HPV, low-risk HPV, CIN, dysplasia, precancer;
9. Provision of information useful for males or male partners;
10. Referrals to reliable Internet resources for current information understandable to patients without health-care experience, and for support as needed.

Written materials should be used as a supplement or reinforcement for individually tailored provider-patient communication, not as a substitute for communication at the critical time of disclosure.

Resources for reliable, current information include The American Social Health Association (ASHA) and the American Society for Colposcopy and Cervical Pathology (ASCCP). ASHA has developed patient education materials, an information hot line and web site for the public, and a newsletter for health-care providers about advances in HPV

research. The American Society for Colposcopy and Cervical Pathology (ASCCP) also has updated patient education materials that are accessible to health-care providers both in print and on the Internet.

Public education that encourages women to have Pap smears and continues to promote condom use for prevention of STDs is ongoing and could be embellished with additional outreach efforts to populations at risk. Although condoms may not protect against external genital warts, they do appear to be protective against cervical HPV (Dilner et al., 2000, Gerhardt et al., 2000; Dailard, 2003; Waller et al., 2004). Therefore, messages about condom use should be updated to include protection against cervical HPV. Ultimately HPV immunizations will be most effective in abating the consequences of HPV exposure. Efforts to educate the public now will stimulate willingness to be immunized against high-risk HPV types when vaccines become available in the foreseeable future.

Title X funding from the federal government supports family-planning clinics that are a primary source of cervical cancer screening, STD screening, contraception, and STD-prevention counseling. These programs currently provide primary care for reproductive-aged females who do not otherwise have access to health care. The family planning clinics supported by Title X funding have also started to provide services for males. As more information becomes available about HPV in males, and as HPV immunization becomes available for both females and males, the family planning clinics can provide affordable access to HPV information and immunization to both genders.

There may be some concern that people may overreact to public information about HPV, that it may appear more lethal than it actually is, that people may further

confuse HPV with HIV or HSV. However, increasing scientific knowledge about HPV and appropriate dissemination of information can help to place information about HPV into a less threatening perspective. Appropriate public education about HPV and the consequences of HPV will influence public willingness to obtain HPV immunization when it becomes available. Ultimately, information can reduce the uncertainty associated with HPV and abnormal Pap smears both for patients and for the general public.

Future Research

Additional Use of the HPVAPK Instrument

There are additional questions that might be asked from the database collected in this study. These include:

1. Are there age, behavioral risk, or ethnic differences among those females who indicated that they had never had a Pap smear done?
2. Are there age, gender, risk, or experience differences among participants who were willing to be immunized when an HPV immunization becomes available?

Repeated use of the HPVAPK measurement of knowledge in different populations would also further test the validity and reliability of the measurement. It would be useful to target other populations to determine level of knowledge about HPV and abnormal Pap smears among many different groups: health-care providers, high-school health-education teachers, marginalized populations, Internet chat groups for patients with abnormal Pap smears, people in other countries with high Internet usage. Internet delivery of the survey could also provide a means to deliver health-education messages at the completion of the survey.

Nursing Research

There are multiple issues related to patients' experiences and informational needs regarding abnormal Pap smears and HPV that warrant further study. The following topics are suggested as a sequel to the present study:

1. A qualitative assessment of patient informational needs;
2. Ethnic differences in patient-provider communication;
3. Disclosure of abnormal Pap smears: differences in information content provided during disclosure;
4. Content analysis of patient education materials;
5. Comparative sources of patient education: the media, the provider, the Internet, family, friends;
6. Assessment of health-care provider informational needs;
7. Concept development: the paradigm shift.

Concluding Statement

It is my responsibility as a health-care practitioner to explain to women that they have an abnormal Pap smear as a result of probable exposure to HPV. I have seen a wide variety of responses to this news, and I am certain that many people do not express their true concerns during disclosure. Some patients have told me about the end of relationships; I have seen both supportive and unsupportive partners; I have seen women exasperated with uncomfortable medical procedures, as well as people who seem to cope easily without consequence at all. Some women have told me that they will never have sex again. Women have told me several years after an abnormal Pap smear that they thought HPV was the same as HSV or HIV. I have heard women say that their partner

gave them cancer. I would like to believe that there is a way to talk about abnormal Pap smears and HPV that clarifies and simplifies sometimes complex issues and dispels rather than perpetuates myth. Western medicine's gift of early detection and cancer prevention undoubtedly saves lives. In doing so, it may be necessary to take more time to place the concept of impending disease into a more realistic perspective and reduce the uncertainty in the lives of our patients.

APPENDIX A

INFORMED CONSENT AND SURVEY

Abnormal Pap smears are detected in millions of women every year. This is a potentially very serious public-health problem. Fear, anxiety, anger in relationships, a change in feelings about sexuality, worry, and confusion, not to mention expensive health-care visits can be a consequence of an abnormal Pap smear. Both men and women are affected by this. The purpose of this survey is to assess common knowledge and beliefs about HPV (Human Papillomavirus) and abnormal Pap smears. It will be used to better understand what information people need regarding this important and personal subject. Explanations to each question will be available after completion of the questionnaire. Both males and females are invited to complete this survey. You must be age 18 or over to participate.

CONSENT

This questionnaire is being sent to all University of Hawai`i undergraduate students with a university email address. Participation is entirely voluntary and if you decide not to participate, this will not affect your status as a student at the University of Hawai`i. This research involves **simply answering the questions according to your current beliefs. It should take about 10 minutes** to answer the survey. There are 37 questions, 7 of which are demographic. To assure that the responses are **anonymous,** identifying email addresses will be separated from the completed survey when it is received. Your answers will be **confidential** and no one aside from the researcher associated with this questionnaire will be able to read your answers. You will not be required to do anything else after completing the survey. There are no risks involved in completing this survey aside from the time required to complete it. There are no direct benefits to you by completing this survey aside from the process of learning more about the subject by going to the explanation page at the end of the survey. By completing this survey, you might also be helping others that could benefit from research on this subject.

By reading this consent form and completing the questionnaire, you are giving your consent to participate in this research survey. If you would like to contact someone regarding this study, please go to the explanation page at the end of the survey. The explanation page is separate from the survey in order to maintain confidentiality. You will be able to make comments at the explanation page where you can leave your email address for a response.

THE SURVEY

1. What is your age? (enter number)

2. Are you a U.S. citizen?
   a. yes
   b. no

3. What is your ethnic background? (if mixed, please mark more than one)
   a. Hawaiian/part Hawaiian
   b. African American
   c. Caucasian/ European
   d. Chinese
   e. Filipino
   f. Japanese
   g. Korean
   h. Micronesian
   i. Native American
   j. Samoan
   k. Vietnamese
   l. Hispanic/Latin
   m. Other Pacific Island
   n. Other Asian
   o. Middle eastern
   p. All other

4. How many years of school have you completed?
   a. 12 (high school)
   b. 13
   c. 14
   d. 15
   e. 16
   f. 17
   g. 18
   h. 19
   i. 20
   j. over 20

5. What is the education level of your mother?
   a. none
   b. high school
   c. trade school
   d. college
   e. professional or graduate degree

6. What is the education level of your father?
   a. none
   b. high school
   c. trade school
   d. college
   e. professional or graduate degree

7. Are you:
   a. Female b. Male

8. Routine medical screening for sexually transmitted infections usually includes a test for HPV (Human Papillomavirus).
   a. True
   b. Don't know
   c. False

9. Which of the following describes your sexual relationships?
   a. In a monogamous relationship
   b. Sexually involved with more than one person
   c. No sexual activity
   d. Frequent short term relationships

10. HPV (Human Papillomavirus) can cause genital warts.
   a. True
   b. Don't know
   c. False

11. Genital warts can cause cervical cancer.
   a. True
   b. Don't know
   c. False

12. You can tell if someone has been exposed to HPV by looking for warts.
   a. True
   b. Don't know
   c. False

13. Genital warts are not curable.
   a. True
   b. Don't know
   c. False

14. There is a screening test that is commonly used to test males for HPV.
   a. True
   b. Don't know
   c. False

15. A family history of cervical cancer places a woman at higher risk for cervical cancer.
   a. True
   b. Don't know
   c. False

16. Most women with an abnormal Pap smear are able to have a completely normal pregnancy in the future.
    a. True
    b. Don't know
    c. False

17. "Low-grade" abnormal Pap smears are usually not harmful and often go away completely without treatment.
    a. True
    b. Don't know
    c. False

18. "High grade" abnormal Pap smears are treated by removing or destroying a small part of the cervix in order to prevent cervical cancer.
    a. True
    b. Don't know
    c. False

19. Abnormal Pap smears can be treated successfully with less invasive methods like vitamins and dietary supplements.
    a. True
    b. Don't know
    c. False

20. I have known at least one person with HPV (Human Papillomavirus).
    a. True
    b. Don't know
    c. False

21. **(Women only)** I have **never** had an abnormal Pap-smear result.
    a. True
    b. Don't know
    c. False
    d. Never had a Pap smear done

22. Prior to reading this questionnaire, I did **not** know that a virus was in any way related to abnormal Pap smears.
    a. True
    b. Don't know
    c. False

23. If a heterosexual woman has HPV, her partner should be seen by his health-care provider to be treated for it even if he has no signs of warts.
    a. True
    b. Don't know
    c. False

24. Condoms will help prevent women from having abnormal Pap smears
    a. True
    b. Don't know
    c. False

25. Risk factors for the development of cervical cancer include (mark all that are true):
    a. Persistent positive HPV results
    b. Smoking cigarettes
    c. History of multiple sexual partners
    d. Birth control pills
    e. None of the above
    f. Don't know

26. HPV is **not** a very common virus.
    a. True
    b. Don't know
    c. False

27. If a new vaccine (immunization) to prevent HPV were available to you would you take it?
    a. Yes
    b. Maybe
    c. Don't know
    d. Probably not
    e. No

28. In your opinion, at what age should people be immunized to prevent a sexually transmitted virus?
    a. Birth to age 4
    b. Age 5 -10
    c. Age 11-15
    d. Age 16-20
    e. Age 21-25
    f. Age 26-30
    g. Age 31-35
    h. Over 35

29. Have you ever been told that you had a sexually transmitted infection?
    a. Yes
    b. No

30. Do you consider yourself at risk for being exposed to HPV?
    a. Yes
    b. No

31. Do you use condoms:
    a. Always
    b. Usually
    c. Sometimes
    d. Never
    e. Not applicable
    f. No sexual activity

32. Have you ever talked with a doctor or health-care provider about HPV?
    a. Yes b. No

33. Have you taken any university courses that include the subject of sexually transmitted infections?
    a. Yes b. No

34. Have you ever participated in the HPV study conducted by the Cancer Research Center of Hawai`i at the UH student health service, Kaiser, Queen's Medical Center, Kapiolani or Leeward Community College?
    a. Yes b. No

35. Do you have a friend or relative who has been worried about having an abnormal Pap smear or HPV?
    a. Yes b. No

36. What program of study are you enrolled in within the University of Hawai`i? (e.g. education, liberal arts, biochemistry, nursing, etc.)_____

37. Have you ever done an Internet search on the topic of HPV or abnormal Pap smears before answering this survey?
    a. Yes
    b. No
    c. Only from reading the information at this web site

For an answer/explanation to each survey question, go to: _____
You may leave your name and/or email address or comments if desired at the answer page link. This information will be kept separately from your answers to maintain an anonymous survey.

Thank you for participating in this research survey
For more information about HPV and abnormal Pap smears, contact ASHA (American Social Health Association) at www.ashastd.org or call 1-800-4CANCER

APPENDIX B

HPVAPK
(Human Papillomavirus and Abnormal Pap smear Knowledge Composite)

14-item composite with indication of correct answer:

1. Routine medical screening for sexually transmitted infections usually includes a test for HPV (Human Papillomavirus)–False

2. HPV can cause genital warts–True

3. Genital warts can cause cervical cancer–False

4. You can tell if someone has been exposed to HPV by looking for warts–False

5. There is a screening test that is commonly used to test males for HPV–False

6. Most women with an abnormal Pap smear are able to have a completely normal pregnancy in the future–True

7. "Low grade" abnormal Pap smears are usually not harmful and often go away completely without treatment–True

8. "High grade" abnormal Pap smears are treated by removing or destroying a small part of the cervix in order to prevent cervical cancer–True

9. If a heterosexual woman has HPV, her partner should be seen by his health-care provider to be treated for it even if he has no signs of warts–False

10. Condoms will help prevent women from having abnormal Pap smears–True

11. Risk factors for the development of cervical cancer include: Persistent positive HPV–True

12. Risk factors for the development of cervical cancer include: Smoking cigarettes–True

13. Risk factors for the development of cervical cancer include: History of multiple sexual partners–True

14. HPV is **not** a very common virus–False

APPENDIX C

EXPLANATION OF SURVEY QUESTIONS

[Questions 1-7 are demographic only; no explanation required.]

8. Routine medical screening for sexually transmitted infections usually includes a test for HPV.

   False. Routine medical screening for sexually transmitted infections does NOT usually include testing for HPV. HPV testing is just beginning to be utilized by some health-care providers in Hawai`i, although it is not yet widely covered by most health insurance plans and remains very expensive. HPV testing is available in a research setting in Hawai`i at this time. (See website.)

[9. This question was asked to determine level of risk.]

10. HPV can cause genital warts.

    True. A certain type of HPV can cause genital warts. There are approximately 30 HPV subtypes that have been identified as genital HPV. Among these, subtypes #6 and #11 are associated with genital warts.

11. Genital warts can cause cervical cancer.

    False. Genital warts do not cause cervical cancer. The type of HPV in genital warts is not the same type of HPV associated with cervical cancer. However, more than one HPV type can exist together.

12. You can tell if someone has been exposed to HPV by looking for warts.

    False. You can NOT tell if someone has been exposed to HPV by looking for warts. The HPV type that causes warts can be "subclinical". There may be wart virus present on the skin before a wart appears or there may be wart virus present without producing a wart. However, if warts are seen, you can assume that it is due to exposure to a type of HPV.

13. Genital warts are not curable.

    Unknown. Many people use the word curable to mean that once a problem is gone it will never return. Some, but not all people with genital warts may have periodic recurrences. This might be due to reinfection. It is not yet known if the wart virus is at some point inactivated, or why it sometimes is persistent in causing warts to recur.

14. There is a screening test that is commonly used to test males for HPV.

    False. There is a test that can detect HPV DNA in males. However, at this time it is not commonly used. There may be a research project beginning in Hawai`i to better understand how to detect HPV in males.

15. A family history of cervical cancer places a woman at higher risk for cervical cancer.

    False. Although family history is significant in some gynecologic cancers, it does not appear to be a high risk factor in cervical cancer.

16. Women with an abnormal Pap smear are able to have a completely normal pregnancy in the future.

    Yes, **most** women with an abnormal Pap smears are able to have a completely normal pregnancy in the future. This is true unless a woman has actual cervical cancer and must undergo treatment involving removal of the uterus, chemotherapy or radiation. It is possible that a small number of women may have difficulty carrying a pregnancy if a very large portion of the cervix has been removed.

17. Low grade abnormal Pap smears are usually not harmful and often go away completely without treatment.

    True. "Low-Grade" abnormal Pap smears indicate that some cell changes have occurred, but approximately 50% of these resolve without treatment between 3 months and 2 years. However, some do progress to become "high grade" or even cervical cancer. Sometimes a low-grade abnormal Pap smear can be detected when there are more serious cell changes found on a biopsy. For this reason it is important to monitor for changes on a regular basis by having Pap smears or colposcopy done. Treatment can be done to remove the abnormal cells to prevent further changes.

18. High-grade abnormal Pap smears are treated by removing or destroying a small part of the cervix in order to prevent cervical cancer.

    True. High-grade abnormal Pap smears show cell changes on the cervix that can progress to become cervical cancer. This is also known as "pre-cancer", because cancer has not occurred yet. By removing the abnormal cells, cervical cancer is usually prevented. However, follow up testing after treatment remains important.

19. Abnormal Pap smears can be treated successfully with less invasive methods like vitamins and dietary supplements.

False. Although research is now being done to understand the relationship between diet and cervical cancer, there are no treatments that have **proven** to be effective in preventing cervical cancer except for removal or destruction of the abnormal cells. Research is also being done to study other methods to prevent cervical cancer.

[20–22. These questions were asked to better understand your experience with the subject.]

23. If a heterosexual woman has HPV, her partner should be seen by his health-care provider to be treated for it even if he has no signs of it.

False. At this time, there is no treatment for HPV in males unless there are visible warts. Although HPV is believed to be transmitted through skin contact, not through semen, it is not yet known how long HPV virus exists in skin, at what times it is contagious, or what can be done to clear the virus.

24. Condoms will help prevent women from having abnormal Pap smears.

True. Condoms help to prevent internal transmission of HPV virus to the vagina and cervix. However, condoms are not effective in protection against external genital warts.

25. Risk factors for the development of cervical cancer include: persistent positive HPV results, smoking cigarettes, history of multiple sexual partners.

All of the above have been identified as risk factors for the development of cervical cancer. The relationship between oral contraception and HPV infection is not clearly understood although this is an area of current research.

26. HPV is not a very common virus.

False. The incidence of HPV exposure in reproductive aged people in the U.S. has been estimated as high as 50%. Although the incidence of HPV is high, a much smaller percentage of people develop genital warts or abnormal Pap smears.

[27, 28. These questions were asked to obtain your opinion about an HPV vaccine that is currently being developed.]

[29-37.These questions were asked to better understand your experience with this subject or your risk of exposure to HPV.]

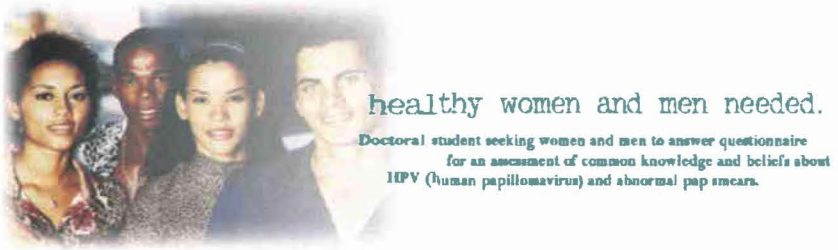
Thank you for participating in this research survey. The results will be used **to help people** who need information about this important and often confusing subject. References used to support the above explanations are available upon request. To make comments or request a reply, please leave your name or email address. This information will be kept separately from your answers to the questionnaire to maintain an anonymous survey _____.

For individual questions about HPV or abnormal Pap smears, please call the Cancer Information Service 1 800 4-CANCER, or ASHA(American Social Health Association): (www.ashastd.org).

APPENDIX D

WEB PAGES

WEB PAGE:www.hawaii.edu/hpv/cathy/index.html



Abnormal pap smears affect millions of women every year. Many people are not aware that there may be a sexual component involved. Both men and women need to know more about this condition in order to put it into perspective.

This online survey was created by a doctoral student to better understand what people know and do not know about HPV (Human papillomavirus) and abnormal pap smears.

Even if you have never heard about HPV and don't know much about pap smears, your reply is IMPORTANT and valuable.

Please click on HPV Online survey. The entire survey should take you about 10 minutes to complete.

Answers to some common and some subtle questions about HPV and abnormal pap smears will be provided at the end of the survey.

Website:about us page/credentials

PhD student at the University of Hawaii School of Nursing. She is a collaborator with the Cancer Research Center of Hawaii 's clinical HPV study, which is now being conducted at the University of Hawaii Student Health Center, The Queen's Medical Center, Kaiser Permanente, Kapiolani Medical Center and Leeward Community College.

Education:
Bachelor of Science – Cornell University
Master of Science- Pace University Graduate School of Nursing

Certification:
Certified Women's Health Nurse Practitioner (NCC)
Certified Family Nurse Practitioner (ANA)
Member of the American Association for Colposcopy and Cervical Pathology (ASCCP)

This survey is being conducted to better understand the informational needs of both women and men regarding HPV and abnormal pap smears. Cathy is concerned about the experiences of Women's Health patients and their partners when an abnormal pap smear has been detected.

APPENDIX E

IRB EXEMPTION

OMB No. 0990-0263
Approved for use through 07/31/2005

Protection of Human Subjects
Assurance Identification/IRB Certification/Declaration of Exemption
(Common Rule)

Policy: Research activities involving human subjects may not be conducted or supported by the Departments and Agencies adopting the Common Rule (56FR28003, June 18, 1991) unless the activities are exempt from or approved in accordance with the Common Rule. See section 101(b) of the Common Rule for exemptions. Institutions submitting applications or proposals for support must submit certification of appropriate Institutional Review Board (IRB) review and approval to the Department or Agency in accordance with the Common Rule.

Institutions must have an assurance of compliance that applies to the research to be conducted and should submit certification of IRB review and approval with each application or proposal unless otherwise advised by the Department or Agency.

1. Request Type	2. Type of Mechanism	3. Name of Federal Department or Agency and, if known, Application or Proposal Identification No.
[ ] ORIGINAL [ ] CONTINUATION [X] EXEMPTION	[ ] GRANT [ ] CONTRACT [ ] FELLOWSHIP [ ] COOPERATIVE AGREEMENT [ ] OTHER:_____	
4. Title of Application or Activity "Use of An Internet Questionnaire to Assess Beliefs About Human Papilloma Virus and Abnormal Pap Smears Among a Population of University Students in Hawaii"		5. Name of Principal Investigator, Program Director, Fellow, or Other Cathy Cramer Bertram

6. Assurance Status of this Project *(Respond to one of the following)*

[X] This Assurance, on file with Department of Health and Human Services, covers this activity:
Assurance Identification No. F-3526, the expiration date October 15, 2005 IRB Registration No. IORG0000169

[ ] This Assurance, on file with *(agency/dept)*_____, covers this activity.
Assurance No._____, the expiration date_____ IRB Registration/Identification No._____*(if applicable)*

[ ] No assurance has been filed for this institution. This institution declares that it will provide an Assurance and Certification of IRB review and approval upon request.

[X] Exemption Status: Human subjects are involved, but this activity qualifies for exemption under Section 101(b), paragraph 2 .

7. Certification of IRB Review (Respond to one of the following IF you have an Assurance on file)

[ ] This activity has been reviewed and approved by the IRB in accordance with the Common Rule and any other governing regulations.
by: [ ] Full IRB Review on (date of IRB meeting) _____ or [ ] Expedited Review on (date)
[ ] If less than one year approval, provide expiration date _____

[ ] This activity contains multiple projects, some of which have not been reviewed. The IRB has granted approval on condition that all projects covered by the Common Rule will be reviewed and approved before they are initiated and that appropriate further certification will be submitted.

8. Comments

CHS #12045

9. The official signing below certifies that the information provided above is correct and that, as required, future reviews will be performed until study closure and certification will be provided.	10. Name and Address of Institution University of Hawaii at Manoa Office of the Chancellor 2444 Dole Street, Bachman Hall Honolulu, HI 96822
11. Phone No. *(with area code)* (808) 956-5007 12. Fax No. *(with area code)* (808) 539-3954 13. Email: dendle@hawaii.edu	
14. Name of Official William H. Dendle	15. Title Compliance Officer
16. Signature	17. Date 11/8/02

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