HPV Communication: Review of Existing Research and Recommendations for Patient Education

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ABSTRACT The potential for human papillomavirus (HPV) DNA testing in cervical cancer prevention programs has been a topic at the forefront of cervical cancer policy discussions in recent years. To prevent some of the anxiety and psychological distress often experienced on HPV diagnosis and during the period of management, mass patient education must accompany the incorporation of HPV DNA testing into screening protocols. To contribute to a growing body of work that provides an empiric basis for development of effective counseling messages about HPV and HPV testing, this paper highlights women's most common information gaps and psychosocial concerns and describes the different perspectives offered by women's usual sources of information about HPV, including the crucial role of the clinical community in creating a shared decision making environment in which screening decisions and results can be discussed. (*CA Cancer J Clin 2004;54:248–259.*) *© American Cancer Society, Inc., 2004.*

Research in the last decade has conclusively demonstrated that sexually-transmitted infection with carcinogenic types of HPV, often referred to as high-risk types of HPV, is required for the subsequent development of virtually all cervical cancers.[1] However, HPV infections are extremely common in sexually active women and the vast majority will spontaneously resolve or cause only transient minor lesions. HPV DNA testing is now included in cervical cancer screening guidelines as an adjunct to cytological screening.[2,3] Mass patient education must accompany the incorporation of HPV DNA testing into screening protocols to prevent the anxiety and psychological distress often experienced on HPV diagnosis and during the period of management. To contribute to a growing body of work that provides an empiric basis for development of effective counseling messages about HPV and HPV testing, this paper will highlight women's most common information gaps and psychosocial concerns and describe the crucial role of the clinical community in creating a shared decision making environment in which screening decisions and results can be discussed.

EPIDEMIOLOGY AND PATHOGENESIS

HPV is associated with nearly all cases of preinvasive and invasive cervical neoplasia.[1] Eighty HPV types have been sequenced, although more than 200 types likely exist based on data from partially sequenced DNA fragments.[4] Approximately 30 specific HPV types infect the male and female genital tract and two-thirds of these are classified as high risk because of their etiological association with cervical cancer. In most countries, HPV-16 accounts for more than 50% to 60% of cervical cancer cases followed by HPV-18 (10%–12%) and HPVs 31 and 45 (4%–5% each).[5] HPV types associated with genital warts, such as HPV-6, and HPV-11, are referred to as low risk because they are rarely associated with malignant disease.

Infection of the cervical epithelium with high-risk types of HPV plays a key role in the pathogenesis of cervical cancer and its precursor lesions, although very few women infected with HPV ultimately develop cervical cancer.[6] Although HPV infection of young women is frequent, it is transient in the large majority of women. Persistence of high-risk types of HPV is a prerequisite for the development of cervical intraepithelial neoplasia (CIN) 3 lesions and invasive cervical cancers although the biological reasons that determine persistence in individual women are poorly understood. Cofactors that further increase the risk of invasive cancer among HPV DNA positive women include older age, long-term use of oral contraceptives (five or more years), high parity (five or more full-term pregnancies), smoking, and HIV infection.[7,8] Many factors initially thought to be associated with cervical cancer—for example, number of sexual partners—likely are indicators of HPV exposure rather than independent risk factors.

There is strong evidence to support a multistep model of cervical cancer pathogenesis that involves, as the first step, infection with high-risk types of HPV. The median duration of HPV infection is about one year for high-risk types of HPV and shorter for the low-risk types.[6] Many women with transient HPV infections will develop cytological abnormalities although CIN 1 lesions have a high rate of spontaneous regression in the absence of treatment. CIN 3 lesions and carcinoma in situ have lower rates of spontaneous regression. The rates of progression and regression of CIN 2 lesions appears to fall between that of CIN 1 and CIN 3 lesions.

Worldwide, approximately 500,000 cases of invasive cervical cancer are diagnosed each year, the majority of which are in developing countries.[3] Cervical cancer mortality has decreased over the last 50 years in the United States by over 70%, in large part due to widespread cytology-based screening with the Papanicolaou (Pap) test.[9] It is important to note that cytological screening has not been equally accessible to all subpopulations and incidence and mortality from cervical cancer are higher in ethnic minorities and poor women.[10,11] In fact, in this country more than half of the incident cases of invasive cervical cancer are diagnosed in women who have not been adequately screened. The poor sensitivity of a single cytology smear, reported to range from 32% to 92%,[12] has led to repeated screening at frequent intervals, as reflected in screening guidelines developed in the early 1990s, many of which recommended annual screening with a Pap test.[13,14]

CLINICAL USE OF HPV DNA TESTING

The availability of sensitive assays to detect carcinogenic types of HPV, together with the poor sensitivity of a single Pap test, has generated substantial interest in the use of HPV DNA testing as a cervical cancer screening tool.[15] The most well-defined use of HPV DNA testing is for triage of equivocal Pap test results, referred to as atypical squamous cells of uncertain significance (ASC-US).[16] Following diagnosis with ASC-US, HPV testing for high-risk types can determine whether a woman requires colposcopy or can just return for repeat screening one year later for another Pap test. HPV testing is more sensitive than a single repeat Pap test alone in finding high-grade dysplasia.[16,17] Studies have found this strategy can also reduce unnecessary colposcopies and is cost-effective.[18] For primary screening of women older than 30 years of age, HPV DNA testing has been reported to achieve approximately 10% to 20% greater sensitivity (but lower specificity) than a single conventional cytology.[19–24] Due to the high negative predictive value of combining HPV DNA testing and cytology, women who are negative on both tests could potentially attend screening at increased intervals (eg, every 2–3 years).[15] Prospective data that established the safety of this approach are anticipated to be increasingly available over the next several years.

CLINICAL GUIDELINES

The turn of this century, 2001, brought with it the new Consensus Guidelines for Cervical Cancer Screening that included the use of a

viral test for HPV.[2] In addition to the American Society for Colposcopy and Cervical Pathology, the American Cancer Society, the US Preventive Services Task Force, and the American College of Obstetrics and Gynecology publish guidelines on the use of cytology for cervical cancer screening and the management of cytologic abnormalities and CIN (Table 1).[2,3,25–27] Those guidelines that include recommendations for the management of CIN stated that HPV DNA testing be considered an acceptable option for women with equivocal cytology results, thus providing women with three options for the safe management of an ASC-US result on a Pap test. In contrast to recommendations about the use of HPV testing for ASC-US, which are based on well-established evidence for efficacy, there is less concordance in the wording of guidelines with respect to how best to integrate HPV DNA testing for primary cervical cancer screening. This reflects the lack of definitive prospective data yet available for primary screening. For example, US Preventive Services Task Force concluded that there is insufficient evidence to recommend for or against the routine use of HPV testing as a primary screening test.[25] On the other hand, the American Cancer Society concluded that it would be reasonable to consider using HPV testing and cervical cytology in combination in women aged 30 years and older[3] and the American College of Obstetrics and Gynecology acknowledges the US Food and Drug Administration (FDA) approval of HPV DNA testing as an adjunct to cervical cytology screening and states that women whose HPV test is negative and Pap test is normal do not need to be retested for three years.[26] In fact, the approval by the FDA for use of HPV DNA testing as an adjunct to cervical cytology screening in women aged 30 years and older[28] has served as the motivation for recent efforts to provide interim guidance to clinicians and patients while awaiting the availability of prospective data.[2] This published guidance emphasized the importance of restricting the primary screening use of HPV DNA testing to women aged 30 and older, since younger women would experience a very high false-positive rate given their high prevalence of transient HPV infection.

Implementation of any new guidelines, even those that are evidence-based such as HPV DNA testing for ASC-US results on Pap tests, can take as long as a decade to reach most physicians and patients.[29] For example, the variety of options available for management of ASC-US results may create some confusion for patients; however, more than one option also provides a unique opportunity for women to participate in decision making about screening and for clinicians to incorporate each woman's preferences into the selection of the best-suited screening option. Understanding interim guidance about the use of HPV DNA testing as a primary screening test, while awaiting prospective data that will support more definitive recommendations, will be even more challenging. Women will undoubtedly ask about HPV DNA testing given its availability, recent FDA approval, and market forces. To prevent some of the anxiety and psychological distress that may be experienced on HPV diagnosis and during the period of management, mass patient education must accompany the incorporation of HPV DNA testing into screening protocols.

AWARENESS AND KNOWLEDGE OF HPV

Although HPV is the most prevalent sexually transmitted infection in the United States, fewer than one-third of men and women in the general population have heard of it,[30] and similarly low awareness has been reported among women in high school and college settings.[31–33] While nearly all surveyed university students have heard of genital warts, between 28% and 67% have never heard of HPV.[32,33] University students have also reported that they know less about HPV than about other common sexually transmitted infections.[32]

Of those who have heard of HPV, few are aware that it is associated with cervical carcinoma,[30,34] that it can be present without symptoms,[34] or that HPV can be transmitted by genital contact, regardless of whether sexual intercourse has taken place or a condom has been used.[32] More than half of surveyed women at universities

TABLE **1** Screening Guidelines

	Interim Guidelines	USPSTF* Preventive Services Task Force Guidelines	ACOG† Guidelines¶	ACS‡ Guidelines**
HPV DNA testing for triage of ASC-US results on Pap tests	Yes	Not addressed	Yes	Not addressed††
HPV DNA testing in conjunction with Pap test for primary screening	HPV DNA testing *may be added* to cervical cytology for screening in women aged 30 years and older§	Insufficient evidence to recommend for or against routine screening for HPV infection	Once a woman reaches age 30, *it is appropriate* for her to have the test for the HPV at the same time as the Pap	*It would* be reasonable to consider that for women aged 30 or over screening may be performed every three years using cytology combined with a test for high-risk HPV types

*USPSTF = United States Preventive Services Task Force.
†ACOG = American College of Obstetricians and Gynecologists.
‡ACS = American Cancer Society.
§Women negative on both HPV DNA testing and cytology should not be rescreened before three years; those negative by cytology, but high-risk HPV DNA positive, should have repeat HPV DNA testing along with cervical cytology at six to 12 months and if either test is abnormal, colposcopy should then be performed.
¶ACOG: Annual screening with a Pap test should begin approximately three years after a woman has participated in sexual intercourse for the first time, or at the age of 21, whichever comes first. Until the age of 30, women should have a Pap test every year. Women whose HPV test is negative and Pap test is normal do not need to be re-tested for three years. In contrast, a woman older than 30 who only has the Pap must be tested annually unless their last three Pap results were negative in which case the interval between Pap tests, if used alone, can be increased to every two to three years. Exceptions would be women with a history of serious cervical disease, infected with HIV, immunosuppressed (such as those receiving kidney transplants), prior exposure to DES in utero.
**ACS: Screening with a Pap test should begin approximately three years after a woman has participated in sexual intercourse for the first time, or at the age of 21, whichever comes first; Until the age of 30, women should have a Pap test every year if her doctor takes a conventional "smear" of cervical cells to send to the lab. If the doctor uses a "liquid-based" Pap test, screening may be performed every two years. Once they have reached the age of 30, the test for the human papillomavirus (HPV) may be done at the same time as the Pap, with repeat testing necessary no more than every three years when results are normal. [Note that this is listed as a preliminary recommendation, since these guidelines were developed prior to the approval of the HPV test for this purpose by the US Food and Drug Administration in March 2003.]
††HPV DNA testing for triage was considered outside the scope of the screening guidelines. Consensus recommendations for the management of women with abnormal cytology tests were developed through a process sponsored by ASCCP in April 2002. These guidelines recommended that HPV DNA testing be considered an acceptable option for women with equivocal cytology results.

in the United States who know about HPV do not know how it is transmitted,[32,34] although knowledge of HPV signs, symptoms, and treatments is higher among women who have been diagnosed with HPV or who have received abnormal Pap test results.[35,36]

A survey of female students at a US university reports that while one-third know that a woman under age 18 should have her first Pap test soon after having sexual intercourse for the first time, fewer than one-third are aware that a Pap test might detect changes indicative of HPV.[34] In a study of minority adolescent and adult women who have had Pap tests, only about one-third could precisely identify that the purpose of the Pap test is to detect changes in the cervix suggestive of precancerous or cancerous conditions.[37]

Studies of university students and employees in England report that many women underestimate the likelihood of receiving abnormal Pap test results.[36,38]

PSYCHOSOCIAL RESPONSES TO HPV TESTING AND DIAGNOSIS

Although there is limited literature on psychosocial reactions to HPV diagnosis, research among women who have received abnormal cer-

vical smear results indicates that they often experience psychological consequences, including anxiety, fears about cancer, sexual difficulties, changes in body image, and concerns about the loss of reproductive functions (Table 2).[39–42] In addition to the distress caused by these psychological side effects, fears about gynecologic investigations and treatments have been shown to decrease adherence to follow-up recommendations among women with abnormal Pap tests,[41] suggesting that patient counseling to reduce such side effects has the potential to both enhance psychological well-being and improve follow-up and clinical outcomes.

University students predict that, hypothetically, they would feel scared, anxious, regretful, angry, and panicked if told they received positive test results for HPV.[33] These findings are consistent with the experiences of those diagnosed with other sexually transmitted infections; genital herpes patients, for example, have been reported to experience depression, anguish, anger, loss of self-esteem, and hostility toward the person believed to be the source of the infection.[43] Additionally, some women diagnosed with *Chlamydia* experience concern about future reproductive morbidity and anxiety about negative reactions from friends, family, and sexual partners.[44]

An American Social Health Association study of 489 HPV-positive men and women, 60% of whom had visible genital warts, reported that initial reactions to HPV diagnosis include anger, depression, isolation, fear of rejection, shame, and guilt.[45] Concerns about transmitting HPV or being judged negatively by an acquaintance or potential sexual partner were also common. Many respondents felt less sexually desirable and reported less enjoyment from sexual contact due to their HPV infection. Another study of patients with genital warts indicated that HPV transmission was generally of greater concern than cervical cancer on HPV diagnosis.[46] In contrast, a cross-sectional study of sexually active, mostly white women aged 18 to 60 found no significant differences between those diagnosed with HPV and those not diagnosed with regard to physical intimacy activities and emotions about sex and relationships.[47] This suggests that the observations from studies of patients with visible genital warts may not be generalizeable to those with asymptomatic HPV.

TABLE 2 Possible Psychosocial Responses to HPV Diagnosis

Anxiety
Anger
Regret
Fears of cancer
Concerns about loss of reproductive functions
Concerns about negative reactions from friends, family, or sexual partners
Concerns about partner infidelity or hostility towards person believed to be the source of infection
Changes in body image
Decrease in physical intimacy activities

PATIENTS' DESIRED INFORMATION ABOUT HPV

To respond to women's informational needs, education and counseling must address both the data gaps identified by the HPV knowledge literature and the informational preferences expressed by women. Two qualitative studies, a review of frequently asked questions at the American Social Health Association National HPV and Cervical Cancer Prevention Resource Center,[48] and a series of focus groups with lower income and minority women in Massachusetts,[49] have investigated women's desired information about HPV. The two studies concur that women's basic areas of desired information are: transmission, prevention and detection, treatment and progression without treatment, and risk of cervical cancer. Specifically, with regard to transmission and prevention, women in both studies were interested in knowing that HPV is sexually transmitted, that transmission can occur through genital contact regardless of whether intercourse has taken place, and that condoms are not wholly protective against transmission. With regard to progression, treatment, and risk of cancer, women wanted to know the typical duration of HPV infection, the nature of spontaneous resolution of the infection, the likelihood of developing cancer, and the screening and follow-up treatment that prevent most women from developing cancer.[48,49] Please see Table 3 for the American Social Health Asso-

TABLE **3** Most Frequently Asked Questions about HPV*

How, When, or from Whom Did I Get HPV?	Genital HPV is primarily a sexually transmitted virus. It is usually impossible to know from whom or when one acquired HPV because most people don't know they have it. HPV is very common
Will HPV Affect a Pregnancy or a Baby?	Most treatments for cervical dysplasia will leave the cervix intact enough to preserve fertility. During pregnancy, warts and lesions may grow faster. Warts may have to be removed if they are bleeding or obstructing the birth canal. HPV is rarely passed on from mother to child; in rare instances, HPV types 6 and 11 can cause wartlike growths in the throat; this condition is called Juvenile Onset Recurrent Respiratory Papillomatosis.
Can a Person Get or Give HPV through Oral Sex or from Hands?	Although HPV may be transmitted this way, it has been impossible to prove that it happens. Recent studies indicate a relationship between HPV and some head and neck cancers, but the route of acquisition is not clear.
How Can I Get Tested for HPV?	Warts are diagnosed by clinical visual inspection. In women, HPV-related cervical lesions (dysplasia) can be detected by Papanicolaou (Pap) tests. Women with uncertain Pap tests may undergo HPV testing or repeated Pap screening. There is no FDA-approved screening test for detecting HPV in men.
Will I Always Have HPV?	A healthy immune system suppresses the virus. It is difficult to predict when HPV is no longer contagious. Experts disagree on whether the virus is eliminated from the body or whether it is reduced to undetectable levels.
How Can I Prevent Giving or Getting HPV?	Lifetime mutual monogamy and abstinence are the best possibilities for prevention. Most sexually active people will get HPV. Condoms prevent many bacterial and viral infections, but if HPV is present on uncovered skin, transmission is possible.
Can Partners Reinfect Each Other?	Reinfection with the same type of HPV is unlikely; however, no studies have been conducted regarding reinfection or the effects of treatment on infectivity. Partners are likely to share the same HPV type. Exposure to the same HPV types does not appear to cause a person to experience more symptoms.
Does HPV Cause Cervical Cancer?	HPV causes cervical cancer, but regular screening and appropriate follow-up treatment prevent most women from getting cervical cancer. Other factors (immune system, other STDs, smoking, genetics, number of partners, hormonal contraceptive use) might increase the risk of cancer.
What Should I Tell My Partner about HPV?	Most sexually active people will get HPV. For most people, the signs and symptoms of HPV are only temporary. The majority of people do not develop symptoms; therefore, they do not know they are infected. Understanding the psychological, social, and physical impact of HPV will help put the virus in perspective.
What Are the Best Treatment Options for HPV?	HPV itself is never treated; however, symptoms and signs of the virus are. Providers treat warts by freezing, burning, or cutting them off or by prescribing creams that are self-applied. Providers usually do not treat minor Pap test abnormalities because most will go away on their own. The most common treatments for abnormal Pap tests are cryotherapy (freezing of abnormal cells) or LEEP (the excision of the abnormal cells). Patients should discuss all treatment options with their provider before deciding on one treatment.

*Content adapted from Gilbert LK, Alexander L, Grosshans JF, Jolley L.[48]

ciation list of frequently asked questions about HPV and the accompanying answers developed by an expert panel.

The findings of the focus group study expand on the list of most frequently asked questions by investigating differences in desired information by age group and exploring women's areas of confusion. The study found that while the core areas of desired information were similar among women of different age, ethnic, and income groups, women expressed some particular informational interests according to their age. Younger women seemed more focused on the symptoms associated with "low risk" (ie, noncancer-causing) strains of HPV and predicted that they would feel regret, a psychological response consistent with other sexually transmitted disease (STD) diagnoses, if diagnosed with HPV, while older women conveyed more concern about "high-risk" (ie, cancer-causing) strains. While most women participating in the focus groups felt that they were at risk for HPV, those who were older than 55, married, or not currently sexually active were less likely to feel at risk.[49]

The focus group study also highlighted several potential areas of confusion in HPV education. First, many women had difficulty understanding the distinctions between low- and high-risk strains of HPV, a finding that has been corrobo-

rated by qualitative exploration with women in the United Kingdom.[50] Most women were interested in assessing their own risk of HPV and wanted to receive HPV information that was specific to their own HPV types.[49]

Second, many women in the focus groups were uncertain about the level of alarm warranted by HPV. Although the women who had heard of HPV were aware of its link to cervical carcinoma, they overestimated the likelihood that women with HPV would develop cancer. Some women struggled to balance the understanding that HPV usually regresses without treatment with the knowledge that HPV can, in some cases, progress to cervical cancer.[49]

Third, many women were confused about how Pap test results could be normal if HPV is present, and some questioned the value of the Pap test if it could not detect every case of HPV. This finding is consistent with research showing that adolescents have difficulty differentiating between the function of Pap tests, pelvic exams, pregnancy tests, and STD tests[51] and that women are confused by the meaning of normal Pap test results.[52]

Although no research has been conducted to specifically explore women's understanding of new cervical cancer screening guidelines, existing levels of confusion regarding screening test options and results suggest that the new guidelines will present further comprehension challenges for many women.

SOURCES OF HPV INFORMATION

Women's sources of information about cervical cancer screening and HPV extend beyond health care providers to include friends and family, health education classes (among university students), and the mass media, such as magazines, newspapers, radio, television, and books.[34,36,53] Given different motivating and constraining factors, presentation of HPV information varies considerably across information sources, leaving substantial informational gaps for clinicians to satisfy during patient visits (Table 4).

Mass Media as a Source of HPV Information

Although the news media serve as major sources of information about cancer and cancer screening,[53–55] time deadlines and pressures to create newsworthy content often constrain journalists' ability to provide comprehensive and wholly accurate health content. A content analysis of HPV news stories from 1995 to 2002 found that many stories failed to provide complete information about HPV's link to cervical cancer.[56] Of the 111 news stories evaluated from top 10 newspapers and three major television networks, many stories were missing vital information regarding HPV prevention, transmission, and symptoms. For example, many of the stories that mentioned condoms as a preventive method did not indicate, as the scientific literature suggests, that condoms are imperfect at preventing HPV transmission.[57] Similarly, only a minority of stories mentioned risk factors for HPV, informed that HPV can be asymptomatic, or described HPV's most common prognosis, regression without treatment. Only one-quarter of stories mentioned that most women with HPV do not develop cervical cancer. Compounding this confusion, more than 90% of the stories did not report that the types of HPV that cause genital warts are different from the types that cause cervical cancer.

TABLE 4 Lay Resources on HPV

American Cancer Society: What Women Should Know about Cancer and the Human Papilloma Virus http://www.cancer.org/docroot/CRI/CRI_2_5x.asp?dt=8
National HPV and Cervical Cancer Prevention Resource Center http://www.ashastd.org/hpvccrc/ 877-HPV-5868
National Cervical Cancer Patient Education Campaign www.cervicalcancercampaign.org
National Cancer Institute: Human Papillomavirus and Cervical Cancer http://cis.nci.nih.gov/fact/3_20.htm 800-4CANCER

Although all of the HPV news stories that made recommendations about cervical cancer or HPV screening were in concordance with professional guidelines, only half of stories offered recommendations. Few news stories about screening options addressed wrong, uncertain, or unnecessary test results and their consequences.[56]

Media have the unique reach to create blanket awareness of HPV basics, including transmission, prevention, treatment, and risk of cancer. Thus far, however, the media have not adequately conveyed appropriate levels of HPV risk perception or the distinction between low- and high-risk types of HPV. Since the lay population frequently misunderstands these issues, the clinical community will be called on to fill these informational gaps. Similarly, since media coverage often fails to mention screening guidelines or describe the challenges posed by new screening options, clinicians must discuss recommended screening tests and their characteristics with patients.

Commercial Providers as a Source of HPV Information

Approval of HPV tests, and insurance coverage of their use, have allowed and encouraged test manufacturers to promote HPV DNA tests to the public. The 2001 FDA decision to approve the Hybrid Capture 2 HPV DNA Test (HC2, Digene Diagnostics, Gaithersburg, MD) for use in the management of women with equivocal cytology results (ASC-US) allows Digene to market its HPV test in conjunction with the Pap test for screening.[2]

Commercial manufacturers of HPV tests have undertaken substantial advocacy to promote HPV test approval among regulators and acceptance among the general public.[58,59] These efforts emphasize the sensitivity of HPV testing and capitalize on women's interest in pursuing the latest medical technology;[60] however, the resulting communication materials and conference proceedings typically do not mention the costs or consequences of unnecessary testing and follow up. As additional manufacturers introduce new HPV DNA tests to the market, they are expected to aggressively promote the competitive advantages of their products. Although the unique features of these new tests may provide limited clinical benefit to patients, promotions via paid advertising or additional media coverage will likely further increase the number of patients who inquire with clinicians about new screening options.

CONCLUSIONS AND RECOMMENDATIONS

Clinical Community as a Source of HPV Information

When interacting with patients about cervical cancer screening and HPV DNA testing, clinicians encounter substantial challenges: patients are not generally knowledgeable about HPV, nonclinical sources of HPV information provide incomplete background, several complex options exist for cervical cancer screening, and limited time is available for patient counseling.

This clinical scenario lends itself to the "shared" or "informed" decision making approach, in which patients and clinicians exchange information and ideas and collaborate to make a clinical decision.[61] In their *Typology of Shared Decision Making, Informed Consent, and Simple Consent*, Whitney, et al. suggest the shared decision making model as most suitable for scenarios in which there is a diagnostic intervention of low risk and a decision involving two or more acceptable choices (Figure 1).[62] As HPV testing and cytology are low-risk diagnostic procedures, and the guidelines offer several cervical screening options, patient counseling about this topic is situated in Quadrant D, an area of shared decision making.

In shared decision making, clinicians provide relevant information about the clinical decision, alternatives, risks, and benefits, discuss the uncertainty regarding best alternatives, ensure that the patient comprehends the options, and encourage patients to express their preferences.[63,64] In the two-way communication required for shared decision making, clinicians provide technical information, such as the background characteristics of available screening tests, the benefits and risks of each, and the potential effects on the patient's psychological and social well-being. Patients, on the other hand, express their beliefs and anxieties about

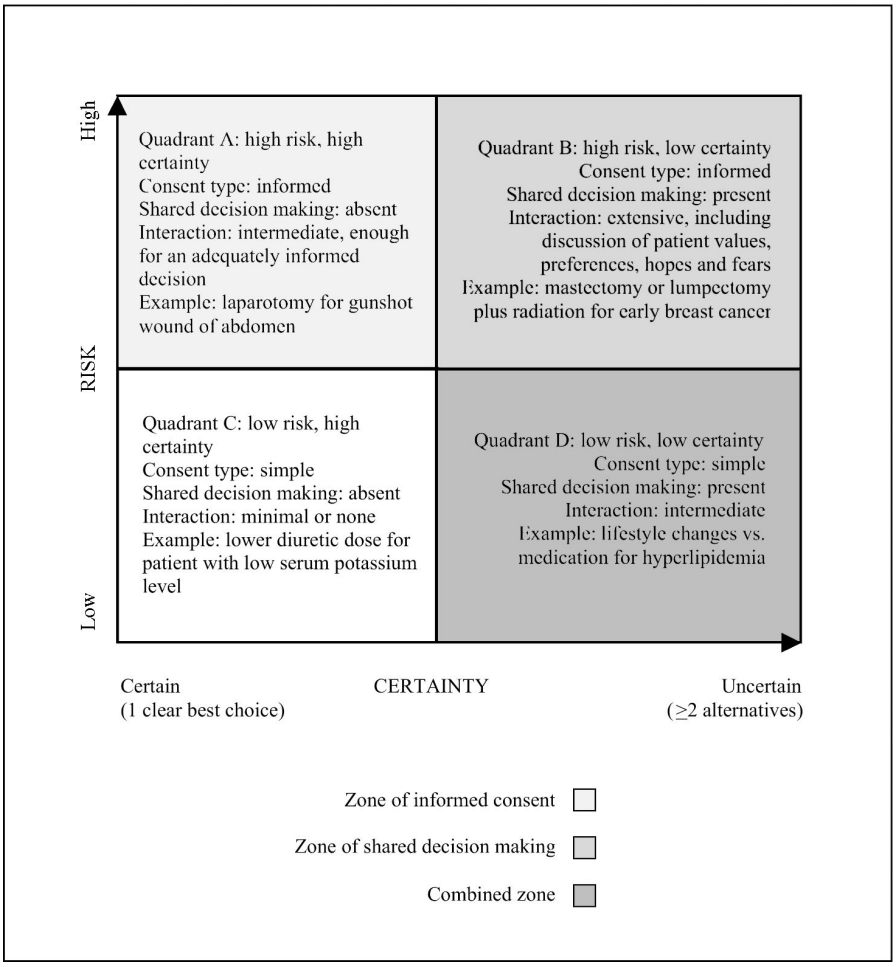

FIGURE **1** Decision Plane showing the distribution of simple consent, informed consent, and shared decision making within four types of medical decisions.
Selection of a cervical cancer screening option falls into Quadrant D, low risk and low certainty. (Figure reprinted from Whitney SN, McGuire AL, McCullough LB. A typology of shared decision making, informed consent, and simple consent. Ann Intern Med 2004;140:54–59.)

HPV, their existing knowledge of screening tests, and their preferences for screening options.[65] This exchange of information ensures that all options are jointly reviewed and that they are evaluated within the context of each patient's preferences and clinical profile.[65,66]

In a recent editorial, Monk and Wiley recommended six points that should be emphasized when providing patients technical information about HPV and HPV testing: (1) HPV is sexually transmitted; (2) HPV is very common; (3) most women with HPV will not develop cervical cancer; (4) HPV's most common prognosis is clearance without treatment; (5) the purpose of a Pap test is to detect HPV-related lesions in the cervix suggestive of precancerous or cancerous conditions; and (6) most women who test positive for high-risk HPV will not be diagnosed with cervical cancer or a precursor on further evaluation.[67]

To tailor HPV information according to patient's background characteristics, age, type of HPV diagnosed (ie, low risk versus high risk and symptomatic versus asymptomatic), and literacy level are especially pertinent:

Age

Relevant information about HPV and HPV testing varies by age group. For example, the FDA restricts its approval of HPV testing to

women over the age of 30 in large part because younger women have frequent and transient infections; guidelines also emphasize the risk of adding HPV testing to screening in younger women for primary screening in addition to, for the first time, recommending age-specific screening strategies. In addition, younger women have expressed more interest in information about the sexually transmitted nature of HPV than in its role in the development of cervical cancer.

HPV Types

Both the relevant clinical information and the psychosocial consequences of HPV diagnosis are substantially different between those who experience visible genital warts (resulting from infection with HPV-6 or -11, low-risk types not associated with malignancy) and those who do not. As noted earlier, women with visible genital warts have shown more interest in information about sexual transmission of the virus and reported feelings of lower sexual desirability and interest. Women have also expressed preferences for HPV education that is tailored to the low- or high-risk strains identified by HPV testing.

Literacy

Health literacy is increasingly recognized as an important factor affecting communication across the continuum of cancer prevention and treatment.[68] Insufficient and inaccurate health knowledge, poor numeracy skills, and impaired ability to assimilate new information and concepts can interfere with patients' ability to communicate with providers about cancer screening. Given this context, patients may find it difficult to articulate their questions about the complex set of choices presented by HPV DNA testing. In these instances, the onus is on the clinician to provide adequate information about screening options in plain, colloquial language.

To facilitate shared decision making and circumvent the consequences of low health literacy and limited background knowledge, clinicians' communication style is as important as content. Davis, et al. have developed practical guidelines for patient education that can serve as a structure for both practice and research.[68] The guidelines suggest that clinicians take extra time to listen to patients' questions and concerns; use plain language when describing alternatives, risks, and benefits; provide materials, such as stories, pictures, or women's magazine articles to supplement hard facts; provide a limited amount of information at each visit; and use a "teach back" approach, in which patients describe new information in their own words, to ensure comprehension.

Given the time pressures of clinical practice, it is often impossible for physicians to offer the extended counseling sessions suggested by the shared decision making approach. However, given the importance of involving women in their cancer screening choices, other clinical providers (eg, nurse practitioners) should play an integral role in conveying HPV information and reviewing screening options.

Particular attention must be paid to the informational needs of patients subject to disparities in cervical cancer screening, such as low-income patients living in rural areas, older women, immigrants, and those with low health literacy. The potential for new technology in cervical cancer screening to reduce the risk of cervical cancer is ultimately tied to increasing screening rates among the underscreened, since unscreened women currently account for more than half of cervical cancer cases. Moreover, there is a real possibility that screening disparities could widen with the introduction of new HPV DNA testing technology, given that it may be preferentially used in women least likely to benefit (ie, those already visiting their doctor regularly and getting annual screening with Pap tests). By counseling patients effectively and conducting dissemination research, the clinical community can play a valuable role in translating existing understanding of patient preferences and knowledge gaps into an actionable plan for educating the public—especially unscreened women—about screening guidelines.

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