

Women's Desired Information about Human Papillomavirus

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BACKGROUND. As human papillomavirus (HPV) DNA testing is incorporated into cervical carcinoma screening programs, educational messages must be developed to inform women's screening choices and manage psychosocial responses to HPV DNA test results. However, little is known about women's questions and concerns about HPV or their attitudes toward HPV testing.

METHODS. Eight focus groups with 48 ethnically diverse, low-income women were conducted at community centers, family planning and primary care clinics, and substance abuse rehabilitation facilities in Massachusetts.

RESULTS. The participants' comments and questions about HPV revealed five major themes. First, most women overestimated the likelihood that women with HPV would develop cancer. Second, women struggled to balance the anxiety of knowing that HPV infection causes cervical carcinoma with the information that HPV infection often regresses without treatment. Third, many women were confused that Papanicolaou smear results could be normal when HPV infection is present. Fourth, women preferred to receive a personalized risk profile to assess their own likelihood of contracting HPV infection and cervical carcinoma. Fifth, younger women focused on the sexual transmission of HPV infection, rather than on its potential to cause cancer.

CONCLUSIONS. Effective HPV education must include information about transmission, prevention, treatment, and cervical carcinoma risk; tailor messages to describe HPV susceptibility according to age and risk profile; present clarification regarding HPV strains and their consequences; offer explanations of different types of tests and their results; and provide a balance between accurate discussion of cancer risk and reassurance that following recommended screening practices will reduce risk to negligible levels. *Cancer* 2004;100:315-20.

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Research in the last decade has demonstrated conclusively that infection with carcinogenic types of human papillomavirus (HPV), often referred to as high-risk HPV types, represents a nearly universal event in cervical carcinoma development and that sexual transmission is the predominant mode of HPV infection.¹ Although natural history studies have demonstrated that the majority of HPV infections produce only transient minor lesions, a small percentage may persist and progress to a cancer precursor, known as cervical intraepithelial neoplasia (CIN) 3.

The availability of sensitive assays to detect carcinogenic types of HPV has led to substantial interest in the use of HPV DNA testing as a cervical carcinoma screening tool.²⁻⁶ Recently, the Food and Drug Administration approved HPV DNA testing in conjunction with cyto-

TABLE 1
Core Focus Group Questions

1. Most women have never heard of HPV. Before coming here today, had you ever heard of HPV? If so, where did you learn about it?
2. What would you like to know about HPV? What information would you like your favorite source of health information to give you about HPV?
3. *For each informational paragraph:* What information in this paragraph is most useful to you? Is there any other information you would like to know about HPV that is not in this paragraph? Is there any information currently in the paragraph that is not useful to you? What changes would make this paragraph easier to understand? Based on the information in this paragraph, do you feel that HPV is relevant to you? Based on the information in this paragraph, is there anything you would change about your health behaviors?
4. Imagine that you have no symptoms, have a normal Pap smear, and receive screening test results that say that you have HPV. How would you feel? Bearing in mind that most women with HPV do not develop cervical cancer, imagine again that your doctor tells you that you have HPV. How would you feel?
5. Are you interested in receiving a test for HPV? Why or why not? If interested, which would you prefer, a test the doctor did or a test you did yourself? Why?

HPV: human papillomavirus; Pap: Papanicolaou.

logic analysis in primary screening for cervical carcinoma in women ≥ 30 years.⁷ Clinical guidelines from the American Society for Colposcopy and Cervical Pathology (ASCCP) also recommend HPV testing to identify women with ASCUS (atypical squamous cells of undetermined significance) Papanicolaou (Pap) smear results who require colposcopy and biopsy.⁸

Although the sensitivity of the HPV DNA test for detecting CIN 3 is better than cytology, there are also potential adverse outcomes. For example, most young women who are sexually active will experience HPV infection. Although these infections are usually transient and nonsignificant, detection of carcinogenic HPV types on a screening test will likely precipitate additional diagnostic testing and potentially unnecessary invasive procedures. In addition, many women may experience psychological distress, uncertainty, and anxiety in response to an HPV diagnosis and during the period of management.⁹ A thorough evaluation of the appropriate clinical use of this emerging technology must include investigation into women's preferences and concerns regarding the use of the test.¹⁰⁻¹²

A substantial body of literature has shown low lay awareness and knowledge of HPV.¹³⁻¹⁹ Introducing HPV DNA testing into a patient population that is largely unfamiliar with HPV will necessitate mass education. However, little research has explored women's questions and concerns about HPV or their attitudes toward HPV testing. To identify the educational messages most salient to women about HPV and HPV testing, we conducted focus groups, a qualitative research methodology that is useful for identifying and exploring beliefs, attitudes, and behaviors.²⁰

MATERIALS AND METHODS

Participants

In August and September 2002, we convened 8 focus groups, each composed of 3-12 women. We employed a purposive sampling method²¹ to recruit low-income

and minority women, as these populations have been identified by the National Institutes of Health and Centers for Disease Control and Prevention as priority groups for cervical carcinoma screening, sexually transmitted disease (STD) prevention, and health information provision.^{22,23} To identify patterns across different age groups, we stratified focus groups by the age ranges 18-29, 30-54, and ≥ 55 years when possible.

We recruited participants by posting signs at family planning clinics and local community centers, sending invitation letters to patients in a primarily Hispanic primary care practice, and requesting discussion time in substance abuse rehabilitation facilities. The study protocol was reviewed and approved by the Harvard School of Public Health Human Subjects Committee as qualifying for exemption from institutional review board review because it met criteria set forth in the Code of Federal Regulations (CFR), in 45 CFR 46.101 (b)(2).

Focus Group Method and Data Collection

Before each focus group, a written background survey was administered to gather information about demographics, Pap smear history, and HPV awareness. Two of the researchers facilitated the groups. One focus group was conducted in Spanish with the translating assistance of a Spanish-speaking physician. The groups met for approximately 1 hour and were audiotaped and transcribed. Participants gave verbal consent and were compensated for their time.

Table 1 presents the core focus group questions. A semistructured discussion guide was developed to ensure that facilitators could both pose consistent questions to each group and explore participants' responses.²⁰ To further probe the participants' interest in HPV, participants were also asked to respond to a series of paragraphs containing HPV information. Open-ended questions and paragraph messages were formulated based on previously published HPV

knowledge research^{14–19} and lay literature on HPV.^{24–27} To optimize question wording and conversational flow, the discussion guide was pilot tested in several one-on-one interviews and one focus group and edited accordingly before formal focus groups began. Because the discussion format encouraged participants to ask questions about HPV, facilitators acted as educators, answering queries as they arose to ensure that participants left the groups fully informed about HPV and recommended screening practices.

Coding and Analysis

Transcripts were analyzed with a grounded theory approach, using open and then axial coding techniques.²¹ Investigators independently reviewed the transcripts to identify themes and then met to discuss interpretations and create a list of open codes. As transcripts were coded and specific themes within the participants' narratives were recognized, more specific axial codes were developed. To enable easy identification of major themes and demonstrative quotations, two coders used QSR NVivo qualitative software (QSR International Pty Ltd, Doncaster, Victoria, Australia) to code all the transcripts. To minimize interpretive bias by the principal investigators, an unaffiliated third party participated in the discussion of themes and coded transcripts.²⁸ To confirm the credibility of findings, we conducted a "member check," by seeking feedback on the research results from four research participants to verify that their views and those of other participants in their focus group were reflected in the findings.²¹

RESULTS

Twenty-seven percent of the 48 participants had heard of HPV before the focus group began and 85% had received a Pap smear within the last 2 years (Table 2). Participants ranged in age from 18 to 81 years: 38% were ages 18–29 years, 40% were ages 30–54 years, and 23% were age > 55 years. Forty-four percent were Hispanic, 13% were African American, and 40% were white. Most of the sample (69%) had a household income < \$15,000, and 73% had a high school education or less.

Women's primary questions about HPV dealt with transmission, prevention, treatment, and level of cervical carcinoma risk. In addition to these core areas of desired information, our grounded theory analysis distilled five major themes from women's comments and questions about HPV: 1) overestimation of cancer risk; 2) uncertain level of anxiety about HPV; 3) confusion about screening test results; 4) desire for a personalized risk profile; and 5) focus on HPV as an STD.

TABLE 2
Characteristics of Focus Group Participants (*n* = 48)^a

Characteristic	No. of participants (%)
Heard of HPV	13 (27)
Pap smear within last 2 yrs	41 (85)
Age (yrs)	
18–29	18 (38)
30–54	19 (40)
> 55	11 (23)
Race/ethnicity ^b	
Hispanic	21 (44)
African American	6 (13)
American Indian	3 (6)
White	19 (40)
Education	
Less than high school	17 (35)
High school graduate	18 (38)
Some college	10 (21)
College graduate or more	3 (6)
Household income ^c	
< \$15,000	33 (69)
\$15,000–\$29,999	5 (10)
\$30,000–\$44,999	3 (6)
\$45,000–\$59,999	2 (4)
≥ \$60,000	3 (6)

HPV: human papillomavirus; Pap: Papanicolaou.

^a Values in some categories do not sum to 100% due to rounding. All values are based on participant self-reporting.

^b Values for ethnicity sum to more than 100% due to multiple ethnic affiliations for one participant.

^c Values for income sum to less than 100% due to nonresponses from two participants.

Theme 1: Overestimation of Cancer Risk

Most of the women in the current study reported that they had never heard of HPV. Those who were most knowledgeable about HPV typically became aware of it because they had been tested or diagnosed. 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 expressed surprise that most women with HPV do not develop cervical carcinoma: "When I was diagnosed with this [HPV], all I heard was cervical cancer...It wasn't so much *if* I get cervical cancer. It's always been *when*...I always felt like I definitely couldn't escape it."

Theme 2: Uncertain Level of Anxiety about Human Papillomavirus

Some of the women struggled to understand how HPV could "go away on its own" and wondered how concerned they should be about HPV: "By reading these paragraphs, it's like they're saying it's [HPV] important. But then, at the same time, they're saying that it will go away on its own. These paragraphs are kind of

contradicting. . . They're making you scared. But at the same time, they're telling you not to worry about it. That's why I don't really know what to view as important and what not to."

Fears about HPV were rooted in its association with cancer, its easy transmission, and its lack of infallible prevention techniques. Nearly all women wanted to know how to prevent HPV transmission, many asked whether HPV could be transmitted to a baby during pregnancy or delivery, and many expressed surprise and interest at the information that HPV could be passed by skin-to-skin genital contact: "I didn't realize that it [HPV] could be transmitted through foreplay and fooling around. I thought it was more sexual intercourse. That's sort of scary."

When asked to imagine how they would feel if they received a positive HPV test and a normal Pap smear result concurrently, nearly all women responded that they would feel a general sense of worry. Many women, especially those age > 30 years, anticipated that they would fear cancer upon HPV diagnosis. Informing the groups that most HPV does not progress to cervical carcinoma did little to change women's anticipated feelings.

Interest in receiving an HPV test was dependent on whether participants were concerned about feeling undue worry. Those who did not wish to receive the test preferred to avoid unnecessary anxiety about HPV: "If it's not going to hurt me, like you were saying, if it goes away on its own, then what you don't know won't hurt you. So, that's my aspect of it. Like, I don't think I would need to know."

However, most women expressed an interest in receiving an HPV test, citing HPV status as an important part of their sense of well-being: "I need to know. It's my body, and I'm living in it. I mean, I need to know what's wrong, and if something could be wrong."

Theme 3: Confusion about Screening Test Results

Many women were confused about how Pap smear results could be normal if HPV is present. Some questioned the value of the Pap smear if it could not detect every case of HPV: "Well, because the Pap smear. . . came out fine and everything. And then they want you to do this one [HPV test]. So what good is a Pap smear? I would say, 'Why the hell am I having a Pap smear every year if it's not really finding out what we really need to find out?' I would be really upset."

When presented with the option of self-administering the HPV test, most women preferred that the physician administer the test or indicated that even if they conducted the test on themselves, they would want a physician examination as well. Those who pre-

ferred the physician-administered test claimed that they wanted to ensure that the test was done correctly and that the sample was not contaminated. Those who preferred a self-administered test liked it because it offered more privacy than a pelvic examination.

Theme 4: Desire for a Personalized Risk Profile

To assess their own risk of HPV, several participants asked whether some women are more susceptible to HPV than others, and if so, which risk factors contribute to susceptibility. Similarly, women requested HPV information that was specific to their HPV type: "I think, when they do the brochures and the pamphlets, they should aim it at the strain you have. Because the paragraphs. . . we read, if you gave me those after telling me I had it, of course I'm going to think the worst. So, if you have this kind, and this is what it should be, and you're likelihood it's going to be this, then that would be nice. But a generic, overall, I don't think would work well."

A number of women tried to equate descriptions of HPV as low risk or high risk with risky behaviors or risky individuals, as opposed to strains of the virus. Most women believed that they were at risk for HPV; however, women age > 55 years, women who were married, and women who were not sexually active at the time of the study were less likely to feel at risk.

Theme 5: Focus on Human Papillomavirus as an STD

In general, younger participants expressed more questions and concerns about the consequences of HPV as an STD. When asked to imagine how they would feel upon receiving a positive HPV test result, several women ages 18–29 years focused on the embarrassment of receiving a diagnosis of an STD: "If I have a partner who is tested positive for HPV, or myself, how would you tell him that you have it? How would he feel? How would he feel that you have HPV? I wonder myself, how would he feel if I tell him that I have HPV? And, I would ask, what would be his reaction?"

Many women of all ages inquired about the symptoms of HPV, and in particular, wanted to know how to differentiate these symptoms from those caused by other STDs, especially herpes. Women were very curious about genital warts. Specifically, many women wanted to know where they could appear, what they look like, and how they are treated. Some women found it confusing to hear about nongenital types of HPV that correspond to different types of warts on the body. Many women asked whether warts on other parts of the body could be transmitted to the genitals.

DISCUSSION

The themes described by the current purposive sample of women suggest an educational agenda for HPV information that will prepare women both to make choices about cervical screening and to cope with HPV diagnosis. In keeping with a recent review of frequently asked questions at the American Social Health Association National HPV and Cervical Cancer Prevention Resource Center,²⁹ the women in our focus groups posed HPV questions that emphasized the following core areas: 1) transmission; 2) prevention; 3) treatment and progression without treatment; and 4) risk of cervical carcinoma.

Although these core areas of information were sought across age, ethnic, and income groups, women in our study expressed different informational interests according to their age. Younger women were more focused on the symptoms associated with low-risk (i.e., non-cancer-causing) strains of HPV and predicted that they would feel regret, a psychologic response consistent with other STD diagnoses.³⁰ Older women conveyed more concern about high-risk (i.e., cancer-causing) strains. Women of all ages were particularly interested in identifying their own HPV risk status and understanding their risk factors.

The focus groups revealed three potential areas of confusion in HPV education. First, many women in our sample had difficulty understanding the distinctions between low-risk and high-risk strains of HPV. Second, many women were confused by the meaning of HPV test results compared with Pap smear results. Third, many women were uncertain about the level of alarm warranted by HPV infection.

Our study suggests that, to satisfy women's HPV information needs, mass media stories and other educational vehicles must include complete and accurate information regarding transmission, prevention, treatment, and cervical carcinoma risk of HPV; tailor messages to describe HPV susceptibility according to age and risk profile; present clarification regarding HPV strains and their consequences; offer explanations of different types of tests and their results; and, most importantly, provide information in a manner that balances accurate discussion of cancer risk with the reassurance that following recommended screening practices will reduce risk to negligible levels. As HPV DNA testing is incorporated into primary cervical screening, media and other communication materials developed to fill the corresponding educational need should be assessed to determine if they address these priority areas of women's desired information about HPV.

The current study has several limitations. Quali-

tative methods and purposive sampling allowed us to generate themes and to explore in-depth information about women's desired knowledge about HPV. However, data gathered in a small, purposive sample may not be generalizable to other groups. The participants in the current study exhibited more recent cervical carcinoma screening records than national averages for minority individuals with similar incomes and educational backgrounds, suggesting that our recruiting strategy may have favored those who proactively seek medical care. The generalizability of the results could, once again, be questioned; however, it appears unlikely that women who do not receive regular screening would know more about, or have different questions about, HPV than the recently screened women in the current study.

Although our research focused on minority and low-income women, its themes are consistent with the findings of HPV awareness studies conducted with women in other ethnic and socioeconomic groups.¹⁴⁻¹⁹ Consequently, we are confident that the findings of the current study, although preliminary, are broadly applicable. To determine its relevance to specific settings, the 'transferability' principle, whereby readers assess the methods, setting, and results to determine generalizability, should be applied.³¹ Broader surveys aimed at understanding women's HPV testing preferences and informational needs will be necessary to hone policies and educational materials directed at specific socioeconomic and ethnic groups.

The current study is subject to the limitations of any qualitative inquiry; however, its findings offer rich insights distinct from those that can be observed in a quantitative trial. The women in the current study enjoyed participating in group discussions about HPV and valued the opportunity to ask questions and express their opinions about HPV testing. Their comments indicated that although there is currently a substantial deficiency in knowledge about HPV, provision of basic background information allows women to contribute meaningfully to decision-making about HPV testing and react more knowledgeably to HPV diagnosis. Soliciting further input from women will be crucial to both determining the appropriate role of HPV testing in cervical carcinoma screening and developing and assessing much-needed educational and counseling materials.

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