Awareness of Diagnosis and Knowledge of HPV in Women Patients: Data from a Multi-site Study

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ABSTRACT

Background: *Persistent infection with high-risk types of human papillomavirus (HPV) is associated with cervical and other anogenital cancers.* ***Purpose:*** *This paper reports results of awareness of an HPV diagnosis and HPV knowledge from a multi-site study of HPV knowledge, attitudes and behavior, and the impact of an HPV diagnosis on women and their partners.* ***Methods:*** *During September 2003 - November 2005, a survey containing shared and site-specific items was administered to 736 women who had received HPV DNA testing in conjunction with cytology for cervical cancer screening.* ***Results:*** *Overall, there was low knowledge about HPV transmissibility, curability and the effects of an HPV diagnosis across all sites regardless of a woman's racial/ethnic and/or socio-demographic background. Further, only about 50% of the women were aware of their HPV diagnosis even after receiving their results and counseling from a health care professional.* ***Discussion:*** *There is need for consistent and clear information about HPV and HPV DNA testing as part of cervical cancer screening. Research concerning methods or best practices for improving communication between practitioner and patient about testing, diagnosis, counseling, behavioral consequences and follow-up care may be warranted.* ***Translation to Health Education Practice:*** *General messages as well as population-specific messages need to be developed and disseminated to reduce confusion emanating from HPV diagnosis. Modes for delivering messages may need to vary. Further research should address message content and delivery.*

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BACKGROUND

Genital human papillomavirus (HPV) infection is significant because epidemiologic research has shown that persistent infection with high-risk or oncogenic types of HPV is a necessary but not sufficient cause of cervical cancer.[1-7] Whereas genital HPV infection is common, cervical cancer is rare; most infections are transient, often produce no symptoms and are cleared by the body's immune system.[2,5-9] The Food and Drug Administration (FDA) approved an HPV DNA test, (Hybrid Capture 2®,

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Digene Corporation), for the management of patients with abnormal Pap smear results and as an adjunct to Pap smears for women ≥30 years of age.[10-12] In addition, two prophylactic HPV vaccines, HPV4 (Gardasil®, Merck and Co., Inc Whitehouse Station, NJ) and HPV2 (Cervarix®, GlaxoSmithKline, Rixensart, Belgium) have been approved.[14,15] Current guidelines recommend use of HPV4 or HPV2 for vaccination of women and girls 9-26 years of age and HPV4 in 9 – 26 year old males to reduce their likelihood of acquiring genital warts.[14,15] Routine vaccination for males is not recommended.[15]

Uptake of the vaccine and HPV DNA testing in cervical cancer screening may have a profound impact on women as the available literature suggests that women have variable knowledge of HPV[16-28] and few understand linkages among HPV, abnormal Pap tests, and the development of cervical cancer.[16,17,19,20,28] Further, studies have shown that women with a positive test result for high-risk HPV DNA may experience negative psychological outcomes such as anxiety, distress, uncertainty, confusion, embarrassment and stress.[20,29-35] Accurate knowledge about HPV and its link to cervical cancer is crucial if women are to make the best choices about acceptance of the current and anticipated vaccine options, cervical cancer screening, and recommended follow-up care.

PURPOSE

This paper reports results from a multisite, two-phase study conducted prior to approval of the vaccines that included the following components: (1) in-depth interviews and focus groups (Phase I) to assess knowledge, attitudes, behavior and the impact of an HPV diagnosis on women and their partners; and (2) quantitative interviews using an instrument with core elements developed from Phase I data to assess differences in diagnosis impact and health care needs among different populations of women. The study was funded by the Centers for Disease Control and Prevention (CDC) under a Congressional Mandate to conduct behavioral research on the impact of HPV-related diagnoses on individuals and formative research to assist with the development of educational messages. The focus of this manuscript is women's knowledge of HPV and awareness of their HPV diagnosis based on data from the quantitative phase.

METHODS

Data are from the following sites: University of South Carolina Arnold School of Public Health (USC); University of South Florida College of Public Health (USF); University of Oklahoma Health Sciences Center (OUHSC); and the University of California Los Angeles (UCLA)/ Los Angeles County Health Department. Because of variability in study populations (i.e., demographic composition and literacy level) and the purpose of the study, each site used different methods for recruiting subjects and administering the instrument. The study protocol was reviewed and approved by the Human Subjects Review Boards at each site, the participating clinics and the CDC. Site-specific descriptions follow.

University of South Carolina

Between September 2003 and January 2005, 206 women completed a telephone interview.[36] Study sites consisted of seven federally funded, primary health care settings located in a rural region where the population is economically depressed, and educational attainment and literacy are low. Moreover, about 42% of the region's population is comprised of racial and ethnic minorities (predominantly African American). The region has the highest cervical cancer incidence rate of all state health districts. Women whose Pap test results showed Atypical Squamous Cells of Undetermined Significance (ASC-US) or higher were reflexively tested for HPV DNA (Digene, Hybrid Capture II®, Gaithersburg MD). This protocol was in place at the participating health care centers prior to study implementation.

Health care professionals (most frequently nurses) at each of the centers determined eligibility status and informed qualifying women about the study in person or through telephone contact. A health care center staff member obtained informed consent in person. Eligibility criteria required that participants were between 18 and 64 years of age, were English-speaking with no cognitive impairments, received an abnormal Pap test result and had been tested for HPV within the previous 120 days, and were informed of their test results by health care center staff.

A professional survey research firm conducted the interviews, which averaged 23.4 minutes (SD=6.6) in length. Each woman received a $10 money order and a thank-you letter by mail upon completion of the interview.

University of South Florida

Between November 2003 and June 2005, 154 women 18- to 45- years old completed a paper-and-pencil questionnaire. Specifics on the study population and protocol have been reported elsewhere.[27] Approximately 3500 women were screened and 154 interviewed at five separate sites (Planned Parenthood and USF Student Health Service clinics) in West Central Florida. About 14% (n=490) had abnormal Pap tests with positive HPV results.

University of Oklahoma

Between December 2003 and June 2005, 270 women 15- to 64- years old completed individual computer-assisted self interviews (CASIs). Participants were recruited from clinics and Indian Health Services facilities in metropolitan Oklahoma City and in the cities of Lawton, Ada, and Shawnee.

Participants were recruited by physicians and nurses at the participating clinics or by research staff from women who received an HPV test provided through the study or had previous HPV testing. Alternatively, participants also were recruited through flyers (on public bulletin boards in clinics, university settings and Indian community facilities) and notices (in the health and advertisement sections of newspapers). All participants provided informed consent. Parental consent and adolescent assent were obtained for participants who were minors 15- to 17- years of age. Interviews required up to two hours to complete. Participants were reimbursed $30 for time and travel.

University of California at Los Angeles/ Los Angeles County Health Department

Participants were recruited from women tested for HPV in an ongoing HPV surveillance study. Between March 2005 and November 2005, 106 women were randomly assigned to complete either CASIs or face-to-face interviews. Staff recruited eligible women by telephone from two health care facilities, an STD clinic and a primary care clinic. The STD clinic serves predominantly African American and Latina patients. The primary care clinic population was mostly of Korean descent. Eligible participants were 18- to 65- years old who were seeking a routine Pap smear or pelvic examination, who were not pregnant and who had an intact cervix.

Interested women were scheduled for an interview at the clinic where they received HPV testing and reimbursed $40 for their time and travel.

QUESTIONNAIRE DEVELOPMENT

The quantitative study instrument was developed in consultation with investigators at the project sites and CDC experts, and with reference to a review of the literature on HPV and to the Phase I data. Phase I included qualitative interviews with women who had a positive test for HPV, discussion groups with health care providers and focus groups with women with a positive test for HPV and men and women with no history of an HPV diagnosis. The instrument included common core elements that were administered by each site and site-specific questions. The core elements were: (1) time since diagnosis, (2) HPV knowledge, (3) perceived stigma, (4) counseling messages received, (5) attitudes toward HPV, (6) emotional impact of HPV-related diagnoses, (7) health seeking and health care utilization behavior, (8) treatment experiences, (9) partner disclosure, (10) informational sources accessed, (11) treatment compliance, and (12) impact of the diagnosis on reproductive decisions.

Each site administered these core items; using common or closely related wording, along with site-specific questions relevant to the respective site objectives and unique populations.

Findings from Phase I at the South Carolina site revealed that about half of the women with positive HPV tests were unaware of their results, despite having been informed by a health care provider. To avoid asking questions about HPV of women who were unaware of their results, a series of initial screening questions were included to determine if the woman was aware of having had an abnormal Pap test result, had ever heard of HPV and could recall being told by her health care provider that she had a positive HPV test. Based on the woman's answers to these initial questions, the interviewer could ask each woman a series of questions about abnormal Pap tests and HPV that were appropriate for her level of awareness. To avoid similar concerns about inadvertently revealing a woman's HPV result to her in the course of the interview, research staff at the Oklahoma site did not schedule an interview until receiving notification from the clinic that the patient had been informed of her HPV test results. Because of the testing and notification of diagnosis protocols utilized at the Florida and Los Angeles sites, no modifications to the study instrument were required.

NOTIFICATION OF HPV DIAGNOSIS

Women were notified of their HPV diagnosis by clinic staff at each of the participating study sites. Women at the South Carolina site were contacted by a health care provider through mail or telephone and instructed to contact the clinic and speak with a health care provider regarding test results and/or to come into the clinic for an in-person visit. Women were not notified of their HPV diagnosis through the mail or over the telephone. Women at the Oklahoma sites were notified of their results by telephone, letter, or in person during a clinic visit. The standard of care at the participating clinics was utilized for providing an HPV diagnosis to women at these sites. No scripts were developed by the study.

Women with abnormal Pap tests and positive HPV results at the Florida sites were contacted according to the individual clinic protocols. Planned Parenthood participants received letters via mail notifying them of their abnormal Pap test results and instructing them to follow-up with an Advanced Registered Nurse Practitioner for questions. At the USF Student Health Service, clinic nurses informed participants of their test results via telephone and clinic appointments were made for participants who had questions. To promote understanding of the diagnosis at all USF sites, a Medical Advisory Committee comprised of medical and behavioral scientists developed a diagnosis "script" (reading level approximately 8th grade). The script included information on the sexually transmitted nature of HPV. Special attention was given to differentiating whether a woman had low-risk, high-risk or mixed low-and-high-risk HPV types, and what that designation might mean in terms of disease sequelae.

At the Los Angeles clinics, participants were notified of their HPV results by one of three methods: by the physician during a scheduled appointment, by study personnel via telephone, or by letter. All abnormal Pap results were followed up by the clinical staff using an IRB-approved algorithm to ensure that the patient received the appropriate treatment. Each clinic had counseling materials specific to an HPV diagnosis and Pap test results to provide for the women. The algorithm and counseling materials were provided by the sentinel surveillance study.

DATA ANALYSIS

Descriptive statistics were computed to report similarities and differences in awareness of HPV diagnosis and HPV knowledge across the four sites. Frequency distributions, means and standard deviations were computed to explore the sample demographics and results of the HPV knowledge measure. The knowledge measure was an index intended to assess basic HPV knowledge. A knowledge score was calculated by assigning correct responses "1" and incorrect "0" and summing the total score for each respondent. Possible scores ranged from 0 to 16.

RESULTS

Table 1 provides a summary of demographics. Of 265 women who provided informed consent at the South Carolina site, 78% (n=206) completed the interview. The South Carolina population was comprised of women with a mean/median age of 40.8 years. The plurality of these women (38%, n=73) were married and most of the women (68%, n=139) were African American. About equal proportions of the women had attended high school (31%, n=64) or had a high school diploma or GED (31%, n=63). The Florida study site population consisted of women with a mean age of 23.5 years and a median age of 22 years. The majority (71%, n=110) were unmarried, Caucasian (69%, n=106), and had attended (51%, n=79) college. An additional 29% (n=44) had completed college.[27] The Oklahoma population had a mean age of 29.3 years (median = 26 years) and were unmarried (44%, n=119), and American Indian (n=117, 43%). About one-third (n=84) had some college credit but no college degree. The Los Angeles cohort had a mean age of 37 years (median = 37.5 years), and were predominantly Asian (n=48, 45%) and African American (n=44, 42%). The largest percentage was married (n=44, 42%) and had a high school diploma or GED (n=38, 36%).

All respondents in the South Carolina sample had a Pap test result of ASC-US or higher and an HPV test. Of the 206 women interviewed, 50 (24%) reported that a health care professional told them they had HPV, whereas the health care center reported that 74 (36%) of the women tested positively for HPV. The HPV status of 30 women (15%) was unknown; these women declined consent for the provider to disclose their results. Of the 154 Florida women who completed the survey, only 59 (39%) of the self-reported responses correctly matched their laboratory-reported test results.[27]

Of the 270 women in the Oklahoma sample, 112 (42%) had a negative HPV test and 158 (58%) had a positive test. A review of medical records showed that of the 158 women who tested positively, 45 (28%) were informed of their test results by a telephone call from a clinician, 42 (27%) received their results by letter, and 71 (44.9%) received their results in person from a clinician. Only 68 (43%) of the women who tested positive for HPV and were informed of their results stated that their HPV result was positive.

Of the 106 women interviewed at the Los Angeles site, 44 (42%) tested positively and 62 (58%) tested negatively for HPV. Almost all of the women were aware of their HPV diagnosis and responded correctly based on laboratory reports to a question about their test results. Of the 44 women who tested positively for HPV, 19 (43%) received their diagnosis in person, 20 (45%) by telephone call, and 5 (11%) by letter.

Table 2 provides a summary of the HPV knowledge results. Of the 206 South Carolina women, 108 who said they had ever heard of HPV completed the knowledge questions. Among the 50 women who reported that they received a positive HPV test result, the mean number correct was 10 of 17 (SD = 3.69), the median was 11, and the range was 2-16.

At least two-thirds of South Carolina participants answered correctly to the following: the link between HPV and abnormal Pap smears, and that HPV is a virus, a sexually transmitted infection (STI), and can cause cervical cancer. However, the majority of the women answered "don't know" to items related to whether HPV causes HIV/AIDS or herpes, occurs in different types, can be cured by antibiotics, or can affect your ability to get pregnant. Additionally, most answered "false" to the knowledge item addressing the transient nature of an HPV infection.

Similarly, Oklahoma participants answered correctly the knowledge items addressing the link between HPV and abnormal pap smears; and that HPV is a virus, an STI, and can cause cervical cancer. Additionally, most answered "not sure" to the item related to the effect of HPV on future pregnancies and that HPV occurs in different types. Conversely, most women answered "false" to the knowledge item addressing the transient nature of an HPV infection and "not sure" to the item related to an HPV vaccine.

In general, Florida women responded correctly to the knowledge items related to causes and outcomes of an HPV infection; the link between HPV, abnormal Pap smears, and cervical cancer; and that HPV is an STI. However, they reported uncertainty about relationships between HPV and other outcomes, e.g., HPV causes HIV/AIDS or herpes and HPV can affect your ability to get pregnant. Further, most women answered "false" to the statement addressing an HPV vaccine.

Based on responses to the knowledge items by women at the Los Angeles site, respondents were unsure about whether HPV causes HIV/AIDS and/or herpes, may be spread on toilets and/or through poor personal hygiene, and may affect their ability to become pregnant. Women were also unsure whether a vaccine may prevent HPV.

DISCUSSION

To the authors' knowledge, this is the first study conducted prior to approval of an HPV vaccine to address awareness of HPV diagnosis among female patients of different racial/ethnic backgrounds and socioeconomic levels of this scale and geographic distribution. There was generally low knowledge in the sample about HPV transmission and curability, the effects of an HPV diagnosis and the existence of a vaccine. However, women across all four sites had knowledge of the link among HPV, an abnormal Pap test and cervical cancer, and knew that HPV is an STI. The finding of inadequate knowledge among women in the study corroborates earlier literature concerning women's HPV knowledge. However, findings related to the link among HPV, abnormal Pap test results and cervical cancer are not.[5,17,18,20,21,27,37] Most of the published HPV knowledge studies have focused on the general public and not on patients.[15-25] Therefore, it is possible that women in this study had more knowledge of the link among HPV, abnormal Pap tests and cervical cancer because they had received counseling from a health care professional and had been tested for HPV.

Despite the HPV knowledge findings, only about half of the women at three of the

Table 1. Population Socio-demographics—Awareness of HPV Diagnosis—South Carolina, Oklahoma, Florida, Los Angeles

Characteristic	Florida (n=152)		South Carolina (n=206)		Oklahoma (n=270)		Los Angeles (n=106)	
	n	%†	n	%†	n	%†	n	%†
Age								
Mean	21		40.8		29.3		37.0	
Median	22		42		26		37.5	
15-29	140	92	56	27	168	62	35	33
30-50	12	8	91	44	91	34	60	57
51-64	n/a	n/a	59	29	11	4	11	10
Race								
African American or Black	19	13	139	68	48	18	44	42
Caucasian	103	69	59	29	77	29	0	0
American Indian or Alaska Native	0	0	6	3	107	40	0	0
Asian	6	4	0	0	6	2	48	45
Native Hawaiian/Pacific Islander	0	0	1	<1	3	1	0	0
Other race	20	13	1	<1	29	10	14	13
Hispanic								
Yes	22	15	5	2	*	*	11	10
No	126	85	197	96	*	*	94	89
Don't Know			4	2	*	*	1	1
Relationship Status								
Single/Never Married	106	71	58	28	**119	44	36	34
Never Married Living with Partner	28	18	17	8	**32	12	5	5
Married	7	5	73	35	66	24	44	42
Separated/Divorced	7	5	44	21	49	18	16	14
Widowed	1	1	14	7	4	2	5	5
Level of Education								
Elementary School to 6th grade	1	1	5	2	0	0	1	1
Middle School 7th to 8th grade	0	0	14	7	8	3	5	5
High School – no diploma	3	2	64	31	39	14	8	8
High School Diploma or GED	15	10	63	31	68	25	38	36
Trade School/Technical School	0	0	*	*	23	9	4	4
Some College – no degree	76	51	44	21	84	31	21	20
Associate Degree	0	0	*	*	16	6	6	6
Undergraduate Degree	42	28	12	6	21	8	21	20
Graduate Degree	12	8	4	2	11	4	2	2
Insurance Status								
Private	71	48	53	26	44	16	18	17
Health Maintenance Organization	0	0	*	*	10	4		
Medicaid/Medicare	2	1	71	35	††70	26	21	20
Military or Veterans	1	<1	2	<1	5	2	1	1
No Insurance (Self-pay)	61	41	76	37	16	6	65	61
Indian Health Service/Tribal Clinic	0	0	*	*	110	41	*	*
Other	12	8	2	<1	15	6	1	1
Don't Know	0	0	1	<1	*	*	0	0

† percentage may not add to 100 due to rounding * Option not used ** Oklahoma site option was "Unmarried" ††Option also included "Medical Coupons"

Table 2. Core HPV Knowledge Items—Awareness of HPV Diagnosis—South Carolina, Oklahoma, Florida, Los Angeles

	Responses								
	Oklahoma			Florida			Los Angeles		
True/false question:	"True"	"False"	"Not Sure"	"True"	"False"	"Not Sure"	True"	"False"	"Not Sure"
There are many types of HPV	130* (48%)	29 (11%)	111 (41%)	127 (82%)	10 (6%)	17 (12%)	52 (49%)	5 (5%)	49 (46%)
HPV causes HIV/AIDS	8 (37%)	203* (75%)	59 (22%)	1 (0.6%)	143 93%)	10 (7%)	14 (13%)	45 (42%)	47 (44%)
Antibiotics can cure HPV	25 (9%)	155* (57%)	90 (34%)	5 (3%)	136 (88%)	12 (9%)	26 (25%)	30 (28%)	50 (47%)
You can always tell when someone has HPV	1 (0.3%)	243* (90%)	26 (10%)	1 (0.6%)	152 (99%)	1 (0.6%)	3 (3%)	65 (61%)	38 (36%)
HPV can cause abnormal Pap smears	255* (94%)	8 (3%)	7 (3%)	152 (99%)	0 (0%)	1 (0.6%)	73 (69%)	9 (8%)	24 (23%)
Only women get HPV	59 (22%)	147* (54%)	64 (24%)	15 (10%)	128 (83%)	11 (7%)	38 (27%)	31 (29%)	37 (35%)
HPV causes herpes	30 (11%)	135* (50%)	105 (39%)	26 (17%)	104 (68%)	23 (15%)	29 (27%)	23 (22%)	54 (51%)
HPV affects your ability to get pregnant	51 (19%)	99* (37%)	120 (39%)	26 (17%)	85 (55%)	43 (28%)	42 (40%)	18 (17%)	46 (43%)
HPV is a virus	223* (83%)	21 (8%)	26 (9%)	146 (95%)	2 (1%)	6 (4%)	81 (76%)	4 (4%)	21 (20%)
Once you get HPV, you always have it	127 (47%)	62* (23%)	81 (30%)	13 (8%)	26 (17%)	14 (9%)	21 (20%)	41 (45%)	37 (35%)
A vaccine may prevent HPV	23* (9%)	120 (44%)	127 (47%)	10 (6%)	103 (67%)	40 (26%)	20 (19%)	27 (25%)	59 (56%)
HPV causes genital warts	145* (54%)	44 (16%)	81 (30%)	134 (87%)	11 (7%)	9 (6%)	47 (44%)	14 (13%)	45 (42%)
You can have HPV without knowing it	255* (94%)	0 (0%)	15 (6%)	153 (99%)	0 (0%)	0 (0%)	98 (92%)	0 (0%)	8 (8%)
HPV can be cured	65 (24%)	111* (41%)	94 (35%)	17 (11%)	114 (74%)	23 (15%)	52 (49%)	22 (21%)	32 (30%)
HPV is spread on toilets	6 (2%)	196* (73%)	68 (25%)	7 (5%)	107 (69%)	40 (26%)	13 (12%)	38 (36%)	55 (52%)
HPV is a sexually transmitted infection	210* (78%)	23 (8%)	37 (14%)	146 (95%)	4 (3%)	4 (3%)	71 (67%)	10 (9%)	25 (24%)
HPV causes cervical cancer	209* (77%)	13 (5%)	48 (16%)	14 (52%)	7 (26%)	6 (22%)	84 (79%)	3 (3%)	19 (18%)
HPV may go away by itself	64* (24%)	145 (54%)	61 (22%)	68 (44%)	54 (35%)	31 (20%)	37 (35%)	48 (45%)	21 (20%)
You can get HPV through poor personal hygiene	23 (9%)	152* (56%)	95 (35%)	12 (8%)	112 (73%)	30 (19%)	37 (35%)	26 (25%)	43 (41%)

* indicates correct responses

Table 2. Core HPV Knowledge Items—Awareness of HPV Diagnosis—South Carolina, Oklahoma, Florida, Los Angeles (Con't)

	South Carolina***					
	True		False		Don't Know	
Item	*N*	%†	*N*	%†	*N*	%†
HPV can cause abnormal Pap smears	103	95	2	2	3	3
You can have HPV without knowing it	101	94	0	0	7	6
HPV is a virus	94	87	2	2	12	11
You can always tell when someone else has HPV	3	3	87	81	18	17
HPV causes cervical cancer	81	75	3	3	24	22
HPV is a sexually transmitted infection	68	63	18	17	22	20
HPV causes genital warts	64	59	7	6	37	34
Only women get HPV	21	19	47	44	40	37
HPV causes HIV/AIDS	7	6	46	43	55	51
Antibiotics can cure HPV	9	8	43	40	56	52
A vaccine may prevent HPV	17	16	38	35	53	49
There are many types of HPV	35	32	6	6	67	62
HPV cannot be cured	34	31	23	21	51	47
HPV affects your ability to get pregnant	25	23	26	24	57	53
HPV causes herpes	10	9	25	23	73	68
HPV may go away by itself	9	8	69	64	30	28
Once you get HPV, you always have it	37	34	23	21	48	44

***The South Carolina responses are presented in a separate chart because the order and wording of the knowledge questions were different from those of the other sites due to results from the cognitive interviews.

† percentage may not add to 100 due to rounding

four sites were aware of their positive HPV test results even after being informed of the diagnosis by a health care professional. The patient populations for these sites ranged from mostly low-income, low-literacy level, largely minority women to a university population. Further, each of the sites used a variety of methods to notify women of their results. Regardless of the method and the varying educational levels of the population, however, many women patients were still unaware of their HPV test results.

There are several possible explanations for this finding. It is not known if women received information about HPV, including the implications of a positive test result, before the test was conducted or after the result was received. Therefore, women may not have understood the meaning of a positive or negative result. Women may have been more aware of their test result if they were provided information about HPV and the implications of a positive result before the test was ordered.[17] Further, the materials used or methods employed for informing women of their results may have lacked clarity or been presented in medically technical language that was difficult for the women to interpret. There is also the possibility that women focused only on cancer rather than the outcome of their test result. Additionally, there was no direct observation by the study staff of the information provided to patients by health care professionals, so the authors cannot be sure of exactly how the results were delivered, even at the site that used a pre-developed diagnosis script. Also, there is no information on whether patients were given the opportunity to seek clarity on their test results and receive additional feedback from health care providers at a later date.

There was higher awareness of diagnosis at the Los Angeles site. As previously stated, women at this site were recruited from the patient population of an ongoing study. Women in this study received uniform information about HPV and their test results and additional information if requested when they were recruited into this study.

It is interesting that women at all four sites were unaware that a vaccine may prevent HPV. This finding is important because an HPV vaccine was approved before data collection was completed. Although many

women in this study are beyond the recommended age for the vaccine, the experiences of these women with HPV and their understanding of HPV-related diseases may be crucial in their acceptance of a vaccine for their children.[38, 39]

This study had limitations. The sample was a purposeful sample; this limits the generalizabililty of the findings. Additionally, there were varying methods of survey administration and different clinic protocols for testing, and different methods for informing patients of their diagnoses. These factors influenced what and when women were told about HPV and their results. Further, with regard to the knowledge measure, because a large proportion of the women were unaware of their HPV diagnosis, the participating sample may be biased toward relatively well informed women.

Certain study strengths also should be acknowledged. The multi-site nature of the study enabled women of many age, race and ethnic backgrounds to be included. The study design also permitted recruitment of patients from a diverse set of primary care clinical venues from both urban and rural locations. Whereas, data collection mode was not a focal area of this study, investigators were able to employ multiple methods of data collection to ensure inclusion of a broad range of participants. Finally, the inclusion of a set of common items enabled cross-site comparisons and pooling of some of the data to add richness and conclusion validity to the results.

TRANSLATION TO HEALTH EDUCATION PRACTICE

If women are to make informed decisions about uptake of the vaccine, and participation in cervical cancer screening and appropriate follow-up care, they must have an understanding of HPV, its link to cervical cancer and the meaning of a positive HPV DNA test result.[35, 40, 41] This fact is particularly relevant for women who are disproportionately affected by cervical cancer. Further, although HPV vaccines are available, use of the vaccine does not eliminate the need for future cervical cancer screening even in women who are vaccinated.[13,42]

Therefore, there is a clear need for consistent and clear information about HPV and HPV testing as part of cervical cancer screening, as well as the connection between HPV and HPV-related diseases, including cervical cancer.[39,43,44] New research that employs rigorous study designs is needed concerning best methods for informing women of their HPV test results, determining training needs of providers, and optimal counseling methods and messages to accompany a positive HPV test result to reduce negative emotions, increase knowledge and promote adherence to recommended follow-up care. Moreover, the advent of FDA-approved vaccines and the recent approval of HPV4 for use in males argue further for expeditious development and dissemination of effective messages and strategies to reduce the burden of disease. Further, the results of the studies presented here focus exclusively on females and most of the messages around the vaccine have focused on prevention of cervical cancer. There is a need for further study that includes males and for additional messages that incorporate a focus on the benefits of HPV4 for prevention of genital warts and other types of cancer that affect men.

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Please add the following statement after the citation: The contents of this article are solely the responsibility of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention or the Association for Prevention Teaching and Research (APTR; formerly ATPM)

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