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Changes in Knowledge of Cervical Cancer Prevention and Human Papillomavirus Among Women With Human Immunodeficiency Virus: 2006-2008

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Abstract

Objective—To estimate changes in high risk women's knowledge of cervical cancer prevention, human papillomavirus (HPV), and HPV vaccination since introduction and marketing of HPV vaccines.

Methods—At study visits in 2006 and 2008, women with the human immunodeficiency virus (HIV) and at-risk comparison women in a multicenter U.S. cohort study completed 44-item self-report questionnaires exploring their knowledge of cervical cancer prevention, HPV, and HPV vaccination. Results from 2006 were compared to those obtained in 2008. Knowledge scores were correlated with demographic variables, measures of education and attention, and medical factors. Significant associations were assessed in multivariable models.

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Results—HIV-seropositive women had higher knowledge scores than seronegative women at baseline (13.2 +/− 5.7 vs 11.8 +/− 6.0, P = 0.0002) and follow-up (14.1 +/− 5.3 vs 13.2 +/− 5.5, P = 0.01), but the change in scores was similar (0.9 +/− 5.3 vs 1.5 +/− 5.5, P = 0.13). Knowledge that cervical cancer is caused by a virus rose significantly (P = 0.005), but only to 24%. Belief that cervical cancer is preventable only rose from 52% to 55% (P = 0.04), but more than 90% of women in both periods believed regular Pap testing was important. In ANCOVA models, higher baseline score, younger age, higher education level, higher income, and former- as opposed to never-drug users, but not HIV status, were associated with improved knowledge.

Conclusion—High-risk women's understanding of cervical cancer and HPV has improved, but gaps remain. Improvement has been weakest for less-educated and lower-income women.

Introduction

Persistent infection by human papillomaviruses (HPVs) can lead to cervical cancer, but effective screening and treatment of cancer precursors can substantially reduce cancer risk. Women with the human immunodeficiency virus (HIV) face high prevalence rates of HPV and high incidence rates of cervical intraepithelial neoplasia, the precursor to cervical cancer (1-5). Cervical cancer prevention is a complex process, potentially including vaccination against highest risk HPV types before sexual debut, repeated Pap and HPV DNA screening, triage with HPV DNA assessment and colposcopy, and cervical therapy. Loss to follow-up can occur at each step, and noncompliance with cancer prevention protocols is common among women at highest cervical cancer risk, including minority and poor women and those with HIV (6, 7). Women with HIV, like HIV-uninfected women of similar background, have significant knowledge deficits related to HPV, cervical cancer prevention, and HPV vaccination (8-11), even in the face of repeated visits for management of abnormal Pap tests and cervical cancer precursors. This may be because underlying educational deficits are a barrier to understanding cancer prevention messages (11). Little is known about how women's knowledge of cervical cancer causation and prevention has evolved recently, influenced by clinician-based and public health education about HPV as well as marketing campaigns for HPV vaccination, available since 2006. We set out to estimate how knowledge and attitudes about cervical cancer prevention, HPV, and HPV vaccination might have changed from 2006-8 before and after the 2006 U.S. commercial introduction of HPV vaccine.

Methods

This investigation was nested in the Women's Interagency HIV Study (WIHS), an ongoing U.S. multicenter prospective cohort investigation of the course of HIV infection and related health conditions among HIV seropositive women and seronegative comparison women at risk for HIV. The protocols, recruitment processes, procedures, and baseline results of the WIHS have been described (12, 13). Enrollment began with 2,623 women in 1994-5 at 6 study consortia (Bronx, Brooklyn, Chicago, Los Angeles, San Francisco, and Washington, D.C.). The cohort was expanded to 3,766 women during 2001-2002 (13). Written informed consent was obtained after local human subjects committees approved study protocols. HIV serostatus was determined by ELISA with confirmatory testing at study entry for all participants and annually thereafter for those initially seronegative.

Follow up continues, but this analysis compares information from previously reported cross-sectional questionnaires administered first between April and October, 2006, and again between April and October, 2008 (11). Following initial administration, women were provided with an answer sheet containing correct answers and explanations and were encouraged to bring questions to their clinicians.

The 44-item questionnaire included items related to knowledge of HPV, risk factors for cervical cancer, the HPV vaccine, and care following abnormal Pap smears. This analysis included only women who completed questionnaires in English. Responses were coded as correct or incorrect. McNemar's test for correlated matched pairs was used to compare each woman's baseline and follow-up responses, with further stratification by HIV status. A previous principal component analysis for item reduction was conducted, reducing the number of items to 24 items (11) that were used to compute a factor-based scale for knowledge score at baseline and follow-up (Cronbach's alpha for follow-up data = 0.85). Each participant received a score of 1 for a correct and 0 for an incorrect response, with a maximum possible score of 24. A change score analysis, using the paired t-test, was conducted to assess whether and to what extent each individual's knowledge score improved between baseline and follow-up.

Analysis of covariance (ANCOVA) models were used to examine change in knowledge between baseline and follow-up, where the follow-up score was the dependent variable. Independent variables included baseline score, HIV status, and other demographic and medical characteristics, including age at questionnaire administration, self-reported ethnicity, education attained by study entry, household income, abnormal Pap history, prior colposcopy, cervical disease treatment, reading level using the Wide Range Achievement Test-Version 3 (WRAT, 14), where scores can range from 0 to 42, and information processing and attentiveness using the Symbol Digit Modalities Test (15). For the initial model, each independent variable was evaluated for fit using the Type III SS value and p-value and were included in the analyses if they had a p-value <0.05. Raw symbol digit and WRAT score were added to subsequent models, as these had been shown to be significant in prior models assessing baseline knowledge (11). Final models are presented using the PROC Generalized Linear Models (GLM) procedure in SAS software 9.2 (SAS Institute Inc., Cary, NC).

Results

Of the 1,812 women completing study visits in 2006, 1,451 (80%) had completed questionnaires in English and are the focus of this study. Of these, 1,214 completed questionnaires again in 2008, but 93 were missing responses to at least one question and were excluded. Of the remaining 1,121 women included in this analysis, 773 (69%) were HIV seropositive and 348 (31%) were seronegative. The 93 women missing data on the follow-up questionnaire were slightly older (45.7 vs 43.1 years, P = 0.01 vs included patients), with lower education levels (P = 0.004) and lower WRAT scores (median 26 vs 29, P = 0.0009), were more likely to be a current or former intravenous drug users than those with complete questionnaire data (48.4% vs 23.2%, P< 0.0001), and were more likely to have CD4 counts <200/cmm (20% vs 13%, P = 0.04). Demographic and medical characteristics of included women are presented in Table 1. Of the women with HIV, 500 (65%) were using highly active antiretroviral therapy at the time of the first survey.

Summary knowledge scores increased modestly between baseline and follow-up (12.7 +/− 5.8 vs 13.8 +/− 5.3, P < 0.0001). HIV-seropositive women had higher scores than seronegative women. This was true both at baseline (13.2 +/− 5.7 vs 11.8 +/− 6.0, P = 0.0002) and follow-up (14.1 +/− 5.3 vs 13.2 +/− 5.5, P = 0.01). However, the change in scores was statistically similar for the two groups (0.94 +/− 5.3 vs 1.47 +/− 5.5, P = 0.13).

Knowledge of cervical cancer prevention improved across a range of questions during follow-up. Nevertheless, substantial knowledge deficits persisted. For example, while significantly more women at follow-up understood what part of the body a Pap test evaluated (P = 0.0002), the proportion rose only to 52%. Knowledge of risk factors,

indicating understanding of the causal factors underlying cervical cancer, remained marginal, with substantial proportions of women not understanding the link between cervical cancer and sexual activity, screening compliance, and smoking. Knowledge that cervical cancer is caused by a virus rose significantly (P = 0.005), but only to 24%. Belief that cervical cancer is preventable only rose from 52% to 55% (P = 0.04). Despite this, more than 90% of women continued to believe that regular Pap testing was important for both HIV infected and uninfected women. The proportion of women who knew HPV is a sexually transmitted virus causing warts and cervical cancer rose from 66% to 71% (P < 0.0002). About a third believed incorrectly that HPV could be cured with medication and roughly half believed that individuals can tell when they are HPV infected, proportions that did not change significantly across time. Awareness of the availability of HPV vaccination rose between 2006 and 2008 among the 1,121 women completing follow-up questionnaires, from 505 (45%) to 739 (66%), (P < 0.0001). This increased awareness appeared to arise from multiple sources, as women's recognition of most sources of information increased over baseline (doctors 18% in 2006 vs 20% in 2008, nurses 10% vs 19%, WIHS staff 16% vs 33%, and advertising 69% vs 79%, P <0.0001). The proportion of women citing news reports or not recalling their information source did not change significantly (63% vs 55% for news, 7% vs 6% for unknown, P >0.2).

Knowledge about HPV vaccination also improved dramatically between surveys (Table 2), although many women did not understand the utility of vaccination in preventing perianal lesions and many believed it prevented herpes infections. Women also failed to appreciate the importance of targeting young girls for vaccination and incorrectly considered older women as good vaccine candidates. The proportion of women who believed HPV vaccination was extremely or very important for cervical cancer prevention, as compared to those who considered it somewhat/not important or were unsure, rose from 70% to 78% (P < 0.0001). Compared to 2006, more women at follow-up in 2008 believed recommending HPV vaccination to female relatives and friends to be extremely or very important (61% vs 66%, P = 0.001).

Factors associated with an improvement in knowledge score are shown in Table 3. The first model demonstrated that higher baseline score, younger age, higher education level, higher income, and former as opposed to never drug use were associated with greater improvement in knowledge score. R^2 for this model was 0.32, indicating that these factors explained about a third of the magnitude of change. HIV status was not significant after controlling for these factors. When added to the final model (model 3) WRAT reading level replaced education as a significant correlate (0.09, 95% C.I. 0.04-0.13, P < 0.001) and improved R^2 to 0.35, suggesting that educational quality was a more important predictor of change in knowledge than the number of years in school.

Discussion

Between 2006 and 2008, knowledge of cervical cancer prevention rose significantly in a cohort of women at high risk for cervical cancer, yet substantial deficits remained. Although most women could not identify the cervix as the part of the body assessed by Pap testing, most understood the purpose of Pap testing as well as the meaning and appropriate follow-up for abnormal results, with improvement in these knowledge areas over time. In 2008, most women still did not appreciate risk factors for cervical cancer. Of greatest concern, despite these improvements in knowledge, barely half of study participants actually believed cervical cancer to be preventable, suggesting that understanding may not be sufficient to alter beliefs.

Knowledge of HPV and HPV vaccination also improved significantly, but again gaps remain, perhaps because advertising became an even more dominant information source during the study interval. Many women do not appreciate that the target vaccine population is young girls rather than adult women, since the vaccine is prophylactic rather than therapeutic and the efficacy of vaccination in preventing cervical precancer declines with age and sexual experience (17). In combination with study staff and clinicians' efforts at education, media coverage of and advertising for HPV vaccination appears to have communicated effectively the importance of vaccinations, while the vaccines' limitations are less well understood.

Our findings are broadly consistent with those of others, who have found that knowledge of cervical cancer prevention, HPV, and HPV vaccination has improved since the introduction of HPV vaccination in 2006. Media coverage of HPV vaccine has not emphasized basic cervical cancer prevention concepts, and focused education by WIHS staff may have contributed to improvements we identified in these areas. Media coverage is likely to have contributed strongly to improvements identified in HPV infection and vaccine knowledge, as reflected in the substantial proportion of women who described media and advertising as information sources.

Kelly and colleagues found that exposure to media coverage of HPV has been associated with improved knowledge of HPV and cervical cancer, although they along with Wallace and Ache did identify deficiencies in media messages, specifically that new reports often lack information about the importance of continued Pap testing for vaccinated women (18, 19). Habel and colleagues similarly found that media messages after vaccine introduction lacked information about vaccine safety and side effects or about HPV and cervical cancer (20). In a study from Belgium, Donders and associates found that understanding of the oncogenic potential of HPV had improved since vaccine introduction, especially among younger and less educated women, yet many remained reluctant to embrace vaccination because of cost (21). Kelly and colleagues found that U.S. media reports around the time of introduction of HPV vaccination were associated temporally with a persistent increase in awareness of the link between HPV and cervical cancer, although awareness did not rise among less educated and minority women (22). In contrast, in interviews conducted soon after vaccine introduction, Marlow, Waller, and Wardle found that although awareness of HPV as a cause of cervical cancer had tripled since 2002, it remained only 2.5%, and few women understood the sexually transmitted nature of HPV infection (23). Like us, Hughes and associates similarly found that minority women were less aware of HPV vaccine and that advertising played a large role in HPV vaccine awareness, but they also found that clinicians and internet were women's preferred sources (24).

Our study was limited by lack of a control group that did not receive education about cervical cancer risks and screening, omitted for ethical reasons in a population at high risk for cervical cancer with a history of noncompliance with colposcopy. We also could not determine whether improvements in knowledge were due to passive testing effects from repeated exposure to the same questions. However, the two-year lag between questionnaires may minimize testing effects. Our multivariable model, with an R2 of only 0.35, indicates that unmeasured factors accounted for 65% of the improvement in knowledge between 2006 and 2008. We could not determine the relative contribution of staff educational interventions, mass media coverage, advertising, and other sources. Finally, women who completed questionnaires at follow-up may have known more about cervical cancer prevention and HPV than those who did not, skewing scores upward in ways we cannot define.

Several years after the introduction of HPV vaccination, significant gaps persist in women's understanding of cervical cancer prevention, HPV, and HPV vaccination. Clinician education, news and advertising messages, and our directed educational intervention have led to improvements in these areas, but improvements are weakest in knowledge about cervical cancer prevention in general. Low income women and those with lower reading skills may require specific targeted interventions, perhaps using nontraditional media such as video or internet based programs, and trials of interventions for these women are indicated.

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Precis

Between 2006 and 2008, women's knowledge of cervical cancer prevention and human papillomavirus improved, although substantial gaps remain.

Table 1

Baseline demographic and medical characteristics of women who completed questionnaires at baseline and follow-up (n=1121). N (%)

	HIV+	HIV−	P-value[1]	Missing	p-value
	N=773	N=348			
Age at interview (years)					
<30	44 (5.7)	63 (18.1)	<0.0001		
30-39	198 (25.6)	113 (32.5)			
40-49	332 (43.0)	111 (31.9)			
50+	199 (25.7)	61 (17.5)			
Ethnicity					
Non-Hispanic African American	497 (64.3)	219 (62.9)	0.01		
Hispanic	139 (18.0)	84 (24.2)			
Non-Hispanic White	110 (14.2)	30 (8.6)			
Other	27 (3.5)	15 (4.3)			
Average annual household income (n=1062)					
<=$6,000	121 (16.4)	79 (24.3)	0.02		
$6,001-$12,000	216 (29.3)	80 (24.6)			
$12,001-$18,000	105 (14.3)	41 (12.6)			
$18,001+	295 (40.1)	125 (38.5)			
Education level (n=1119)					
Less than high school	249 (32.3)	116 (33.4)	0.26		
Completed high school	234 (30.3)	118 (34.0)			
Some College/College degree	289 (37.4)	113 (32.6)			
Site/Location					
Bronx	116 (15.0)	65 (18.7)	0.0009		
Brooklyn	215 (27.8)	73 (21.0)			
Washington DC	124 (16.0)	47 (13.5)			
Los Angeles	84 (10.9)	62 (17.8)			

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	HIV+	HIV−	P-value[1]	Missing	p-value
San Francisco	110 (14.3)	60 (17.2)			
Chicago	124 (16.0)	41 (11.8)			
Alcohol use					
Abstainer	462 (59.8)	165 (47.4)	<0.0001		
Light (<3 drinks/wk)	225 (29.1)	111 (31.9)			
Moderate/Heavy (3+ drinks/wk)	86 (11.1)	72 (20.7)			
Current Smoker	337 (43.6)	171 (49.1)	0.08		
Injection drug use status					
Current user	13 (1.7)	7 (2.0)	0.003		
Former user	187 (24.2)	53 (15.2)			
Never	573 (74.1)	288 (82.8)			
Non-Injection drug use status					
Current user	177 (22.9)	116 (33.3)	0.0002		
Former user	395 (51.1)	171 (47.1)			
Never	201 (26.0)	61 (17.5)			
English WRAT[2] score (number of words pronounced correctly) (n=898)					
Mean	28.9	28.7	0.80[3]		
Median	31.0	29.0	0.56[4]		
Range	3 - 42	8 - 42			
Lifetime nadir CD4 lymphocyte count (cells/cmm) (n=773)					
<200	355 (45.9)				
200-500	357 (46.2)				
>500	61 (7.9)				
CD4 lymphocyte count (cells/cmm) at visit (n=773)					

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	HIV+	HIV−	P-value[1]	Missing	p-value
<200	101 (13.1)				
200-500	303 (39.2)				
>500	369 (47.7)				

[1] P-value obtained by using the chi-square test unless otherwise specified.

[2] Wide Range Achievement Test

[3] P-value obtained by using the t-test for means.

[4] P-value obtained using the Wilcoxon rank-sum test.

P-value comparing missing to all those who completed entire survey.

Table 2

Percentage of correct responses to questions about vaccination against the human papillomavirus (HPV) at baseline and follow-up. (n=1,121)

	Correct Answer		
Question	Baseline	Follow-up	McNemar's test p-value
Have you heard about an HPV vaccine called Gardasil?	45.1%	65.9%	<0.0001
What do you think the vaccine is meant to prevent?			
Abnormal Pap tests, cervical cancer and precancer	66.0%	72.9%	<0.0001
Lung infections	63.8%	71.0%	<0.0001
Urine infections	54.4%	62.5%	<0.0001
Warts around the genitals and anus	34.4%	38.8%	0.01
Genital herpes	38.7%	43.7%	0.006
For women with HIV, what are recommendations for HPV vaccination?	74.2%	71.4%	0.09
Among women without HIV, who should get the HPV vaccine?			
Girls as young as 9 years of age	28.0%	38.5%	<0.0001
Teenage and young adult women	67.1%	79.0%	<0.0001
Women over 25 years who are at high risk	9.3%	14.6%	<0.0001
Women 50 years of age and older	21.6%	33.8%	<0.0001

Table 3

Regression coefficients for ANCOVA models among participants completing questionnaires assessing cervical cancer prevention knowledge, assessing association between follow-up knowledge score and other factors.

	Model 1 N=1121	**Model 2 N=1056**	**Model 3 N=897**
Adjusted R [2]	0.32	0.33	0.35
F-Value	66.1[1]	57.97[1]	48.1[1]
Predictor variables			
Intercept	7.43 (6.00 – 8.87)[1]	4.95 (3.15 – 6.75)[1]	3.63 (1.64 – 5.62)[1]
Total baseline score	0.44 (0.40 – 0.49)[1]	0.42 (0.37 – 0.47)[1]	0.41 (0.36 – 0.46)[1]
HIV seropositive (vs negative)	0.35 (−0.23 – 0.93)	0.34 (−0.25 – 0.93)	0.52 (−0.10 – 1.15)
Age at visit	−0.03 (−0.06 – −0.001)[2]	−0.01 (−0.04 — 0.02)	−0.007 (−0.04 — 0.02)
Education (vs less than High school)			
High school	0.88 (0.22 – 1.53)[3]	0.74 (0.08 – 1.41)[2]	0.30 (−0.41 – 1.02)
College	1.57 (0.89 – 2.24)[1]	1.22 (0.51 – 1.92)[1]	0.62 (−0.15 – 1.39)
Income > $18,000 (vs <$18,000)	1.03 (0.46 – 1.60)[1]	0.78 (0.20 – 1.37)[2]	0.68 (0.07 – 1.29)[2]
Drug use (vs never used)			
Former user	0.73 (0.06 – 1.39)[2]	0.66 (−0.01 – 1.34)	0.55 (−0.16 – 1.25)
Current user	0.75 (−0.01 – 1.50)	0.63 (−0.14 – 1.40)	0.28 (−0.53 – 1.09)
Symbol digit		0.06 (0.03 – 0.08)[1]	0.04 (0.01 – 0.07)[2]
WRAT[4]			0.09 (0.04 – 0.13)[1]

[1] P ≤ 0.001

[2] P ≤ 0.05

[3] P ≤ 0.01

[4] Wide Range Achievement Test