Published in final edited form as:

Am J Health Educ. 2013 ; 44(6): 293–298. doi:10.1080/19325037.2013.838881.

Factors Associated With Adherence to Follow-up Colposcopy

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Abstract

Background—Understanding the gaps in knowledge about human papilloma virus (HPV) infection, transmission, and health consequences and factors associated with the knowledge gap is an essential first step for the development of interventions to improve adherence to follow-up among women with abnormal Pap smears.

Purpose—To examine the relationship between knowledge about HPV and adherence to scheduled colposcopic evaluation and variables related to lack of knowledge among women with abnormal Pap tests.

Methods—Telephone surveys were conducted with women who attended their scheduled appointments (adherers) and women who did not attend their appointments (nonadherers).

Results—The multivariable analyses indicate that lower HPV knowledge was independently associated with nonadherence to follow-up, controlling for race and education level. Factors related to lower knowledge scores included non-white race, lower education, and lack of health insurance at the time of the scheduled appointment.

Conclusion—Lack of knowledge of HPV was related to nonadherence among women scheduled for colposcopic evaluation.

Translation to Health Education Practice—Health education interventions that deliver complex information about HPV and cervical cancer should be in a format that is accessible and understandable to the women who are most at risk of being nonadherent.

BACKGROUND

Despite population screening rates greater than 80%, the incidence of cervical cancer among US women remains unacceptably high for a largely preventable cancer.¹ In 2012, an estimated 12 170 cases of invasive cervical cancer were diagnosed, and an estimated 4220 women died.² Cervical cancer occurs due to persistent cervical infection with high-risk human papilloma virus (HPV) genotypes.³ The establishment of the causal link between HPV and cervical cancer and a better understanding of cervical carcinogenesis has helped to guide age-appropriate recommendation for screening and follow-up care to prevent cervical cancer.⁴ With early detection and appropriate follow-up care, the likelihood of survival from cervical cancer is nearly 100%.⁵ Timely diagnostic follow-up of abnormal results and the availability and utilization of treatment services are needed to effectively reduce invasive cervical cancers.⁶

Poor adherence to follow-up after abnormal Pap tests has been reported to be associated with younger age,^{7–10} African American race/ethnicity,^{7,11,12} lack of health insurance,^{10,13,14} less knowledge about HPV, and psychological distress.^{7–9,15–17} To develop effective interventions to improve adherence to follow-up, more research is needed to identify individual factors potentially amenable to intervention. Generally, knowledge of HPV transmission and prevention among women in the United States is poor.¹⁸ Few studies have examined specific gaps in HPV knowledge or predictors of lack of knowledge of HPV among women in general or among women with abnormal Pap tests.^{19,20} Understanding the gaps in knowledge about HPV infection, transmission, and health consequences and factors associated with the knowledge gap is an essential first step for the development of interventions to improve adherence to follow-up among women with abnormal Pap smears.¹⁹ Information alone is insufficient to effect meaningful behavior change; however, basic knowledge of HPV transmission and prevention is a critical building block in any health education efforts to improve adherence among women requiring follow-up to an abnormal Pap test.

PURPOSE

In this article, we examine the relationship between knowledge about HPV transmission and adherence to scheduled follow-up among women with abnormal Pap tests and compare specific gaps in knowledge between women who were adherent and nonadherent to recommended follow-up. In addition, we examined the relationship between demographic variables and lack of knowledge among women with an abnormal Pap smear.

METHODS

The women included in this analysis were a subset of the women who were asked to participate in the Cervical Intraepithelial Neoplasia Cohort Study at Duke University in Durham, North Carolina. The Cervical Intraepithelial Neoplasia Cohort Study is a

prospective cohort study that is examining predictors of progression or regression of cervical intraepithelial neoplasia. The study includes women who had cervical cytopathology (Pap) testing at 1 of 10 clinics that are part of the Duke University Health System, had a diagnosis of dysplasia or low-grade squamous intraepithelial lesion, and were scheduled for a follow-up visit at 1 of 4 colposcopy clinics. In accordance with Duke University Health System policy, women with a Pap test requiring follow-up were sent a letter by certified mail informing them of the result and called by the clinic staff to schedule an appointment at a colposcopy clinic. For the present study, women were identified through the electronic clinic appointment logs. In addition to the diagnostic eligibility criteria, women had to be 18 years of age or older, speak English or Spanish, and be mentally competent to give informed consent. Women who attended their scheduled appointment were identified as adherers and women who did not attend their appointments were identified as nonadherers. Interviewers contacted all adherers and nonadherers by telephone after the scheduled appointment to obtain verbal consent and complete the 15-minute telephone survey. The consent script and survey were translated into Spanish and a staff member fluent in Spanish conducted the telephone interviews with Spanish-speaking participants. Initially, all women were offered a \$10 retail gift card as an incentive to complete the survey. To effectively recruit nonadherers, the incentive was increased to \$25. All study procedures were approved by both the Duke University Medical Center and North Carolina Central University institutional review boards. Recruitment took place between January 2011 and January 2012.

Data Collection

The adherence survey included questions on depression, access and barriers to care, knowledge of HPV and cancer, worry about cervical cancer, and perceived health status. Depression symptoms were measured using the 10-item Center for Epidemiological Studies Depression (CES-D) scale.²¹ A score of 10 or higher is considered to be associated with significant depressive symptoms. Knowledge of HPV transmission, symptoms, complications, and treatment was assessed using a 16-item instrument developed for this study based on the Health Information National Trends Survey²² and a previously published HPV knowledge scale.²³ Examples of items include “HPV can cause cervical cancer,” “HPV can cause genital warts,” “You can get HPV through sexual contact,” and “HPV is rare.” Participants were asked whether they thought each statement was true or false and responses were coded as correct or incorrect. Overall knowledge scores were computed as the percentage of correct answers, with “don’t know” responses coded as incorrect. Perceived health status was measured with 1 item, “How would you describe your current health?” with responses excellent, very good, good, fair, and poor.

Survey data were double entered and analyzed using SAS, Version 9.2 (SAS Institute Inc. Cary, NC, 2010) (PC). We performed statistical analyses comparing women who were adherers and nonadherers and those with high and low knowledge scores using chi-square and Fisher’s exact tests for categorical variables and Student’s *t* test for continuous variables. Logistic regression modeling was performed first to identify predictors of adherence and then to identify predictors of higher knowledge scores. Variables that were

statistically significantly associated with the outcome variables in bivariate analyses were included in the multivariable models.

RESULTS

A total of 586 women (285 adherers and 301 nonadherers) were approached and 92 adherers (32%) and 92 nonadherers (31%) completed the survey. The mean age of the total sample was 29.8 years (range 21–64). The majority of the sample was non-white (57%) and most (80%) of the non-white participants were African American. Fifty-nine percent of the women had completed high school and 78% were not married or living as married. Seventy-one percent of the sample reported having health insurance (private or Medicaid). One quarter (25%) screened positive for depression on the CES-D scale and 49% reported being in excellent or very good health.

There were significant differences between women who returned for a follow-up (adherers) and those who had not (nonadherers; Table 1). In bivariate analysis, the nonadherers were more likely to be non-white ($P = .007$), have less than high school education ($P < .0001$), report lower perceived health status ($P = .002$), and have a CES-D depression score higher than 10 ($P = .04$). Nonadherers were more likely to have Medicaid or no health insurance compared to adherers ($P < .0001$). The average knowledge score (percentage correct) was significantly lower among nonadherers compared to those who were adherent (56% and 75%, respectively; $P < .0001$). In the multivariable adjusted analysis, factors that were significantly associated with nonadherence were being non-white (odds ratio [OR] = 3.7, 95% confidence interval [CI], 1.3–10.1), having less education (OR = 6.6, 95% CI, 2.3–19.4), and scoring below the mean on the knowledge questions (OR = 1.16, 95% CI, 1.004–1.33). Perceived health status was not a significant predictor of adherence (OR = 0.6, 95% CI, 0.23–1.6; data not shown).

Overall, women in this sample answered 67% of the HPV knowledge questions correctly (Table 2). When examining responses to individual questions, we observed that the nonadherent women had a lower proportion of correct answers for each of the 16 items on the scale, with statistically significant differences for 11 of the 16 items. The knowledge gaps were apparent for questions on diseases related to HPV as well as questions about modes of transmission. Though the lack of knowledge was more prominent for women who did not adhere to the recommended follow-up appointment, it is noteworthy that the adherent women also had a high proportion of incorrect answers, especially for the questions about diseases related to HPV infection.

We examined predictors of HPV knowledge by comparing women who scored below and above the median percentage of correct answers. In bivariate analysis, non-white race ($P = .003$), lower education ($P < .0001$), worse perceived health status ($P = .003$), and lack of health insurance ($P = .006$) were related to knowledge (Table 3). Variables that were significantly associated with knowledge in the bivariate analyses were entered into a logistic regression model. In the multivariable adjusted analysis, factors statistically significantly associated with having low HPV knowledge scores were being non-white (OR = 2.9, 95% CI, 1.4–6.0) and having less education (OR = 4.6, 95% CI, 2.1–9.8; data not shown).

DISCUSSION

Our analyses show that knowledge scores on a series of questions about HPV and its transmission were lower among women with an abnormal Pap test who were nonadherent to the recommended follow-up colposcopy visit compared to women who were adherent. The multivariable analyses indicate that lower HPV knowledge was independently associated with nonadherence to follow-up, controlling for race and education level. In analyses that examined characteristics associated with lower knowledge scores, statistically significant predictors were non-white race and lower education.

Our findings are consistent with previous studies that demonstrate that lower knowledge scores predict nonadherence to recommended follow-up after abnormal Pap testing.^{20,24} The continued high rate of nonadherence to follow-up after Pap tests and the substantial knowledge deficits suggest the need for improved health education among women who are screened for cervical cancer. Previous studies have shown that patients who do not understand their initial Pap results are more likely not to comply with diagnostic testing.²⁵ Though health education alone is not sufficient for improving follow-up to abnormal Pap smear, decreasing the knowledge gap regarding HPV and cervical cancer is a necessary first step toward improving adherence.

Health education interventions to improve adherence with follow-up to abnormal Pap smears, including telephone counseling, reminder calls, written educational materials, and physician letters, have had modest effects on adherence.²⁶ Data from our study suggest that written materials may not be the optimal way to reach the women most likely to be nonadherent to recommended Pap screening follow-up. In our sample, nearly two thirds of the women who were nonadherent to the recommended follow-up had less than a high school education, compared to only 16% of the women who were adherent. It has been shown that average reading levels are actually lower than the last completed grade.²⁷ Thus, health education materials written at an eighth-grade level may still be too complex for the women most at risk of nonadherence to follow-up recommendations. Further, women with limited reading skills may be disinclined to pick up and read health information brochures.

Regardless of the format of health communication, communicating information about possible outcomes for Pap tests and recommendations for follow-up is particularly complicated. At the time of screening, women need to be made aware that possible outcomes of a Pap screening test are (1) a normal test with no evidence of disease, (2) a diagnosis that requires prompt treatment but may or may not be cancer, or (3) a diagnosis that requires follow-up as in another test to determine the next step. Effective health communication interventions for women with abnormal Pap smears should convey information simply and clearly. Messages should be persuasive enough to convince women of the importance of follow-up evaluation while at the same time minimizing anxiety and distress.²⁸

When interpreting the results, it is important to consider several limitations. First, we were able to complete the survey related to adherence factors on a much smaller proportion of the nonadherers (56%) than the adherers (95%). Although we have no information from the

nonrespondents, if the nonrespondents among the nonadherent women were even more likely to have lower education and no health insurance, our results might have been even more striking. Additionally, our analysis does not include other psychosocial factors that are likely related to nonadherence such as fear or worry, and previous research suggests that anxiety and distress also play a significant role in nonadherence.²⁹

TRANSLATION TO PUBLIC HEALTH PRACTICE

Our data show that women who are most at risk have the greatest lack of knowledge about HPV, and the relationship to cervical cancer and lack of knowledge is associated with poor adherence to recommended follow-up. Adherence to follow-up recommendations is essential to the overall prevention of invasive cervical cancer. Though knowledge alone is insufficient for behavior change, it is necessary for women at risk to have a basic understanding of the problem before they can take any preventive action. Health education interventions that deliver complex information about HPV and cervical cancer should be in a format that is accessible and understandable to the women who are most at risk of being nonadherent.

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TABLE 1

Characteristics of Women Who Were Adherent or Nonadherent to Recommended Follow-up of Abnormal Pap Test^a

	Total (n = 184) Mean (SD)	Nonadherers (n = 92) Mean (SD)	Adherers (n = 92) Mean (SD)	P value
Age (range 21–58 years)	29.8 (8.4)	28.8 (8.4)	30.9 (9.5)	.08
Knowledge score (range 0–100)	66.8 (23.4)	57.9 (24.9)	75.8 (18.1)	<.0001
	N (%)	N (%)	N (%)	
Race				
White	80 (43)	31 (34)	49 (53)	.007
Non-white	104 (57)	61 (66)	43 (47)	
Education				
Less than high school	74 (40)	56 (61)	18 (20)	<.0001
High school or more	109 (60)	36 (39)	73 (80)	
Marital status				
Married/living as married	41 (22)	21 (23)	20 (22)	.85
Not married or living as married	143 (78)	71 (77)	72 (78)	
Health insurance				
Private	54 (29)	9 (10)	52 (57)	<.0001
Medicaid	69 (38)	51 (55)	18 (20)	
None	61 (33)	32 (35)	22 (24)	
Perceived health				
Excellent/very good	89 (48)	34 (37)	55 (60)	.002
Good/fair/poor	95 (52)	58 (63)	37 (40)	
CES-D (depression) score				
10	138 (75)	63 (68)	75 (82)	.04
> 10	46 (25)	29 (32)	17 (18)	
Worry (1–4)		3.0	3.2	.5
Distress: Tension and discomfort (1–4)		1.8	1.7	.5
Distress: Embarrassment (1–4)		1.5	1.4	.25
Distress: Sexual and reproductive consequences (1–4)		1.6	1.6	.8
Distress: Health concerns (1–4)		2.0	1.9	.6
Pain (1–10)		4.1	4.3	.5

^a CES-D indicates Center for Epidemiological Studies Depression Scale. One participant did not provide data on education

TABLE 2

Response of HPV Knowledge Questions Among Women Who Were Adherent or Nonadherent to Recommended Follow-up of Abnormal Pap Test^a

HPV Knowledge Questions (Correct Answer)	% Incorrect	% Correct	% Don' Know	P Values
HPV can cause cervical cancer (true)				
Adherers	2	89	9	.33
Nonadherers	1	84	15	
HPV infection is rare (false)				
Adherers	15	79	6	<.0001
Nonadherers	22	53	25	
HPV can cause genital warts (true)				
Adherers	18	64	18	.001
Nonadherers	17	40	43	
HPV can cause herpes (false)				
Adherers	29	47	24	.005
Nonadherers	25	29	46	
You can get HPV through sexual contact (true)				
Adherers	2	94	4	<.0001
Nonadherers	12	65	23	
HPV can be cured (false)				
Adherers	26	59	15	.0001
Nonadherers	37	29	34	
HPV can cause penile cancer in men (true)				
Adherers	16	38	46	.17
Nonadherers	22	25	53	
Condoms completely protect against HPV (false)				
Adherers	26	64	10	.17
Nonadherers	24	59	17	
A person may be infected with HPV and not know it (true)				
Adherers	1	97	2	.04
Nonadherers	0	89	11	
Regular pap tests can help to prevent complications (true)				
Adherers	1	96	3	.08
Nonadherers	0	89	11	
Men can carry HPV (true)				
Adherers	2	86	12	<.0001
Nonadherers	8	52	40	
<i>HPV Transmission Questions</i>				
A person gets HPV from sharing a plate, fork, or glass with someone who has HPV (false)				
Adherers	8	88	4	.06
Nonadherers	9	77	14	
A person gets HPV from unprotected sexual intercourse with someone who has HPV (true)				

HPV Knowledge Questions (Correct Answer)	% Incorrect	% Correct	% Don' Know	P Values
Adherers	1	97	2	<.0003
Nonadherers	8	77	15	
A person gets HPV from oral sex with someone who has HPV (true)				
Adherers	10	72	18	.05
Nonadherers	17	54	29	
A person gets HPV from kissing, with exchange of saliva, with someone who has HPV (false)				
Adherers	19	62	20	.26
Nonadherers	23	50	27	
A person gets HPV from sharing a toilet or shower with someone who has HPV (false)				
Adherers	11	82	8	.19
Nonadherers	13	71	16	

^aHPV indicates human papilloma virus.

TABLE 3**Bivariate Associations With HPV Knowledge Score**

	Not Low Knowledge (n = 97)	Low Knowledge (n = 87)	P value
	Mean (SD)	Mean (SD)	
Age (mean)	30.2 (9.0)	29.4 (7.7)	.51
	<i>N (%)</i>	<i>N (%)</i>	
Race			
White	54 (56)	26 (30)	.0004
Non-white	43 (44)	61 (70)	
Education			
Less than high school	19 (20)	55 (63)	<.0001
High school or more	80 (80)	32 (37)	
Marital status			
Married/living as married	22 (23)	19 (22)	.89
Not married or living as married	75 (77)	68 (78)	
Health insurance			
Private	49 (50)	12 (14)	<.0001
Medicaid	24 (25)	45 (52)	
None	24 (25)	30 (34)	
Perceived health			
Excellent/very good	56 (58)	33 (38)	.007
Good/fair/poor	41 (42)	54 (62)	
Brief CES-D (depression)			
10	75 (77)	63 (72)	.44
>10	22 (23)	24 (28)	

HPV indicates human papilloma virus; CES-D, Center for Epidemiological Studies Depression scale. One participant did not provide data on education.