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Development of an HPV Educational Protocol for Adolescents

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Abstract

Study Objectives—To develop an educational protocol about HPV and Pap tests for adolescents, to evaluate the protocol for understandability and clarity, and to evaluate the protocol for its effectiveness in increasing knowledge about HPV.

Design— In phase 1, investigators and adolescents developed the protocol. In phase 2, adolescents evaluated the protocol qualitatively, investigators evaluated its effectiveness in increasing HPV knowledge in a sample of adolescents, and the protocol was revised. In phase 3, investigators evaluated the effectiveness of the revised protocol in an additional adolescent sample.

Setting— Urban, hospital-based teen health center.

Participants— A total of 252 adolescent girls and boys in the three study phases.

Main Outcome Measures— Pre- and post-protocol knowledge about HPV, measured using a 10- or 11-item scale.

Results— Scores on the HPV knowledge scale increased significantly ($p<.0001$) among adolescents who participated in phases 2 and 3 after they received the protocol. Initial differences in scores based on race, insurance type and condom use were not noted post-protocol.

Conclusion— The protocol significantly increased knowledge scores about HPV in this population, regardless of sociodemographic characteristics and risk behaviors. Effective, developmentally appropriate educational protocols about HPV and Pap tests are particularly important in clinical settings as cervical cancer screening guidelines evolve, HPV DNA testing is integrated into screening protocols, and HPV vaccines become available. In-depth, one-on-one education about HPV may also prevent adverse psychosocial responses and promote healthy sexual and Pap screening behaviors in adolescents with abnormal HPV or Pap test results.

Synopsis— The investigators developed an educational protocol about HPV and Pap tests and evaluated its effectiveness in increasing knowledge about HPV among adolescents.

Keywords

Education; Human Papillomavirus (HPV); Pap tests; Adolescents

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Introduction

Human papillomavirus (HPV) is one of the most common sexually transmitted infections (STI) in the U.S. Adolescents are at high risk for HPV infection: cumulative prevalence rates up to 82% have been reported in sexually active adolescent girls.(1) Although HPV infection is often transient due to the host immune response, persistent viral replication may lead to genital warts, abnormal Papanicolaou (Pap) tests, cervical dysplasia, and cervical cancer.(2) Infection with HPV is also associated with vulvar, anal, penile, oropharyngeal and esophageal carcinomas. A positive test for high-risk (cancer-associated) HPV types is highly sensitive for the detection of cervical dysplasia, due to the etiologic role of HPV in the development of cervical cancer. HPV DNA testing recently has been incorporated into guidelines for primary cervical cancer screening in women older than 30 years of age, and follow-up of adolescent and adult women with abnormal cervical cytology and cervical dysplasia.(3–8)

Despite its high prevalence and potentially serious consequences, adolescent and young adult women demonstrate poor understanding of HPV and Pap tests. (9–14) This lack of knowledge may lead to significant psychosocial distress in women diagnosed with HPV or abnormal Pap tests, including fear and anxiety. Research suggests that these types of negative responses could decrease follow-up for diagnostic or treatment procedures.(13,15–18) Education may prevent or alleviate psychosocial distress by addressing women's concerns about HPV.(19) Finally, HPV vaccines have been developed that target the HPV types most commonly associated with cervical cancer, genital warts, or both. The Food and Drug Administration (FDA) recently approved an HPV-6,11,16,18 vaccine for use in girls and women 9 to 26 years of age. Although parents will likely be the primary decision-makers regarding vaccination in preadolescents, older adolescents and young women will hold some or all of the responsibility for making decisions about vaccination. Lack of knowledge about HPV may make it difficult for these young women to make appropriate decisions.(20)

Existing educational materials about HPV and Pap tests generally consist of pamphlets or documents, some of which are available on the internet. These include materials available on the websites of the Centers for Disease Control and Prevention (http://www.cdc.gov/std/HPV/, accessed 12/11/06), the American Social Health Association (http://www.ashastd.org/hpv/hpv_overview.cfm, accessed 12/11/06), the American College of Obstetricians and Gynecologists (http://www.acog.org/departments/dept_notice.cfm?recno=7&bulletin=3097, accessed 12/11/06), and others. These materials can provide basic information about HPV to large numbers of women; however, they are limited in that they cannot provide in-depth information that is individualized to women with specific test results or educational needs. In addition, most resources were developed for adult women, and may not be developmentally appropriate for adolescent populations. Age-appropriate educational protocols are urgently needed for HPV education in clinical or research settings, where one-on-one, interactive counseling occurs both before and after HPV or Pap testing. Furthermore, many women prefer face-to-face interaction with a provider for education about HPV because it ensures privacy, provides an opportunity to ask the provider questions, and enables them to receive information from a trusted, reliable source.(17) Finally, existing information is of varying quality and its effectiveness in increasing knowledge about HPV is largely untested and unknown. Therefore, the aims of this study were: 1) to develop an educational protocol about HPV for adolescents that could be used for individual HPV counseling in clinical or research settings, 2) to evaluate the protocol for understandability and clarity, and 3) to evaluate the protocol for its effectiveness in increasing knowledge about HPV infection and Pap tests.

Materials and Methods

The HPV educational protocol was developed in three phases. Approval was obtained for each phase from the hospital's Institutional Review Board. Written informed consent was obtained from participants ≥ 18 years of age, and from parents of participants who were < 18 years of age. Participants < 18 years of age provided assent to participate.

In phase 1, a group of five experts in adolescent medicine, adolescent gynecology, and HPV (including research faculty, physicians, and nurse practitioners) met to discuss the content and format of the protocol. The decision was made to include information about the virology and natural history of HPV infection and abnormal Pap tests, transmission of HPV, clinical sequelae of HPV, and prevention of HPV infection and HPV-related diseases. The protocol was arranged as a two-booklet set; one booklet for the patient containing pictures, diagrams, and key phrases, and one booklet containing a script for the educator. The booklets were designed so that the educator followed the script while the participant looked at corresponding brief phrases, diagrams, and photographs. Although the protocol was designed so the brief phrases could be read by an adolescent who had attained a fourth or fifth grade reading level, reading skills were not necessary to benefit from the protocol because the educator restated what was written. The protocol took approximately 10–15 minutes to administer. In order to evaluate the protocol for understandability and clarity, it was reviewed in depth by a Teen Advisory Board consisting of patients of the Teen Health Center at Cincinnati Children's Hospital Medical Center. The fifteen members of the Teen Advisory Board critiqued the protocol for understandability and relevance. The protocol was then revised based upon their comments and brought back to the group for a second evaluation and revision.

In phase 2, the revised protocol was evaluated in a cohort study of 121 sexually active adolescent girls recruited from an urban, hospital-based teen health center. Details of patient recruitment have been described previously.(15) The study involved both quantitative and qualitative data collection. Participants first completed a survey assessing sociodemographic factors, sexual history and knowledge about HPV. The knowledge assessment consisted of 11 true or false questions related to HPV transmission, sequelae and risk factors for infection. These items were developed previously by the investigators.(21) The educational protocol was then administered by one investigator to all participants and the knowledge items were completed a second time, immediately after the protocol. Participants returned two weeks later and completed the knowledge scale a third time to assess retention of knowledge.

Descriptive and univariate analyses were used to examine the participants' change in knowledge after receiving the educational protocol. First, the 11 items were summed to create a total knowledge score. Three knowledge scores were calculated: before the educational protocol (pre-protocol), after the educational protocol (post-protocol) and at the two week follow-up visit. The mean values for the individual items comprising each knowledge scale and for the 11-item scale were calculated. The mean values both for individual items and scale scores were compared (pre-protocol vs. post-protocol, post-protocol vs. two week follow-up visit) using paired t-tests, in order to evaluate whether baseline knowledge improved significantly after the educational protocol was administered, and whether this increase in knowledge was sustained two weeks later.

Fifty of the 121 subjects also participated in a semi-structured interview to collect additional qualitative data about the understandability and clarity of the educational protocol. Four questions were asked: 1) What information from the protocol stands out in your mind/made an impression on you? 2) What new information did you learn that you didn't know before? 3) Is there anything you learned that was different from something you heard before? 4) Do you have any suggestions for improving or changing the protocol? Participants' responses were

documented on a standardized form. The investigators first reviewed all responses, then met to reach consensus about the key ideas and recurrent themes. Direct quotations were placed into a master chart consisting of theme headings. The team met twice to review the chart and reach consensus on themes and placement of quotations. The investigators then revised the educational protocol based upon the qualitative interview data, the quantitative data concerning knowledge at the pre-, post- and two-week follow-up visits, and a review of existing educational materials and Internet-based resources about HPV. The knowledge scale was modified slightly by dropping one item related to risk of cancer, based on feedback from participants that it was confusing.

In phase 3, the revised educational protocol was tested in an additional adolescent sample, 116 sexually active adolescent girls from the same clinic population who received the educational protocol one-on-one in a clinical setting. They completed a pre- and post-protocol knowledge assessment consisting of 10 true-false questions related to HPV, and a survey assessing sociodemographic factors, sexual history, and knowledge about HPV. Finally, we explored the utility of the protocol in a classroom setting. The protocol was adapted for use in a group of 48 male and female peer educators participating in an established school-based sexuality education program. They completed a pre- and post-knowledge assessment as well. Mean values for each item and scale were calculated and a paired t-test was used to compare the results of the pre-to post-protocol knowledge assessment for participants in phase 3 as well as the exploratory study of peer educators.

Using data from phases 2 and 3, univariate methods were used to examine associations between HPV knowledge scores or change in knowledge (pre- vs. post-protocol) and the following variables: sociodemographic characteristics (race, age), self-reported risk behaviors (e.g. condom use), self-reported history of STI (e.g. any STI, Chlamydia, gonorrhea, and genital warts) and history of an abnormal Pap test. Wilcoxon rank-sum tests were used to assess associations between knowledge and dichotomous variables and one-way analysis of variance (ANOVA) to assess associations between knowledge and categorical variables.

Results

The mean age of the participants in phase 2 was 17.8 (SD, 1.9, range 13–21) years. Ninety-eight (82%) of the participants self-identified as black, 15 (13%) as white, and one participant reported Latino ethnicity. Of the 121 adolescents, 90 (74%) reported having Medicaid health insurance, while 19 (16%) reported having private insurance. Mean age of first sexual intercourse was 14.3 (SD 2.0) years and mean number of lifetime sexual partners was 5.7 (SD 5.9). Eighty-four (69%) of the participants indicated they used a condom the last time they had sexual intercourse. Of the participants in phase 2, 81 (67%) reported a previous history of an STI, including 47 (39%) reporting Chlamydia and 7 (6%) with genital warts.

Knowledge about HPV before and after the educational protocol in phase 2 is shown in the Table. The percentage of items answered correctly increased from 63% to 87%, a statistically significant difference. The percentage of items answered correctly fell slightly to 82% at the two week follow-up visit. This value was significantly higher than the percentage responding correctly at the pre-protocol visit, but was not significantly different from the percentage responding correctly at the post-protocol visit, indicating that participants retained knowledge over the two week period.

Qualitative data was collected in phase 2 to assess participants' understanding of the protocol and suggestions for improvement. Analysis of participant responses demonstrated that they had little baseline knowledge about HPV but were eager to learn more about HPV and found the protocol to be an effective mechanism for increasing their knowledge. The images included

in the protocol, particularly those of genital warts, had a significant impact on participants. When asked how the protocol could be improved, participants suggested that more pictures were needed because they were a highly effective way to convey information to adolescents and to emphasize that the consequences of infection could be serious. Information concerning the natural history and management of HPV infection was new to most adolescents. For instance, some participants mistakenly believed that HPV infection and genital warts could be treated using antibiotics or over-the-counter creams. Most participants were surprised to learn that HPV was associated with genital warts and cervical cancer. Even those who had heard of HPV in sexuality education classes or from health care providers reported that the link between HPV and cervical cancer had not been made clear to them from previous educational or clinical experiences. The information concerning transmission of HPV also made a substantial impression on the participants, particularly the fact that condoms do not completely protect women from HPV acquisition. Participants suggestions for changes to the protocol included adding advice to postpone sexual involvement and stressing the importance of talking to sexual partners about their history of sexual involvement or STIs.

Univariate analyses for phase 2 demonstrated that pre-protocol knowledge scores did not differ by age, history of an STI, or history of an abnormal Pap test. However, knowledge scale scores pre-protocol were significantly higher in white compared to black participants (mean score 7.87 vs. 6.79, p=.014), those with private compared to Medicaid insurance (mean score 7.89 vs. 6.73, p=.003), and those who did not use condoms at last sexual intercourse compared to those who did (mean score 7.38 vs. 6.75, p=.027). In contrast, knowledge scores post-protocol did not differ by sociodemographic factors, self-reported behaviors, or history of STI.

The mean age of the participants in phase 3 was 17.7 (SD, 1.8, range 14–21 years). Of the 116 participants, 94 (81%) reported they were black, 18 (16%) white, and 5 (4%) Latino. Sixty-nine (60%) reported a previous STI, with 57 (49%) reporting a history of Chlamydia and 5 (4%) a history of genital warts. The results of the pre- and post-protocol knowledge assessments in phase 3 were similar to those for phase 2 (Table). The percentage of knowledge items answered correctly increased significantly pre- to post-protocol (72% to 91%, p<.0001). Knowledge level before and after the educational protocol was not associated with specific sociodemographic characteristics, self-reported risk behaviors or history of STIs. For the exploratory study of peer educators, this percentage increased from 76% pre-protocol to 86% post-protocol (p<.0001).

Analysis of individual knowledge items demonstrated that almost all participants in phases 2 and 3 understood the asymptomatic nature of HPV before the educational protocol. Before receiving the educational protocol, most participants believed incorrectly that HPV could cause problems getting pregnant, and scores for this particular item increased substantially post-protocol. In phase 3, almost all participants knew pre-protocol that HPV was transmitted via sexual contact, and thus scores for this item did not increase as much post-protocol as did scores for participants in phase 2. Finally, in phase 3 participant knowledge regarding treatment of genital warts actually decreased after receiving the protocol, which led to a modification of the protocol.

Discussion

In this study, we developed and tested the effectiveness of a comprehensive, evidence-based HPV educational protocol developed specifically for adolescents. The protocol significantly increased knowledge about HPV among adolescents of varying age, race and gender. We found that prior to receiving the educational protocol, adolescents had fair knowledge of HPV infection, its transmission, and its consequences. Previous studies similarly have demonstrated that most adolescent and young adult women have a poor understanding of HPV. In one study,

87% or high school students had never heard of HPV.(10,11,22) After receiving the educational protocol, knowledge scale scores increased significantly and these changes were sustained after two weeks.

In adolescents participating in the first phase of testing, but not the second, knowledge scale scores were lower before the educational protocol in black compared to white participants, those with Medicaid compared to private insurance, and those who reported using condoms compared to those who did not. The baseline differences by race and insurance status may be related to differences in access to preventive services and education about STIs.(23) The inverse association between condom use and STI knowledge has been noted in other studies.(24) One possible explanation is that adolescents who practice riskier sexual behaviors have received more education about STIs from parents and providers. Differences in knowledge scores before the educational protocol were not noted after participants received the protocol, suggesting that the protocol is effective regardless of adolescent sociodemographic characteristics or risk behaviors.

The incorporation of HPV DNA testing into cervical cancer screening guidelines, along with a growing understanding among providers and adolescents about the link between HPV infection and abnormal Pap tests, presents a challenge to health care providers in terms of patient education about HPV. Many adolescent and young adult women will learn that their abnormal Pap test indicates they have been exposed to an STI or that they are HPV-positive. In preliminary studies of both adults and adolescents, HPV testing has been associated with anxiety, distress, perceived stigma, and fear of further testing and treatment procedures.(13, 15,16,25) These types of responses may adversely impact adolescent decisions about future STI screening and follow-up.(26,27) Our previous work has demonstrated that cognitive understanding of HPV infection and Pap tests is a key factor in predicting psychosocial and behavioral responses to HPV infection and abnormal Pap tests.(15) These responses may be negative, as noted above, but adolescents also report positive responses to test results, including empowerment based on knowledge of test results and intention to practice safer sexual behaviors and return for Pap screening. Providers who educate adolescents effectively about HPV infection may be able to prevent the potentially harmful psychosocial and interpersonal responses to HPV and Pap test results, while promoting healthy sexual behaviors and regular Pap screening. The protocol developed in this study may serve as a tool for providers as they design educational strategies for their patient populations.

Another challenge to health care providers in terms of patient counseling about HPV is the ongoing development of guidelines for cervical cancer screening. Different guidelines from various organizations allow flexibility in decisions about screening and follow-up.(3–7,28) In the context of different and sometimes inconsistent guidelines, some experts have advocated for shared decision-making regarding choices about cervical cancer screening procedures.(18) However, some adolescents may find it difficult to make an informed choice about such a complex issue given their evolving cognitive development, poor understanding of HPV infection, and the psychological implications of positive test results. Educational protocols such as the one developed in this study may help providers to guide adolescents as they participate in decisions about testing.

There are many possible approaches to education about HPV, based on provider and patient preferences as well as educational objectives. Written brochures and internet-based materials are useful for reaching large numbers of women and providing answers to the most commonly-asked questions about HPV. However, most women with positive HPV or abnormal Pap test results will present in clinical settings and require one-on-one education. Some women also prefer to receive information about HPV directly from their providers due to accessibility, trust and privacy issues.(17) These women may benefit from protocols such as the one developed

in this study, which allows clinicians to share information interactively in a private setting. Individualized educational protocols that rely on simple graphics and are delivered in a clinical setting, such as this one, may be particularly useful for adolescent or adult women who have difficulty reading or do not have access to the internet. These women may in fact be at particularly high risk for HPV infection and cervical cancer, given that there are substantial socioeconomic dispartities in cervical cancer screening, incidence, and mortality in the U.S. (29) Finally, protocols such as this may be useful in school-based settings. School health educators may recognize the importance of teaching their students about HPV, but many lack the knowledge and resources to do so.(22) Although developed as a tool for one-on-one education, this protocol was effective in improving knowledge about HPV among a small sample of peer educators involved in a school-based program to postpone sexual initiation. The protocol has since been used in this city-wide program to educate middle school and high school students about HPV infection and its prevention and could serve as a model to develop similar curricula in other schools.

One limitation of this study is that most, but not all, participants were recruited from a hospital-based teen health center. These adolescents were already seeking care, and thus may have had higher baseline knowledge about HPV and more motivation to learn about STIs and/or health-related behaviors than adolescents who were not recruited from a health-care setting. There was not a control or comparison group who received a different protocol with which we could compare this one. Thus, this study cannot demonstrate that this protocol is superior or inferior to other educational interventions. Furthermore, most participants were black and had Medicaid health insurance. Therefore, the results may not be generalizable to adolescents recruited from non-clinical settings or from different racial or socioeconomic backgrounds. Future research should focus on testing the effectiveness of educational protocols such as this in adolescents recruited from other settings. In addition, we were unable to assess whether changes in knowledge were sustained beyond two weeks or translated into healthy attitudes about HPV and Pap testing or safer sexual behaviors. Finally, although the focus of this educational protocol included HPV infection, transmission, clinical consequences and behavioral strategies for prevention, education about HPV vaccines must now be incorporated into educational protocols about HPV. Key information will include data regarding the safety and efficacy of HPV vaccines, recommendations for vaccination, and the importance of safe sexual behaviors and continued Pap screening after vaccination.

Despite these limitations, this protocol may be useful in increasing adolescent knowledge and understanding of HPV infection in both clinical and research settings. The process by which we developed and tested the protocol could be used as a model for the development of other educational interventions for adolescents. Education about HPV, using protocols such as this, is a critical first-line approach to the prevention of HPV infection and HPV-related disease.

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Table

Knowledge about HPV, before and after an HPV educational protocol, in two adolescent samples

Knowledge Item	Second phase of survey development (N=121)			Third phase of survey development (N=116)		
	Pre-protocol mean (SD)[1]	Post-protocol mean (SD)	P value	Pre-protocol mean (SD)	Post-protocol mean (SD)	P value
If a women uses condoms, she is completely protected against HPV	.69 (.47)	.90 (.30)	<.0001	.75 (.44)	.93 (.25)	p<.0001
A person may be infected with HPV and not know it	.99 (.09)	1.00 (.00)	.32	.91 (.28)	.97 (.16)	.04
Most women with HPV have abnormal menstrual periods	.47 (.50)	.79 (.41)	<.0001	.53 (.50)	.86 (.35)	<.0001
HPV is spread from person to person by sexual intercourse	.66 (.48)	.98 (.13)	<.0001	.93 (.25)	.95 (.22)	.04
HPV infection is often found or detected by a Pap test	.91 (.29)	.92 (.28)	.76	.84 (.36)	.92 (.27)	.06
HPV infection can cause problems getting pregnant	.24 (.43)	.92 (.28)	<.0001	.38 (.49)	.95 (.22)	<.0001
Genital warts always go away permanently if a woman gets the right treatment	.75 (.43)	.87 (.33)	.01	.87 (.34)	.76 (.43)	.02
Women with certain HPV types always develop cancer[2]	.33 (.47)	.39 (.49)	.28	N/A	N/A	N/A
HPV infection can be cured with antibiotics	.50 (.50)	.87 (.33)	<.0001	.48 (.50)	.89 (.32)	<.0001
Cigarette smoking increases a woman's chance of getting cervical cancer if she has HPV	.57 (.50)	.95 (.22)	<.0001	.65 (.48)	.97 (.16)	<.0001
Women with HPV may need to get Pap smears more often than those without HPV	.84 (.37)	.98 (.13)	<.0001	.84 (.71)	.88 (.33)	.10
Total Score	**6.96 (1.39)**	**9.57 (1.18)**	**<.0001**	**7.18 (1.5)**	**9.08 (1.1)**	**p<.0001**
Percent answered correctly	**63%**	**87%**		**72%**	**91%**	

[1] Standard deviation

[2] This item was not included in the knowledge assessment in phase 3