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Original Research Article

Knowledge of cervical cancer prevention and human papillomavirus among women with HIV

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ABSTRACT

Objective. To assess knowledge of and attitudes towards human papillomavirus (HPV), Pap testing, and the HPV vaccine.

Methods. In a multicenter U.S. cohort study, women with the human immunodeficiency virus (HIV) and at-risk comparison women completed 44-item standardized self-report questionnaires exploring their knowledge of cervical cancer prevention, HPV, and HPV vaccination. Results were correlated with demographic variables, measures of education and attention, and medical factors. Data were clustered using principal component analysis. Significant associations were assessed in multivariable models.

Results. Among 1588 women, HIV seropositive women better understood facts about cervical cancer prevention and HPV than seronegative women, but both had substantial knowledge deficits. Almost all women considered Pap testing important, although 53% of HIV seropositive and 48% of seronegative women considered cervical cancer not preventable ($P=0.21$). Only 44% of HIV seropositive women knew Paps assess the cervix, versus 42% of HIV seronegative women ($P=0.57$). Both groups understood that HPV causes genital warts and cervical cancer (67% of HIV seropositive vs. 55% of seronegative women, $P=0.002$). About half of both groups considered HPV vaccination extremely important for cervical cancer prevention. HIV seronegative women were more likely to report learning of HPV vaccination through advertising than from clinicians (81% vs. 64%, $P<0.0001$).

Conclusion. High risk women need effective education about cervical cancer prevention, HPV, and HPV vaccination.

Introduction

Women infected with the human immunodeficiency virus (HIV) have high rates of coinfection with human papillomavirus (HPV) [1]. Persistent infection with carcinogenic types of HPV can lead to the development of cervical intraepithelial lesions (CIN) and cervical cancer, and women with HIV face a high risk of abnormal Pap test results and CIN [2-4]. Population based registry studies have shown that women with HIV are at higher risk for invasive cervical cancer than HIV-uninfected women [5,6], though their risk approaches that of the general population when they participate in regular cervical cancer screening and prevention programs [7].

Such participation may be enhanced when women consider themselves at risk for cervical cancer and when they understand the course of HPV infection and the cervical cancer prevention process. Understanding cervical oncogenesis can be difficult, since it involves multistep carcinogenesis, beginning with sexual acquisition of HPV infection, failure of immune-mediated HPV clearance, and the progression of preinvasive lesions to cancer. The mechanics of cervical cancer prevention can be similarly confusing, requiring an often arduous

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program of cytologic screening, colposcopy triage, and treatment. Among women with HIV, failure rates for treatment of cancer precursors are high [8]. For these women, prevention may involve rounds of cytology, colposcopy, and treatment, with multiple opportunities for discouragement and default that may allow cancer precursors to progress. Some 35% of women with HIV default from colposcopy referral [9]. In other populations, educational interventions to address misunderstandings about cervical cancer prevention have improved compliance with follow-up [10-13]. These have not been tested in HIV-infected individuals, and understanding what HIV infected women know about cervical cancer and what contributes to misunderstanding might help guide effective interventions.

Among U.S. women, knowledge of HPV and its consequences is quite limited [14-21]. Women least likely to know about HPV and its relationship to cervical cancer are those from lower socio-economic strata, those with lower educational attainment, and those who do not obtain regular Pap testing [15,16,19]. These in turn are risks for cervical cancer [22].

Despite the particular threat of cervical cancer for women with HIV, little is known about what HIV-infected women understand about HPV and cervical disease. To provide a more complete understanding, we administered a questionnaire to women with HIV and to comparison women uninfected with HIV. We inquired about their knowledge of HPV, HPV vaccination, and the cervical cancer prevention process. We asked about women's sources for knowledge about HPV vaccination. We attempted to identify characteristics of women who knew little about these areas as a basis for interventions.

Methods

This investigation was part of the Women's Interagency HIV Study (WIHS), an ongoing multicenter prospective cohort study of the natural history of HIV infection and related health conditions among HIV seropositive women and at-risk HIV uninfected comparison women. The protocols, recruitment processes, procedures, and baseline results of the WIHS have been described [23,24]; seropositive WIHS participants are representative of U.S. women with HIV [23]. Enrollment began with 2,623 women in 1994 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 to recruit younger, AIDS-free, and therapy naïve HIV seropositive women, along with HIV-uninfected women with similar socio-demographic and sexual risk characteristics [24]. Comparisons by WIHS administrators to statistics from the Centers for Disease Control and Prevention have shown that the demographics and HIV risk characteristics of the cohort are broadly similar to those of U.S. women with HIV, though WIHS does not include Southern women and so has marginally greater representation of Latinas from the New York and Los Angeles areas than the U.S. population. Adolescents and young women are also underrepresented. Written informed consent was obtained after local human subjects committees approval. Follow up continues, but this analysis reports information from a cross sectional questionnaire on knowledge of and attitudes toward cervical cancer prevention and HPV administered between April and September, 2006. Reading level and a neuropsychological screen for attention and cognitive dysfunction were assessed between October 2004 and September 2005. HIV status was determined by Western blot at study entry for all participants and annually thereafter for those initially seronegative. Ethnicity and years of education were self-reported.

The English version of this questionnaire has been previously described [16]; it was translated into Spanish for this study. Questions asked about HPV, Pap tests, cancer risks, and HPV vaccination. The WIHS National Community Advisory Board reviewed a draft of the questionnaire and provided feedback prior to field implementation. Multiple choice questions and response options were read by participants or to participants by trained interviewers, and responses were recorded. Interviewers were instructed to clarify questions as needed but to defer requests for information until after the questionnaires had been completed. On completion, participants were given written explanations of the correct answers with background, and further information was supplied if requested.

Responses to the 44-item questionnaire were tabulated and compared by HIV status using a global chi-square test. Responses then were coded as correct or incorrect where applicable and subjected to a principal component analysis for item reduction. The principal axis method was used to extract the components, and this was followed by a varimax (orthogonal) rotation [25]. A single summary factor-based score was computed for each subject based on the remaining 26 questionnaire items from the principal component analysis (Chronbach's alpha = 0.88). It included items related to knowledge of HPV, risk factors for cervical cancer, the HPV vaccine, and care following abnormal Pap smears.

Scores were correlated with demographic variables, including age at questionnaire administration, ethnicity, education attained by study entry, reading level, and household income; medical factors, including HIV serostatus, abnormal Pap history, prior colposcopy, and cervical disease treatment; and measures of attention, depressive symptoms, and reading level as a proxy for educational attainment. To explore links between study responses and general cognition, we used information gathered during the Neurocognition Substudy in WIHS. The Wide Range Achievement Test-Version 3 (WRAT) for English speakers and the Word Accentuation Test for Spanish Speakers [26,27] were used to assess basic academic skills. A cognitive task, the Symbol Digit Modalities Test, was used to assess information processing and attentiveness, including visual scanning and mental and motor speed, and immediate paired recall of the same test was used to assess short-term memory [28]. Clinically significant depressive symptoms were screened for using the Center for Epidemiologic Studies Depression (CES-D) scale, with a cutoff score of 16 considered as positive [29].

Multivariable analysis was carried out with the knowledge factor-based score as the outcome. Linear regression was used to assess characteristics associated with knowledge score. 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. Due to minor but potentially confounding connotative differences between English and Spanish speakers, 137 women who completed their questionnaires in Spanish were excluded from multivariable analyses. All final regression models were created using the PROC Generalized Linear Models (GLM) procedure in SAS software [30].

Results

Of the 2,091 women seen at WIHS visit 26, a total of 1,597 (76%) completed questionnaires on cervical cancer and HPV, while 156 (7%) did not receive questionnaires, 167 (8%) refused or did not return questionnaires, and 171 (8%) returned substantially incomplete questionnaires. No significant differences were seen between those who were excluded because of missing data from questionnaire and those who were not except for site and age; those missing data were slightly older 44.5 vs. 43.1 ($P=0.05$) and more likely to be from the Washington, Los Angeles, and Chicago sites compared to other sites. Nine additional women were excluded because of HIV seroconversion during the years of study, a group too small for analysis. This left 1588 women for analysis. Women who were excluded were more likely to come from the District of Columbia, Los Angeles, and Chicago sites and were marginally older (44.5 vs. 43.1 years, $P=0.05$). There were