Who Should Decide? Decision-making Preferences for Primary HPV Testing for Cervical Cancer Screening Among U.S. Women

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Abstract

Revised U.S. guidelines for cervical cancer screening provide the option of primary human papillomavirus (HPV) testing, Pap testing, or co-testing. Primary HPV testing has not yet been an option for American women, and women may be reluctant to change screening methods. The purpose of this study was to assess correlates of women's preferences for primary HPV testing decision-making (self, provider, or shared) for cervical cancer screening. Women, aged 30-65, completed an online survey in June of 2018 (n = 812). The outcome variable was preference for decision-making for an HPV test instead of a Pap test on a scale of, healthcare provider, me, or shared. Predictor variables included testing attitudes, social norms, information seeking, previous screening, and socio-demographics. Women who disagreed that people important to them think that they should get the HPV test instead of a Pap test, who were not willing to receive an HPV test instead of a Pap test, and who did not receive HPV vaccinations were less likely to include a provider in their decision-making. In contrast, women who were not up-to-date with their cervical cancer screenings, who had some college or technical level education, or who were over 50 years of age were more likely to prefer to have a healthcare provider included in their decision-making process. While some variation was discovered, women mostly preferred a shared decision or personal decision for HPV testing. Resources to facilitate the decision-making process about this new option for cervical cancer screening are needed.

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Introduction

Human papillomavirus (HPV) causes virtually all cases of cervical cancer (Walboomers et al., 1999). While cervical cancer was previously the leading cause of cancer death among women in the United States (U.S.), screening has reduced these rates dramatically. In 2017, 12,831 cervical cancer cases were reported in the U.S., and 4,207 deaths due to cervical cancer occurred; rates were higher among black and Hispanic women compared to white women (U.S. Cancer Statistics Working Group, 2020). The majority of cervical cancer cases are attributed to lack of screening among women by failing to identify pre-cancers before they develop into cervical cancer (Melnikow et al., 2018), and current cervical cancer screening data indicate 81% of women in the U.S. are up-to-date on screening (National Cancer Institute, 2020). In order to eliminate cervical cancer in the U.S., increasing screening to 90% can speed up this goal (Burger et al., 2020).

In 2018, the U.S. Preventive Services Task Force revised the recommendations for cervical cancer screening to provide the option of primary HPV testing every five years among women 30-65 years of age.

Women in this age group also have the option of Pap testing every three years or co-testing (Pap testing plus HPV testing) every five years. The rationale for providing the option of primary HPV testing is due to the improved sensitivity of the test and improved cost-effectiveness due to wider screening intervals (Curry et al., 2018).

While studies indicate many U.S. women report primary HPV testing as acceptable, women may find HPV testing less acceptable when they have negative attitudes about delayed screening intervals, are married, and have negative emotions related to HPV testing (Tatar et al., 2018). Similarly, some countries have faced resistance when cervical cancer screening programs transitioned completely to primary HPV testing rather than a Pap test (Chrysostomou et al., 2018). This may be attributed to confusion regarding what a Pap test actually screens (Daley et al., 2010; Perrin et al., 2006). Additionally, healthcare providers may be unprepared for this guideline transition, which may be attributed to concerns about interval length for screening, concerns about patients' reactions to HPV testing being a sexually transmitted infection test, and variation in following guidelines by clinics (Head et al., 2020; Tatar et al., 2019).

According to the U.S. Community Guide, one-on-one counseling is recommended for healthcare providers and patients to promote cervical cancer screening (Community Preventive Services Task Force, 2012). In order to promote cervical cancer screening in the midst of this guideline transition with the option of HPV-only testing, there is a need to explore the screening decision-making role preferences of women with different health histories, sociodemographic backgrounds, attitudes, and knowledge levels. This study explored women's preferences for decision-making for HPV testing instead of Pap testing; specifically, making the decision themselves, a shared decision with their provider, or relying on a provider to make the decision. Findings from this study can inform counseling strategies healthcare providers utilize with their patients in order to promote cervical cancer screening.

Methods

Study Sample

The target population for this study was women who are eligible for receiving HPV testing according to the recent guideline's recommendations: 30-65 years of age, without the history of hysterectomy. The recruitment of participants was conducted through the Qualtrics Online Panel, and African American and Hispanic women were oversampled due to the higher burden of cervical cancer among these populations (U.S. Cancer Statistics Working Group, 2020). Research panel members were invited to participate in the survey. Eligible women participated in the survey after providing informed consent presented at the beginning of the survey. Data were collected in June of 2018 with a sample size of 812 participants. The study was approved with an exempt status by the North Texas Regional Institutional Review Board.

Measures

The outcome variable, using a scaled measure, assessed the decision-making role preference of the participant and asked, "Whether I would have an HPV test instead of a Pap test would be entirely up to..." The participant then had the option of choosing a number on a sliding scale ranging from 1 to 100 with lower values indicating independent decision-making, moderate range values indicating a preference for shared decision making with the provider, and higher values indicating a preference for the healthcare

provider to make the decision. This variable was used as a continuous variable.

The predictor variables included sociodemographic factors and variables that have previously been found to have an association with the cervical cancer screening decision-making preferences of an individual (Tatar et al., 2018). Sociodemographic variables included age (30-50 years, ≥ 50 years), highest educational level attained (high school or less, some college/technical, 4 years of college or higher), race (white, black, others), and ethnicity (non-Hispanic, Hispanic).

HPV knowledge was assessed by utilizing a validated 16-item knowledge scale by Perez and colleagues (Perez et al., 2016). In response to 16 HPV-related statements, participants responded "True," "False," or "Don't Know." Correct responses were assigned a point, and all correct points were summed and averaged, with higher scores indicating increased HPV knowledge. The Cronbach's alpha for this sample was 0.89. For HPV testing awareness, the study asked, "Have you ever heard of HPV testing?" ("Yes," "No," and "Don't know"). Participants who responded "No" and "Don't know" were recoded into a "No" category. Ease of finding and understanding cervical cancer information used questions from the European Health Literacy Survey Questionnaire (HLS-EU-Q), adapted specifically for cervical cancer information (Sørensen et al., 2013). When asked "How easy is it for you to find information on cervical cancer screening?" and "How easy is it for you to understand information on cervical cancer screening?", response options included very easy, easy, somewhat easy, and not easy. Due to response distribution, responses of somewhat easy and not easy were collapsed into a single category.

HPV testing attitudes, subjective norms, and provider recommendation were also assessed. An HPV testing attitude scale adapted from Ogilvie and colleges (Ogilvie et al., 2013) was assessed: "Having an HPV test to screen for cervical cancer every 5 years and after age 30 instead of a Pap smear every 3 years would be: accurate/safe/protect my health/acceptable." Response options ranging from strongly agree to strongly disagree were aggregated to produce a sum score ($\alpha = 0.946$). Ogilvie and colleagues' (Ogilvie et al., 2013) subjective norms question was also adapted: "If national guidelines recommended having an HPV test to screen for cervical cancer instead of a Pap smear, most people who are important to me would think I should/expect me to have an HPV test instead of a Pap smear." Due to the bimodal distribution of the variable, the seven responses were recoded into three categories: "Agree" ("Strongly agree," "Agree," and "Somewhat agree"); "Neither agree nor disagree"; and "Disagree" ("Strongly disagree," "Disagree," and "Somewhat disagree"). Whether the participant agreed to have HPV testing instead of Pap testing based on a healthcare provider's recommendation was assessed, with responses of "Yes," "No," or "Don't know." (Saraiya et al., 2018) "No" and "Don't know" responses were re-coded as "No."

Relevant health history (i.e., screening up-to-date, HPV vaccination, and non-HPV sexually transmitted infection diagnosis history) was also assessed. Up-to-date with 2018 cervical cancer screening guidelines status was determined with two questions: "How long ago did you have your most recent Pap test?" (from the Health Information National Trends Survey), and "An HPV test is sometimes given with the Pap test for cervical cancer screening. Did you have an HPV test with your most recent Pap?" (from the 2014 National Health Interview Survey). If the participant reported having a Pap test within the last three years or an HPV test with their last Pap test within 5 years, the

participant was up-to-date. Otherwise, the participant was not up-to-date. History of any HPV vaccination was assessed, with responses of "Yes," "No," and "Don't know." History of a sexually transmitted infection diagnosis other than HPV was also assessed with responses of "Yes," "No," and "Don't know," recoding "No" and "Don't know" responses into one category.

Data Analysis

We conducted the univariate and bivariate analysis for the continuous outcome variable assessing the shared decision-making preference. Multiple linear regression was used to identify the predictor variables independently associated with decision-making preference. The multiple linear regression model was significant and accounted for 8.7% of the variance with $F(20, 791) = 3.79$, $p < 0.01$. The assumptions for the model were tested and all the assumptions were met. All the variables that are considered essential for health-related decision-making were entered in the model together. Adjusted regression coefficients and *p*-values were reported. The analysis was conducted using SAS 9.4 software.

Results

Among the 812 women surveyed, 63% were between 30 to 50 years old, 68% of the women were white, 23% were black, and 9% were of other race(s); 19% were Hispanic (Table 1).

Table 1

Demographic and Health Behavior Characteristics of Sample (n = 812)

Variable	n (%)
Decision-Making (mean (SD))[a]	44.67 (32.31)
Attitude Towards HPV Test (mean (SD))[b]	20.86 (5.49)
HPV Knowledge Score (mean (SD))[c]	8.10 (4.58)
People Important to Me Think I Should Have HPV Test Instead of Pap Test	
Agree	445 (54.80)
Neither Agree nor Disagree	303 (37.32)
Disagree	64 (7.88)
Up-to-Date with Cervical Cancer Screening	
Up-to-Date	580 (71.43)
Not Up-to-Date	232 (28.57)
Agree to Have HPV Test Instead of Pap Test on Doctor's Recommendation	
Yes	505 (62.19)
No	307 (37.81)
Ease of Finding Cervical Cancer Screening Information	
Very Easy	341 (42.00)
Easy	289 (35.59)
Somewhat/Not Easy	182 (22.41)

Table 1 (continued)

Demographic and Health Behavior Characteristics of Sample (n = 812)

Variable	n (%)
Ease of Understanding Cervical Cancer Screening Information	
Very Easy	303 (37.32)
Easy	285 (35.10)
Somewhat/Not Easy	224 (27.59)
Education	
Less than High School/High School	270 (33.25)
Some College/Technical	296 (36.45)
College	246 (30.30)
Age	
< 50 years	514 (63.30)
≥ 50 years	298 (36.70)
Race	
White	553 (68.10)
Black	187 (23.03)
Other Race, including Bi/Multiracial	72 (8.87)
Ethnicity	
Non-Hispanic	661 (81.40)
Hispanic	151 (18.60)
Heard of HPV Testing	
Yes	507 (62.44)
No/Don't Know	305 (37.56)
Received HPV Vaccination	
Yes	100 (12.32)
No	592 (72.91)
Don't Know	120 (14.78)
Ever Had a Sexually Transmitted Infection Other than HPV	
Yes	135 (16.63)
No/Don't Know	677 (83.37)

Note. [a]Decision-making scale: 1 to 100; [b]Attitudes scale: 4 to 28; [c]Knowledge scale: 0 to 16

Most of the women had some college or technical school education (36%). The mean decision-making score was 44.7 (SD = 32.3), indicating that more women preferred shared decision-making with their healthcare provider (Figure 1). Nearly two-thirds (62%) of the women had heard of HPV testing before, and only 12% of the women had ever received HPV vaccination. The mean score for attitude towards HPV testing was 20.9 (SD = 5.5), with a range between 4 and 28, suggesting that more women agreed that HPV testing is safe, accurate, acceptable, and protected their health. The mean HPV knowledge score was 8.1 (SD = 4.6) out of 16, which shows that women had relatively

low knowledge regarding HPV. Most women agreed that people important to them think they should get an HPV test instead of a Pap test (55%), and they would be willing to get an HPV test instead of a Pap test on their doctor's recommendation (62%). More than two-thirds (71%) of the women were up-to-date with their cervical cancer screening. Most of the women considered it was very easy or easy to find (78%) and understand (72%) cervical cancer screening information.

Table 2 presents the coefficients from the adjusted linear regression model. After controlling for other variables, women who disagreed with the statement that people who are important to them think that they should get HPV test instead of Pap test were less likely to prefer their provider to decide for them (b = -11.03). Women who did not agree to receiving an HPV test instead of a Pap test were more likely to make the decision independently (b = -7.50). Women who had some college or technical level education (b = -6.18) or who were over 50 years old (b = -5.13) were more likely to make the decision independently. Women who did not receive HPV vaccination were less likely to include healthcare provider in their decision-making (b = -8.70). Women who were not up-to-date with cervical cancer screening were more likely to prefer their provider to make a decision (b = 5.27). Furthermore, women from non-white or non-black identified races were more likely to prefer a healthcare provider to be involved in decision-making (b = 10.67).

Discussion

With the recent option of primary HPV testing as a mode for cervical cancer screening in the United States, understanding women's preferences for deciding on primary HPV testing can inform strategies that increase screening for the elimination of cervical cancer. Perhaps most important, this study found women preferred an individual decision-making approach and that decision-making preferences were influenced by sociodemographic and past health behavior variables.

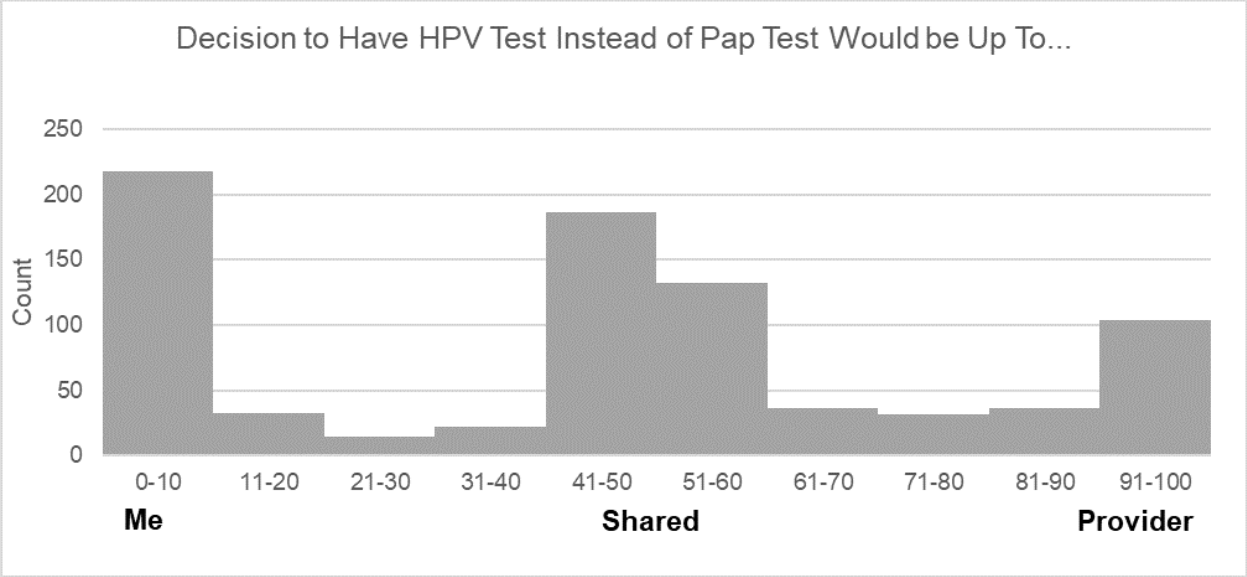

Figure 1. Distribution of the decision-making score for HPV testing (n = 812).

Table 2

Adjusted Linear Regression Model of HPV Testing Decision-making Preference among Women (n = 812)

Variable	Adjusted Linear Regression Coefficients[a] (SE)	*p*-value
Attitude Towards HPV Test	0.07 (0.24)	0.75
HPV Knowledge Score		
People Important to Me Think I Should Have HPV Test Instead of Pap Test		
Agree	Ref	
Neither Agree nor Disagree	-1.81 (2.62)	0.49
Disagree	-11.03 (4.65)	**0.02**
Up-to-Date with Cervical Cancer Screening		
Up-to-Date	Ref	
Not Up-to Date	5.27 (2.59)	**0.04**
Agree to Have HPV Test Instead of Pap Test on Doctor's Recommendation		
Yes	Ref	
No	-7.50 (2.57)	**<0.01**
Ease of Finding Cervical Cancer Screening Information		
Very Easy	3.19 (3.89)	0.41
Easy	2.04 (3.51)	0.56
Somewhat/Not Easy	Ref	
Ease of Understanding Cervical Cancer Screening Information		
Very Easy	1.29 (3.67)	0.73
Easy	0.67 (3.28)	0.84
Somewhat/Not Easy	Ref	
Education		
Less than High School/High School	Ref	
Some College/Technical	-6.18 (2.72)	**0.02**
College	-1.55 (2.94)	0.60
Age		
< 50 years	Ref	
≥ 50 years	-5.13 (2.43)	**0.04**
Race		
White	Ref	
Black	3.68 (2.78)	0.19
Other Race, including Bi/Multiracial	10.67 (4.09)	**0.01**

Table 2

Adjusted Linear Regression Model of HPV Testing Decision-making Preference among Women (n = 812)

Variable	Adjusted Linear Regression Coefficients[a] (SE)	*p*-value
Ethnicity		
Non-Hispanic	Ref	
Hispanic	-2.96 (3.10)	0.33
Heard of HPV Testing		
Yes	Ref	
No/Don't Know	3.39 (2.70)	0.21
Received HPV Vaccination		
Yes	Ref	
No	-8.70 (3.56)	**0.01**
Don't Know	-1.47 (4.48)	0.74
Ever Had a Sexually Transmitted Infection Other than HPV		
Yes	Ref	
No/Don't Know	1.41 (3.05)	0.64

Note. [a]unstandardized

Below, we discuss the findings of this study and highlight implications for clinical practice and future work.

The majority of women in this study indicated that they strongly preferred an individual or shared decision-making approach, with the lowest being a preference for provider-only decision. These findings are consistent with a shared decision-making approach, which "rests on accepting that individual self-determination is a desirable goal and that clinicians need to support patients to achieve this goal" (Elwyn et al., 2012). As the United States considers moving toward HPV testing for cervical cancer screening, incorporating shared decision-making strategies into the one-on-one counseling of patients considering HPV-only testing is imperative.

To incorporate shared decision-making for HPV testing, clinicians should consider providing information to women regarding HPV testing and presenting the options, intervals, risks, and benefits, so women can make an informed decision for their needs. Additionally, it has been noted that guidelines and recommendations for screening do not often address women's preferences or values and do not provide specific recommendations for providers to discuss (Sawaya & Kuppermann, 2015). Studies on cervical cancer screening have noted that women wanted to be knowledgeable enough to weigh their options and choose an option for them based on their values, but women also wanted input from their providers (Wood et al., 2018). Healthcare providers report taking paternal-

istic approaches when discussing options, as they wanted women to have the autonomy to make decisions but remain within the context of the evidence-based recommendations (Wood et al., 2018). In these situations, women may find it difficult to act on their preferred decision if it does not align with their provider's preferred decision, reducing the amount of autonomy women are able to exert over their screening (Adams et al., 2012). Furthermore, when discussing cancer screening decisions with providers, patients report that these discussions mostly focused on the pros of screening and less often included a focus on the potential cons (Hoffman et al., 2010). Instead, it is imperative that any shared decision-making approach reflects the idea that the provider's role is to "be a navigator, not a pilot" by ensuring that patients are using relevant and accurate information in their decision-making and that they understand the ramifications of their choice (McNutt, 2004). Exploring providers' perceptions of shared decision-making for HPV testing may shed light on empowering communication approaches to utilize during these discussions, as people who are involved in decision-making regarding their health report better health outcomes (Hibbard & Greene, 2013; Hoffmann et al., 2014). Further research is needed to determine whether these findings hold true with HPV testing.

Just 12% of this sample reported ever receiving the HPV vaccine, and women who had not been vaccinated for HPV were more likely to prefer making a personal decision for HPV testing, compared to those who were vaccinated. Almost half of providers in one study said that patient HPV vaccine status influenced their cervical cancer screening practices (Cooper & Saraiya, 2017). Receipt of the HPV vaccine has been associated with higher rates of screening adherence (Chao et al., 2017). In the HPV testing recommendation from the U.S. Preventive Services Task Force, many screening approaches and intervals are presented (United States Preventive Services Task Force, 2018). Given these options, the Community Preventive Services Task Force recommends the use of patient-provider communication with a goal of "informing, encouraging, and motivating" patients to seek cervical cancer screening (Community Preventive Services Task Force, 2020), strengthening the argument to consider a shared decision-making approach to HPV testing. Specifically, women who have not received the vaccine may mistrust providers and the healthcare system and have difficulty talking to their providers (Kolar et al., 2015), therefore opting to prefer an individual decision about screening. Tailored materials and counseling strategies addressing this mistrust may improve patient-provider communication and facilitate shared decision-making for cervical cancer screening, as women were more confident in their decision-making without provider influence if they were informed (Wood et al., 2018).

Women who attended some college, compared to women with high school or less education, were more likely to prefer to make the decision themselves about HPV screening. There were no differences, however, between women who completed college and those with a high school or less education for decision-making preferences. Similarly, previous studies have found variation in HPV and cervical cancer knowledge and HPV testing acceptability based of educational attainment (Thompson et al., 2018). In contrast, women who are not white or black were more likely to prefer that a healthcare provider be involved in the decision-making; however, disentangling the heterogeneity within the "other" racial group may identify different patterns among specific groups of women. Future studies should explore the socio-cultural differences

in cervical cancer screening decision-making among women and how these differences may inform prevention programming.

Findings must be considered in light of a few limitations. As a cross-sectional study, generalizations regarding the temporality of associations cannot be determined based on this study alone. Additionally, since the data were collected via Qualtrics Online Panels, generalizability is limited. U.S. participants in online survey panel studies have been shown to be less diverse compared to studies with clinical samples, based on racial and ethnic disparities in language, Internet access, and frequency of survey participation (Grov et al., 2016; Ibarra et al., 2018). Utilizing quota sampling to account for more black and Hispanic women partially addressed this limitation, but women who did not speak English were excluded from the sample. Moreover, data were reported via self-report, which may result in less reliability in reporting screening behaviors when compared to utilizing medical record data (Anderson et al., 2019). Providing educational content within the survey regarding guideline recommendations and explanations of HPV tests and Pap tests mitigated some recall bias. Finally, the question for assessing preference for a decision was on a large, zero-to-100 scale and had significant variability. Future studies may consider utilizing a fixed response option for this type of question.

Implications for Health Behavior Theory

This study examined women's preferences for an individual, shared, or provider-based decision for HPV testing compared to Pap testing. With this new transition in recommended guidelines for cervical cancer screening, recognizing women's preferences is needed for patient-centered programming to improve cervical cancer screening rates. Ultimately, improving cervical cancer screening, particularly among under-screened women, has the potential to contribute to the overall goal of eliminating cervical cancer in the United States.

In order to successfully implement primary HPV testing as a mode of cervical cancer screening, the preferences of women need to be recognized for shared decision-making. Variation in preferences exist for women spanning from individual decision, a shared decision, and a provider –based decision. Providers should incorporate women's preferences when providing one-on-one discussions to promote cervical cancer screening.

Discussion Question

What are strategies to involve women in the decision-making process for transitioning to HPV testing instead of Pap testing for cervical cancer screening?

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