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Perspectives from health-care providers and women about completing human papillomavirus (HPV) self-testing at home

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Abstract

Cervical cancer (CC) incidence and mortality rates are increased, and CC screening rates are low among Appalachian Ohio women. Mailing human papillomavirus (HPV) self-tests to women to complete at home is a potential new strategy to engage women in CC screening. The authors aimed to gain insights into the perceived acceptability of mailed HPV self-tests. Focus groups were conducted (August 2014–January 2015) among providers (physicians, nurse practitioners, nurses) and women in Appalachian Ohio. Providers ($n = 28$) and women ($n = 15$; age range: 32–62 years) reported general acceptance of HPV self-tests, however, for different reasons. Providers thought HPV self-testing would increase the proportion of under-screened women returning to the health-care system, while women thought self-testing would eliminate logistical and reduce psychological CC screening barriers. Findings provide insights into facilitators and barriers of completing an HPV self-test at home, returning it, reporting results, and providing needed follow-up care. To the authors' knowledge, no systematic research exists addressing providers' views regarding women's use of HPV self-tests and the relation of such use to fostering subsequent Pap testing. This information will be useful in developing CC screening programs that include mailed HPV self-tests, as well as encouragement of follow-up Pap testing to meet existing CC screening guidelines.

Keywords

Cervical cancer; human papillomavirus; Pap test; screening

Introduction

Cervical cancer (CC) remains a public health concern in the U.S. In 2016, an estimated 12,990 new CC cases will be diagnosed, and 4,120 women will die from this disease (American Cancer Society [ACS] 2016). CC rates vary according to age, race, ethnicity, income, and geographic location (ACS 2015). One geographic region with increased cancer burden is Appalachia (Blackley, Behringer, and Zheng 2012). Appalachia is a designated region along the Appalachian mountains and home to over 25 million residents (8% of the U.S. population) (Appalachian Regional Commission [ARC] 2016). Appalachian residents are socioeconomically disadvantaged and experience more geographic isolation, higher poverty rates, lower health insurance rates, lower education levels, and less health-care access than non-Appalachian residents (Abramson and Haskell 2006). These social determinants of health contribute to disparities in cancer risk factors, incidence, mortality, and survivorship (Blackley, Behringer, and Zheng 2012; National Cancer Institute [NCI] 2011).

Not surprisingly, women living in Appalachian Ohio have an increased CC burden (Appalachian Community Cancer Network [ACCN] 2009; ARC 2012; Blackley, Behringer, and Zheng 2012; Hopenhayn et al. 2008; Lengerich et al. 2005; Paskett et al. 2011; Reiter et al. 2013a). Cervical cancer incidence rates are 24.4% higher (9.7 versus 7.8 per 100,000 females) and cervical cancer mortality rates are 41.7% higher (3.4 versus 2.4 per 100,000 females) in Appalachian Ohio compared to non-Appalachian Ohio (Ohio Department of Health 2007).

The main contributing factors responsible for the increased CC rates among women in Appalachian Ohio are the high rates of HPV infection (Reiter et al. 2013b), lower CC screening rates, and less frequent follow-up of abnormal Pap tests (Schoenberg et al. 2010) compared to women living in other regions of the U.S. (Hall et al. 2002; Katz et al. 2015). Barriers to receiving CC screening within guidelines are numerous, complex, and include many factors at different levels of influence (e.g., individual, provider, clinic, community, society; Hall et al. 2002; Studts, Tarasenko, and Schoenberg 2013). Examples of these factors include: less education and lower socioeconomic status at the individual level, poor patient-provider communication at the interpersonal level, other medical priorities to address with patients at the provider level, lack of a reminder system at the clinic level, no public transportation and cultural issues at the community level, and lack of a comprehensive screening policy at the societal level (Hall et al. 2002; Katz et al. 2015; Studts, Tarasenko, and Schoenberg 2013).

Persistent HPV infections cause almost all cases of CC (Rimer, Harper, and Witte 2014; Saraiya et al. 2015). If detected early, CC is usually curable, or precursor lesions detected can be treated to prevent a potential cancer from developing (Saslow et al. 2012). Current CC screening guidelines are that women ages 30–65 years may receive a combination of cytology (i.e., Pap test) and HPV testing every 5 years or cytology every 3 years (Moyer, on behalf of the U.S. Preventive Services Task Force [USPSTF] 2012; Saslow et al. 2012). In addition, the Food and Drug Administration (FDA) approved an HPV test as a primary CC screening option for women starting at age 25 years that providers can use to assess the need

for further diagnostic testing (U.S. Department of Health and Human Services 2014). The current screening recommendations and FDA-approved test involve specimen collection in a clinic setting, though interest is growing in women using a device on their own to collect a specimen at home (i.e., HPV self-testing).

In a systematic review and meta-analysis, self-collected HPV samples had a high level of concordance with samples collected by physicians for the detection of HPV DNA (Petignat et al. 2007). Completing an HPV self-test at home is a potential strategy for reaching recalcitrant women who are not within screening guidelines. In a recent systematic review and meta-analysis of randomized trials conducted in different countries, over 20% of women who were mailed an HPV self-sampling kit used and returned their kit (Verdoodt et al. 2015). Limited research, however, has examined the use of self-tests among unscreened and under-screened women in the U.S. because these tests are not currently licensed for use in the U.S. Appalachian women may be an important population in which to use HPV self-testing because they are at high risk for CC, have lower CC screening rates than non-Appalachian women, and have less access to health-care facilities (ACCN 2009; ARC 2012). In addition, because little is known about health-care providers' views of women completing HPV self-tests at home, it is also important to explore the acceptability of this practice among health-care providers who deliver health services to this high-risk population.

Our study sought to understand both providers' (physicians, nurse practitioners, nurses) and women's perspectives on an HPV self-test that could be mailed to women and whether those viewpoints differed and/or concurred. We thought it was particularly important to identify women's barriers and facilitators to completing an HPV self-test at home; however, understanding the perspective of both groups is a critical early step as HPV self-testing begins to be considered for use in the U.S. This information will be useful in the development of HPV self-testing programs if and when this screening methodology is approved for use in the U.S.

Materials and methods

We conducted focus groups among: (1) health-care providers practicing in Federally Qualified Health Centers (FQHCs) located in Appalachian Ohio; and (2) women living in Appalachian Ohio. Health-care providers participated in focus groups during August 2014, and women participated in October 2014 through January 2015. Whenever possible, we conducted focus groups instead of one-on-one interviews to foster dynamic group discussion and a broader range of themes than those produced by information gathering during interviews. The Institutional Review Board at The Ohio State University approved this study.

Participants

We recruited health-care providers from four FQHCs located in three Appalachian Ohio counties. Health-care providers were eligible to participate in the study if they practiced at one of the clinic locations and if each participant provided written signed informed consent. We recruited women living in Appalachian Ohio by posting fliers in the same FQHCs, and women were eligible to participate if they: were ages 30–65 years, had no Pap test in the last

3 years, were not currently pregnant, had no history of hysterectomy or invasive cervical cancer, had an intact cervix, were a resident of an Appalachian Ohio county, and if each participant provided written signed informed consent. Because we recruited convenience samples for this qualitative study, it was not possible to provide accurate participation rates for the providers or women or eligibility rates for the women.

Procedures

A trained moderator led focus groups ($n = 6$; ranging from 3 to 10 participants) or in-depth interviews (if only one individual showed up for the session; $n = 5$) using a guide, and when possible, a staff member recorded field notes and group dynamics. Sessions with providers occurred at the health centers, and sessions with women occurred at different community locations (e.g., libraries, etc.). We conducted sessions until data saturation was reached. Each session lasted about one hour, was audio recorded, and was transcribed verbatim. After the informed consent process, and prior to the start of the focus group or interview, all participants completed a brief demographic survey. Participants received a \$40 gift card and a \$5 gasoline gift card in appreciation of their time.

The focus group guides included open-ended questions that were slightly modified for each group. Key constructs of the Protection Motivation Theory (PMT) were addressed by the questions in the guides (Rogers 1983). The PMT is a theory of persuasive communication, with an emphasis on the cognitive processes mediating behavioral change (Rogers 1983). PMT constructs include: (1) maladaptive response (not completing screening): intrinsic and extrinsic rewards, perceived severity and perceived vulnerability of HPV and cervical cancer, and (2) adaptive response (completing screening): response-efficacy of HPV self-tests, self-efficacy for using and returning an HPV self-test, and response costs (perceived barriers to using and returning an HPV self-test). The moderator used follow-up probes for clarification when needed and encouraged dialogue among focus group participants.

Because a range of HPV self-test devices exist, we presented participants with several devices and the accompanying device instruction during the focus groups. We included devices with varied appearance and functionality to give participants an idea of the range of devices currently available (e.g., a brush or swab that women use to collect the specimen, a lavage paired with a liquid collection receptacle). We have reported results concerning inter-device comparisons elsewhere (Reiter et al. in press); the remainder of this report focuses on issues about HPV self-testing completed at home that are relevant to some or all of the devices.

During the provider and women sessions, the facilitator described mailing HPV self-tests to women to complete at home as a potential new screening strategy. In addition to providing input about the different devices, discussions also focused on the accuracy of using HPV self-tests, methods to provide test results to women (e.g., phone, mail, text message, etc.), what a negative and positive HPV test result meant, the best way to explain the test results to patients, and how to communicate what follow-up was needed after women receive their test results.

Data analysis

Two research team members (BJZ, MLK) read all focus group transcripts to identify major themes to develop the codebook. Both readers independently coded one focus group transcript, reviewed differences between codes and reached a consensus about reconciling discrepancies, and revised the codebook accordingly. One research team member engaged in line by line analysis of the transcripts using (NVivo qualitative software, QSR International Pty Ltd., Version 10, 2012). Both research team members reviewed the transcripts for themes that emerged. Research team members paid special attention to similarities and differences among and between health-care providers and women. The two research team members selected quotations to illustrate the themes.

Results

Participants

Participants included 28 health-care providers and 15 women from Appalachian Ohio (Table 1). Health-care providers had a mean age of 43 years; all were non-Hispanic Whites, and most (71%) were married or living with a partner. Additionally, all but one health-care provider worked full-time, and most (86%) were nurses or nurse practitioners. Appalachian women who participated had a mean age of 45 years; most were non-Hispanic White (93%), and slightly over half were married or living with a partner. Additionally, most (87%) women did not have a college degree and reported annual household incomes equal to or less than \$10,000.

Themes

The following main themes emerged from the focus groups. Most providers thought that the women understood very little about the association of HPV and cervical cancer and the importance of completing CC screening within guidelines. Most women, as well, voiced their lack of understanding about HPV, its association with CC, and the importance of completing recommended Pap tests.

While the majority of women were not keenly aware of CC, they were aware of the high-prevalence of cancer in their geographic region (Table 2). Interestingly, women often attributed cancer risk to environmental factors, including the local “A-plant” that was constructed by the U.S. Atomic Energy Commission and managed by the U.S. Department of Energy.

Pap test barriers—When asked about Pap tests, the majority of Appalachian women tended to emphasize the negative aspects of undergoing the screening test, rather than the benefits of completing the test as recommended (Table 2). Several of the women shared that having a Pap test is embarrassing and causes emotional stress. Some women also discussed the physical discomfort and pain associated with the procedure, as well as the lack of time and money to complete a recommended test.

HPV self-testing at home—Health-care providers and women had different opinions about the main advantage of having women complete an HPV self-test at home.

Many health-care providers viewed the potential of mailing HPV self-tests to women to complete at home as a means by which to encourage women to return to the health-care system. That is, to receive their HPV self-test results women need to come in for a health-care visit, which would then provide an opportunity for providers to complete a Pap test and a routine examination. One provider stated “Well if that was the only way they could get their results ... Do you know what I’m saying? Whether it is negative or positive, your results are back, we need you to come in....”

In contrast, the majority of women expressed preference for HPV self-tests that could be completed at home to avoid a trip to the doctor’s office and the associated issues. For example, one woman stated “I most definitely would rather do it in my home.”

HPV self-tests: Receiving devices—Providers and women conveyed worry about the HPV self-test devices being mailed to women. Both groups mentioned that women were not aware of this new testing device. The culture of Appalachian residents as a potential barrier to their participation in HPV self-testing raised concern, as explained by one provider:

I think too, a lot of people are very suspicious of things medical in general. I have to persuade my patients that it’s not a gimmick, or I’m not trying to sell them something or, you know, something like that, a lot of times. So if they could get that sense from this is not—you’re not participating in, you’re not being a lab rat because people say that to me all the time, ‘Am I being a lab rat?’ or ‘Are you experimenting on me?’

Both groups also mentioned the importance of providing educational materials and detailed instructions with the mailed devices. Suggestions of what to send with the mailed HPV self-test devices included: an explanation of HPV and cervical cancer, step-by-step instructions to complete the test, the meaning of a positive/negative test result, and recommended next steps based on the test results. One woman expressed this viewpoint: “Yes, a letter explaining the importance of the HPV, you know, the test, explaining the test, explaining what HPV is, and then saying, you know, you will be receiving a kit, a very simple kit, and follow instructions, and it’s all self-explanatory, but it may save your life someday.”

HPV self-tests: Facilitators—Several facilitators for completing an HPV self-test at home also emerged during the focus group discussions (Table 3). Because women often raised the issue of embarrassment with regard to completing gynecologic examinations and Pap tests, the idea of completing an HPV self-test at home was appealing. Several participants also described that HPV self-testing may be similar in function to other medical tests that are used at home, indicating that such a practice is a normal occurrence. Several other women mentioned the decrease in time and cost associated with an HPV self-test completed at home, which were identified as significant barriers to completing Pap tests at the health center.

HPV self-tests: Barriers—Several barriers to completing an HPV self-test at home also emerged during the focus groups (Table 4). The main concern raised by both health-care providers and women was that women would not correctly complete the test and thus would receive inaccurate results. For instance, some participants indicated that women would not

know how far to insert the different HPV self-test devices into their vagina, and also mentioned that the tip of the device could break off when it is in a woman's vagina. Additionally, some providers indicated that they recognize when a test is performed incorrectly, and they make the conscious decision to repeat a test; whereas women indicated that they would not know whether they completed a test correctly.

Many women expressed concern with the potential physical pain or discomfort associated with completing an HPV self-test (Table 4). However, due to past clinical experience and feedback from patients, several of the providers were more concerned with the physical difficulties (dexterity-related issues) women might encounter while completing the self-test.

While several providers mentioned the negative associations (i.e., being unfaithful to spouse/partner) that women may have if they were diagnosed with an HPV infection, the majority of women were more concerned with HPV's connection to cancer (Table 4).

HPV self-tests: Returning devices—Providers and women raised a few issues about returning samples in the mail after completing the HPV self-test at home, such as the safety of the sample, the content of the return mail being known by someone else, and the costs associated with mailing the sample (Table 5). Most providers thought that women would be comfortable returning the samples in the mail, however, they expressed women might be concerned with privacy.

HPV self-tests: Results—The main issues raised by health-care providers and women about providing results of the HPV self-tests included the timing of providing results, the manner in which results are provided, and the subsequent need to complete a Pap test, because at-home HPV self-tests are not currently clinically approved for CC screening in the U.S. (Table 5).

Results timing—Health-care providers did not express the need to give women a timeline for receiving their HPV self-test results; however, they did acknowledge that over time women in general tend to have increased anxiety related to test results (Table 5). Several providers also suggested that this anxiety could be used to promote women's re-entry into the health-care system for Pap testing, etc. Yet most women were less concerned about the actual length of time it took to receive the test results; they stated a preference for communication by providers of an approximate timeline for receiving the test results.

Results delivery—Disagreement occurred within and between providers and women about the best manner to use for delivery of HPV self-test results (Table 5). All providers preferred that women come into the office to receive results in person, since the time could also be spent educating women about their results and completing a Pap test. Yet there were a range of beliefs regarding whether it would be possible to get women into the office. Several providers suggested calling women to make an in-person appointment, withholding the HPV self-test results to capitalize on women's related anxiety as a method to bring women into the office. That is, some providers thought that delivery of negative results over the phone could negate the importance of routine follow-up, while delivery of positive results could scare women into denial and could prevent them from further follow-up. Other

providers stated that the only women who would bother coming in are those with questions and that women are not easily reached by telephone; thus, they should be sent a letter in the mail regarding the time to come in for HPV self-test results. Women had mixed thoughts about how they would like to hear the test results, with some women preferring a call from a nurse or doctor, despite the nature of the results, due to the anxiety associated with waiting for an office visit to receive the test results. Some women expressed that it is their right to be told about test results immediately over the telephone; whereas other women stated a preference for receiving results by a mailed letter.

Follow-up—Disagreement also occurred within and between health-care providers and women regarding follow-up care after the HPV self-test (Table 5). Most providers mentioned that patients with abnormal Pap tests frequently do not follow their suggestions to receive follow-up care (i.e., colposcopy). Women also reported disagreement about following recommendations after an abnormal Pap test. Because HPV self-tests completed at home are not currently approved in the U.S., providers expressed the importance of having women come into the health center for a Pap test following completion of the HPV self-test, while the majority of women expressed their preference for not having to go to the health center if their HPV self-test was negative.

Discussion

Many women living in Appalachian Ohio are not within CC screening guidelines (Katz et al. 2015; Paskett et al. 2010). HPV self-testing at home may be a strategy to improve screening rates among this underserved population. The current study examined the beliefs and attitudes about this potential CC testing strategy held by providers and women from FQHCs in Appalachian Ohio. Health-care providers and women reported general acceptance of HPV self-tests completed at home as a potential CC screening test. However, the groups differed on the reasons for acceptance of this potential outreach strategy. Health-care providers expressed that a mailed HPV self-test for women to complete at home was a potential strategy to reach women not within CC screening guidelines and urge them to return to the health-care system. In contrast, women shared positive acceptance of HPV self-tests because they would not have to go to the health center, thus eliminating logistical barriers (e.g., lack of time going to the health center), as well as avoiding psychological barriers (e.g., the embarrassment and stress associated with undergoing a CC screening test).

The findings from the current study are similar to prior studies conducted among women living in other countries (Racey, Withrow, and Gesink 2013; Verdoodt et al. 2015), and in recent research studies completed in the U.S. (Crosby et al. 2015; Galbraith et al. 2014; Montealegre et al. 2015; Nelson et al. 2015; Scarinci et al. 2013). Most studies conducted in the U.S. have found that women were receptive to having an HPV self-test mailed to their home and to completing the test; these studies reported many of the same concerns, especially about correctly completing the test (Galbraith et al. 2014; Nelson et al. 2015). These findings were similar among immigrant women (Barbee et al. 2010; Sewali et al. 2015), among lesbian and bisexual women (Reiter and McRee 2015), and underserved women (Crosby et al. 2015; Galbraith et al. 2014; Montealegre et al. 2015).

In other countries, over 20% of women who were mailed an HPV self-sampling kit used and returned the kits (Verdoodt et al. 2015). Although not all women will complete an HPV self-test, this new screening strategy may potentially be useful for about a third of the women who, for different reasons, are not currently within CC screening guidelines. Health-care providers in the current study raised the concern that women with positive HPV test results will not follow-up with further testing because many women currently do not follow-up with their referrals for colposcopy after an abnormal Pap test. The addition of HPV co-testing to the CC screening recommendations (Moyer, on behalf of the USPSTF, 2012; Saslow et al. 2012), the possibility for discordant test results, and the potential for extending the screening interval adds complexity to provider-patient communication about CC screening and test results. Concerns about HPV self-testing and providing results to women are starting to emerge, as well as barriers to testing reported by providers (i.e., liability) and patients (i.e., missing a cancer) (Lin et al. 2015; Roland et al. 2015). Including HPV self-testing as part of a CC screening program should include: (1) an educational component for women about what will happen after the HPV self-test is completed; (2) health center policies in place for follow-up care, regardless of the HPV self-test results; and (3) an educational component about the process of self-testing for the health-care providers and staff working at the health centers.

Strengths and limitations

This qualitative study had several strengths. We were able to: gain insight about potentially using an HPV self-test as an early step in the CC screening process from health-care providers and women, identify facilitators and barriers to using an HPV self-device at home, and determine potential issues for reporting self-test results to women and ensuring that women attend subsequent visits for follow-up care. This information will be useful in the development of educational materials/programs to emphasize identified facilitators to self-testing (e.g., convenience), address frequently reported barriers to completing HPV self-tests at home, and to explain the importance of completing the HPV self-test and follow-up care.

Study limitations included a modest sample size of providers and women; however, focus groups were stopped when data saturation was reached in the women's and providers' groups. Because of the small sample size of providers, we were not able to compare physicians' and nurses' attitudes about HPV self-testing. Additionally, participants did not complete an HPV self-test but rather only provided their perceptions of HPV self-testing. Because of time constraints, the discussions with providers did not explore to a great extent the potential advantages or disadvantages to give HPV self-test results to women by mail or phone or for self-testing to be a primary screening strategy in the future. Furthermore, convenience samples were used, which makes it impossible to provide meaningful response rates and may limit the generalizability of the findings.

Conclusions

Women and health-care providers living in Appalachian Ohio were accepting of HPV self-tests as a potential CC screening test. However, both groups raised specific differences about the perceived advantages and barriers of using an HPV self-test device in the CC screening

process. Providers thought mailed HPV self-tests could be a strategy for promoting under-screened women's return to the health-care system, while women thought completing HPV self-tests could eliminate logistic and psychological barriers that may be induced by having to go to a health-care facility to receive Pap tests. The findings from this study can be used to inform a future CC screening program using HPV self-testing among Appalachian women, who are not within CC screening guidelines.

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Table 1

Demographic characteristics of focus group participants.

Characteristic	Level	Providers (<i>n</i> = 28)	Women (<i>n</i> = 15)
Gender	Female	24	15
	Male	4	–
Age (years)	Mean	43.1	44.9
	Range	25–58	32–62
Race	White	28	14
	Native American/Alaska Native	0	1
Ethnicity	Non-Hispanic	28	15
Education	< High school	0	1
	High school	8	12
	College	7	0
	Graduate or professional school	13	2
Marital status	Single	0	1
	Married/living together	20	8
	Separated/divorced	7	6
	Widowed	1	0
Employment status	Unemployed	–	6
	Disabled	–	8
	Part-time	1	1
	Full-time	27	0
Annual Household income	\$10,000	–	13
	\$10,001–\$20,000	–	2
Profession	Physician	1	–
	Nurse	16	–
	Nurse practitioner	8	–
	Medical assistant	3	–

Note: Items not assessed are indicated by dashes.

Table 2

Women's focus groups: Cancer and Pap testing.

HPV and Cervical Cancer in Appalachia

Woman (age 38): "I've heard this is the cancer belt."

Pap Test Barriers—Embarrassment

Woman (age 51): "... probably the having to, you know, just get up there and spread 'em'."

Woman (age 51): "I would say the embarrassment. Especially being overweight, you know? It's embarrassing."

Pap Test Barriers—Emotional Stress

Woman (age 38): "I don't like people touching me, so it's very uncomfortable for people to touch me so I can get a Pap smear."

Woman (age 32): "I mean, I think cancer is always really scary. That's a big thing around here, but I think especially feminine stuff, we seem to ignore because it's so uncomfortable too ... when you go to the doctor's.... Umm, I mean because you're just so exposed and you're just so, I mean, not even just physically but emotionally you just feel raw and ..."

Pap Test Barriers—Physical Pain/Discomfort

Woman (age 46): "People are too busy doing other things.... I would get too busy doing other things, raising children, family, you get busy and put it on the back burner. It's just one of the things you don't think about."

Pap Test Barriers—Indirect Costs

Woman (age 38): "No, it's the cost of daycare...."

Table 3

Provider and women's focus groups: Facilitators of self-testing.

HPV self-tests: Facilitators—Avoided embarrassment/more privacy	
<i>Provider:</i> "... if they're self-conscious enough that they would prefer to do this at home and, you know, not be in a doctor setting."	<i>Woman:</i> "And you could do that in your own privacy and not have a male doctor because it's so hard to find a female ..."
HPV self-tests: Facilitators—At-home self-tests are standard	
<i>Provider:</i> "... or a yeast applicator.... Most women are familiar with this type of a device to insert medications into the vagina."	<i>Woman:</i> "I did several tests at home, I mean, there's lots of tests that you do at home anymore for doctors' offices and you send back."
HPV self-tests: Facilitators—Saved time/money	
<i>Provider:</i> "And transportation. It's a rural area. People don't have the means to get here. I'm just thinking, so you would—that would be like an FOBT. You'd give it to the patient and they would take it home and they would mail it back in and then ..."	<i>Woman:</i> "... we would be more apt to do it at home because of the time issue.... We wouldn't have to go out. We wouldn't have to worry about the expense. If we did have insurance, it would cover it."

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Table 4

Provider and women’s focus groups: Barriers to self-testing.

HPV self-tests: Barriers—Worry about correctly completing self-test	
<i>Provider:</i> "... obviously if I mess it up the first time I may try it again...."	<i>Woman:</i> "They see that big long stick in there and they're like um ... How far do I go?" <i>Woman:</i> "That would be my only concern, that I would do it wrong."
HPV self-tests: Barriers—Potential harm/discomfort from device	
<i>Provider:</i> "I'm totally against that one. I just fear that that Q-tip is going to break off in somebody. I just know it." This same concern was raised by several women; "The instructions are easy to follow, but I would be afraid that the little white brush that you take off, that it would like come off [inside of the woman]."	<i>Woman:</i> "The idea of pushing ... Once you have something inside of you and it's already resisting and you've got to push, uh no." <i>Woman:</i> "I know but it's more like a Q-tip and that plastic in it because even like a Q-tip in your ear, that can be uncomfortable, and just thinking a Q-tip down there and I know they use a Q-tip in the Pap smear, and that makes it uncomfortable."
HPV self-tests: Barriers—Women’s physical limitations	
<i>Provider:</i> "... if you're not real dexterous, you know. How am I going to navigate to get where I need to be and push the plunger. It can cause problems." <i>Provider:</i> "I mean, if you have back problems, I mean, sometimes it's not as easy ... if you had short arms it would be difficult...."	<i>Woman:</i> "It's just, will it hurt someone if you're built small?"
HPV self-tests: Barriers—Potential contamination of device	
<i>Provider:</i> "If they touch it the wrong way they might contaminate it...."	<i>Woman:</i> "... but what if it touches something before you put it in there?"
HPV self-tests: Barriers—Negative associations with HPV infection	
<i>Provider:</i> "... so that might be a barrier because if they think, well if I test for this and I test positive, then that means that I have been unfaithful or I've done something wrong in my past or so, just a thought." <i>Provider:</i> "Again, that goes back to the HPV. This is not, I'm not looking for genital warts, you know. I'm not saying that you're promiscuous, I mean, because once they say that, then all of the sudden they're thinking well now you're saying I'm ..."	<i>Woman:</i> "HPV, first thing I thought was 'Okay well this is just another name for a type of cancer.'
HPV self-tests: Barriers—self-test instructions	
<i>Provider:</i> "The pictures are great but there is so much underneath it. And here, number five, 'Spread your labia.' They don't know ..." <i>Provider:</i> "I mean, it seems like it's too much reading The pictures aren't very clear.... The font's too small...."	<i>Woman:</i> "Yeah, what is a labia? I've never heard it called a labia before...." <i>Woman:</i> "I don't much like the instructions. I can't see nothing on this, the pictures or the words...."

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Table 5

Provider and women’s focus groups: Self-test results.

HPV self-tests: Returning devices via mail

Provider: "... if it was just a plain little package with a name on it, I don't think people would have a problem with it."

Woman: "No, as long as it was in a secure container. And as long as my personal information was only inside the container."

Woman: "... Because if I go through all the trouble of taking the test I don't want it, you know, something to happen to it between my house and there."

HPV self-tests: Results—Timing

Provider: "Until they're convinced otherwise, that's the worst thing they can possible have. And so if you say you're positive for HPV, automatically they are going to be like, 'That's it. It's over. Why go back?' ... give them an opportunity to either have, you know, re-testing or to sit down and educate them on what those results.... I think they'll be less anxious."

Woman: "So instruction of this screening test, please follow up with your provider within four weeks for test results or two weeks, whatever the time is."

HPV self-tests: Results—Delivery

Provider: "If my doctor called me and told me to come in and get my test results, I would probably think if it was normal he would tell me over the phone.... I'd have to get in there and find out."

Woman: "I would rather just get a letter, that way, you know, it's confidential.... I would rather be able to in my own private way sit down and read what's what."

Provider: "One day their phone works the next day the phone doesn't work. You can't get in contact with them."

Woman: "If it's good news, you can call me, if not leave me alone."

HPV self-tests: Results—Follow-up

Provider: "There are other kinds of gynecologic issues that should be addressed."

Woman: "We're all busy with our jobs ... if it came back negative and you didn't have to go, I think that would be great."

Provider: "Again, if you got people without insurance, yeah they would probably welcome the test, but if they don't have insurance, they aren't going to want to follow-up...."

Woman: "I'm going to be living in this body for the rest of my life. I want this body to be healthy, wealthy, and wise kind of thing for the rest of my life, so yeah, I'm going to get the sooner appointment because I want to live."

Provider: "And transportation. It's a rural area. People don't have the means to get here."

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