

To what extent will women accept HPV self-sampling for cervical cancer screening? A qualitative study conducted in Switzerland

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Objectives: Human papillomavirus self-sampling (self-HPV) is regarded as an alternative to Pap smear testing for women who do not participate in cervical cancer screening. This qualitative study aimed to determine women's views on cervical cancer screening and the various obstacles to participation in screening, and to evaluate the perceived benefits and disadvantages of self-HPV.

Method: Twenty-four focus groups were conducted in 2012, with a total of 125 participants aged between 24 and 67 years. They were recruited through different channels, including flyers and posters, personal contacts, and an ongoing clinical trial focused on the unscreened population. Interview transcripts have been coded with the ATLAS.ti CAQDAS.

Results: Fifty-seven participants regularly attended screening and 68 had not been screened in the past 3 years. While some participants considered self-HPV as an acceptable screening method, others expressed concerns. Benefits included access, reduced costs, and time-saving. Disadvantages included the fear of not performing the test correctly, hurting oneself, and the accuracy of the test. Participants expressed concern that self-HPV would replace gynecological visits.

Conclusion: Self-HPV is not likely to rapidly or substantially modify women's behaviors in regard to screening. While it may offer benefits in some specific situations, most women emphasized the advantages of regular gynecologist visits.

Keywords: self-HPV, cervical cancer, cervical screening, qualitative study, Pap smear

Background

Initiated in the late 1970s, human papillomavirus self-sampling (self-HPV) was developed for underserved women with limited access to health care.¹ Self-HPV was expected to improve the overall screening rate and reduce inequity in access to screening. The medical literature presents self-HPV as an innovative, promising, and effective alternative to the traditional Pap smear test,²⁻⁴ offering a less intrusive procedure and increasing screening rates in previously under-screened women.³⁻⁶ According to the results of recent randomized controlled trials, invitations for self-HPV are more often accepted than Pap smear invitations,^{4,5} indicating that screening participation is increased.

Some studies have also examined the acceptability of self-HPV in different contexts and emphasized the advantages and limits of this method, as perceived by users. Factors in favor were found to be: respect of privacy and intimacy, provision of comfort, and absence of embarrassment.⁷⁻⁹ The primary justification for self-HPV use and preference for this method of screening tend to be related to practical and emotional issues. Practically, the test can be done at home, at any chosen time,

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quickly and easily.¹⁰ Emotionally, the test appears to be more acceptable, respectful, and private than the traditional Pap smear. Women expressed less shame and embarrassment using self-HPV than undergoing a Pap smear test.^{8,9} Above all, self-HPV does not involve a pelvic examination,¹¹ which has been found to be an important reason for non-attendance at Pap smear screening.⁷ Women with higher education levels are more in favor of self-HPV than those with a disadvantaged or migration background.^{2,4} Studies conducted with hard-to-reach groups, composed mainly of migrants, concluded that self-HPV is a culturally acceptable method for cervical cancer screening,^{1,8} but possibly not universally accepted.¹¹ A number of factors against this method have been identified, including the fear of incorrectly performing the test, hurting oneself, lack of confidence in the efficacy of the method, and the need to talk with a gynecologist.^{11,12}

While self-HPV has often been studied in relation to access issues, other obstacles to cervical cancer screening have been highlighted. Particular difficulties related to interactions with gynecologists (poor communication), the pelvic examination itself (fear and pain), and the public exposure of private body parts (taboo and embarrassment).¹³⁻¹⁶ In Switzerland, these obstacles represent a particularly important issue as screening is opportunistic and Pap smears are only performed by gynecologists. In 2012, 75% of women aged 20 to 60 years had attended cervical cancer screening in the past 3 years, a rate that remained fairly stable since 1992 (unpublished data, Burton-Jeangros et al, 2015).

In this context, we conducted a qualitative study that aimed to assess obstacles to attending cervical cancer screening among regular attendants and under-screened women (a research report was produced at the end of this study and is available online at the website of the University of Geneva).¹⁷ The present study also aimed to determine women's willingness to perform self-HPV. Qualitative data were collected to emphasize participants' views and to identify the range of advantages and disadvantages of self-HPV as identified by participants.

Method

Between May and November 2012, 24 focus groups were conducted in Geneva (Switzerland), with 125 participants aged between 24 and 67 years. Participants were recruited via posters and flyers distributed in different settings (feminine associations, local community centers, educational settings, community associations, and churches), and through personal and professional contacts. Women were also recruited through the DEPIST study (www.depist.ch),

a clinical trial that aimed to identify the characteristics of the unscreened population (ie, those who had not received a Pap smear in the preceding 3 years) and assess the acceptability of self-HPV as an alternative to the Pap test in unscreened women. Women participating in the DEPIST study were randomized to receive either a self-HPV kit or a Pap smear invitation. Women from the DEPIST study were invited to participate in the present study which examined barriers to screening in more detail. A total of 40 participants in the present study were recruited through the DEPIST study.

The focus groups were conducted in two phases. In the first phase, general obstacles to cervical cancer screening were discussed (eg, information, access, and cost). The second phase assessed the acceptability of self-HPV as an alternative to the Pap smear. A self-HPV kit (as used in the DEPIST study, that included written information and drawings on how to perform self-sampling, a sterile flocked swab, and a transportation tube) was circulated to all participants. Participants were then asked to talk about the advantages and disadvantages of the swab. In eight of the 24 focus groups, some women reported that they had used a self-HPV test as part of the DEPIST study (n=20) and these women reported on their personal experience. This means that the results of the present study included a mix of opinions from women who had actually used the method (n=20) and those who had not (n=105). Following the existing literature, an interview guide was elaborated around five main topics: 1) information on screening; 2) emotions associated with screening; 3) the procedure used to perform a Pap test; 4) the practical difficulties encountered, including access, cost, past experiences, and interactions with gynecologists; and 5) the acceptability of HPV self-sampling.

The focus groups took place in non-medical settings, with 17 conducted in French, five in Spanish, and two in Portuguese. With participants' permission, all discussions were tape-recorded and fully transcribed. Those conducted in Spanish and Portuguese were translated into French. On average, the focus groups lasted between 90 and 120 minutes. The transcripts were systematically coded, using the ATLAS.ti CAQDAS. A thematic coding was used. Most codes were a priori defined along the main research questions, but further codes emerged over the coding process itself.

The study protocol was approved by the central commission for ethics of the Geneva University Hospitals. An information document and a consent form were distributed to all participants, and only those who provided written consent were included in the study. A brief questionnaire on social characteristics was filled by each participant at the end

of the focus group. Pseudonyms have been attributed to all participants quoted below.

Results

Half of the participants originated from Europe, including Switzerland, and the others came from further afield (Latin America and Africa). Fifty-four participants had attended university, with the remaining having a lower education level. A total of 57 participants were regularly tested for cervical cancer (at least once in the past 3 years) and 68 had not been screened in the past 3 years (Table 1).

No major differences between migrant and Swiss women were noted in terms of their evaluations of the advantages and disadvantages of self-HPV. Both groups expressed concern about the test accuracy. A generational difference was observed: younger women, used to visiting a gynecologist, did not see the necessity of changing this practice, while some older women, less used to regular gynecological appointments, were more in favor of self-HPV, especially if they had had a bad experience with pelvic examinations in the past.

Self-HPV advantages according to (potential) users

Nearly all participants reported that the test appeared to be practical. The majority of those who had actually used self-HPV reported the test “easy to perform”, “not painful”, or “great”. The kit was often compared to a pregnancy test

and the procedure similar to introducing a tampon or a vaginal suppository. Unscreened participants, who had not previously tested the self-HPV, favorably appraised the apparent “easiness”, “rapidity”, and “comfort” of the swab. Participants who had a prior negative experience with a gynecologist and those considering the pelvic examination to be (psychologically and physically) extremely difficult were particularly interested in self-HPV. The “cheaper cost” or the “gratuity” of the kit was acknowledged by migrants and by women working with minority groups (ie, illegal migrants) who supposed it would be less expensive than the Pap smear.

Some women noted that the waiting list for a gynecological appointment was annoying and discouraging, and considered the time saved by self-sampling very attractive:

It’s very practical and it doesn’t take time. Waiting lists are always very long. [Stephanie, 37 years old]

They also valued the possibility of receiving the test at home for free. Self-sampling was therefore seen as a process that would reduce access issues, particularly in remote areas with no access to a specialist. Self-HPV was considered by some women as an extension of their ability to self-diagnose, similar to breast self-examination:

Aside from the swab and to palpate breasts, I don’t see much interest in a visit, for me it was more for contraception. But if there’s a way I can do it myself, I would do it quickly. [Eline, 26 years old]

With regard to target groups for self-HPV, participants expressed contrasting opinions. Some emphasized its benefits in making life easier for all women, and more specifically, for those who do not get screened for cultural reasons. Some also saw self-HPV as a solution for young women, limiting the need for them to talk with their mothers, reducing shame, and saving time and money. Alternatively, others suggested that the test could be unsuitable for teenagers or young women who need to be seen and informed first by a doctor. Some felt self-HPV was not appropriate for older or disabled women:

My grandmother, she’s 60, obese, she has some mobility difficulties. I think that test is a little limiting. [Marjorie, 28 years old]

It was not considered appropriate for women who “do not know their body”, with a particular reference to uneasiness with anatomy.

Table 1 Participant characteristics

	Screened in the past 3 years	Not screened in the past 3 years	Total
Recruitment			
Non-DEPIST	54	28	82
DEPIST	3	40	43
Age (min =24, max =67)			
Less than 40	29	18	47
40 and over	28	50	78
Origin***			
Swiss	21	10	31
Migrants	36	58	94
Children			
Yes	27	50	77
No	30	18	48
Education			
Professional education*	23	48	71
Higher education**	34	20	54
Total	57	68	125

Notes: *Professional education includes compulsory schooling, apprenticeship, maturity, professional schools; **university diplomas; ***this distinction between Swiss and migrants is not straightforward, some women have several nationalities, and some have migrated at different stages in their life. In the present study, women self-identified as Swiss or migrant.

Abbreviations: min, minimum; max, maximum.

Self-HPV disadvantages according to (potential) users

Use of the self-HPV test elicited a lot of fears, including a fear of hurting oneself, rubbing in the wrong place, not collecting enough cells, creating bias in the results, and the fear of not performing the test correctly:

I wouldn't trust myself to put that, to do what's needed to get cells on this. I don't feel like doing this kind of thing alone at home. [Sarah, 37 years old]

Some women also expressed the fear of doing the test wrong, and then getting wrong results. The procedure itself was questioned by women who had tested the kit, and who reported feeling worried about having done it adequately because they had felt no pain during the swab. To them, the absence of pain, in contrast to the pain usually felt during the pelvic examination with a gynecologist, was suspicious. Others who had tested the self-HPV reported having hurt themselves, especially since they had worried about not being thorough enough.

Some raised questions about the female anatomy, and in particular expressed concern about not being able to find their cervix. They were not sure how far to insert the swab and how hard they had to rub to collect cells:

Am I high enough or not? and then, if I go up too much, do I take cells at the wrong place? [Tamara, 43 years old]

Some participants were concerned about whether the fluid and the swab were sterilized, and among those who had tested the kit, some also wondered if they had cleaned themselves enough before taking the sample. Although the lack of embarrassment was seen as a benefit of the self-HPV, surprisingly, some women who had tested the kit reported that it could be more awkward than a Pap smear. Some participants expressed a wish to test it for the first time with their gynecologist or at least to hear his/her explanation. These statements emphasized the trust placed in the ability of a doctor to perform the test correctly, and a lack of trust of their ability to do it themselves. The lack of confidence in the accuracy of the self-HPV was a common concern, and was the major reason given for preferring a Pap smear by some of the participants who had used the self-sampling test. One participant said she would like to receive an immediate confirmation that the collected cells were "appropriate", like a pregnancy test. Without instant results, she thought the test was useless.

Those participants not attracted by the self-test were mainly women who were regularly screened; they questioned the reliability of the test, its results, and the procedure. They were also worried that it could replace the interaction with

the gynecologist, whom they considered as an essential interlocutor and as the only competent person for such an important check-up:

Nothing can replace the person who has learned all this well, to whom we can ask questions and whom we trust. [Frédérique, 62 years old]

Concern about the risk of missing cancer with self-sampling was prevalent in their comments and they reported feeling safer after a gynecological examination. For them, gynecologists are professional, competent, and legitimate to screen women; an opinion shared by some unscreened women. They also highlighted the importance of the contact and of having someone to answer their questions; a factor that was seen as "irreplaceable". These women often mentioned that the gynecological examination represents "something more", that is, a more comprehensive check-up. As screening is a medical routine ("it runs well", "it's obvious"), the "well checked women" considered that there is no need to change what has been implemented for years. In a more moderate perspective, some participants saw an opportunity to alternate self-sampling with Pap smears, seeing the self-test as a good way to space out gynecological examinations:

Where it can be interesting, it's in the cases, when one is in a fairly remote place, where going to the gynecologist is really complicated or where there are not many. [Christine, 30 years old]

Many participants were clearly not ready to challenge the traditional division of labor between patient and doctor. The risk of missing something by "kicking out" the specialist was mostly expressed by screened women and those who had a family history of cancer. Some even rejected the idea of promoting it as a method of screening.

Several participants pointed out that the self-HPV would not solve the problem of non-attendance due to a poor relationship between doctors and patients. They stated more effort should be directed to improving these relationships, rather than solving the problems by reducing medical visits. They considered that self-HPV should not replace gynecologist visits. Some participants, both screened and not screened, stated that the self-HPV would not guarantee that more women get screened. Considering that women who were not screened regularly were lacking information or a self-care attitude, they suggested that the embarrassment related to the pelvic examination is not the only barrier to uptake:

If this self-sampling was in a pharmacy and if women keep not being informed on how to do the exam, which is important, it will not change anything. They have to be

informed. Nobody will buy it, if they don't know they have to do the test. [Fabienne, 24 years old]

Conclusion

There is growing evidence that self-HPV can be an effective alternative for non-participants to cervical cancer screening programs. However, the implementation of a new screening method is a complex process and acceptance by the population is an important issue. Consistent with other studies, opinions in our study ranged from total enthusiasm to total rejection, and included some ambivalent attitudes toward self-HPV.^{1,7-9,11} Arguments in favor of self-testing were that it is practical, less expensive, easy to use, time-saving, ensures autonomy, produces less shame and embarrassment, limits pain, and is a good complementary method to the Pap smear. Some women highlighted that self-HPV could allow visits to the gynecologist to be spaced out by alternating self-HPV with Pap smears. Conversely, arguments against self-HPV concerned the reliability of the test, the validity of the results, the material used as well as the participant's ability to do the swab correctly, and the fear of getting hurt or of missing something. Some women felt that the swab was confusing and unsuitable, especially for younger, older, or disabled women, and those who know little about their bodies.

The participants represented a mix of socioeconomic circumstances and the focus groups integrated both regularly screened and under-screened women. Beyond the equity issues that are often addressed in relation to studies on self-HPV acceptability,^{1,4} our results suggest that previous experience with a gynecologist plays an important role. In addition, women who had not tested self-HPV, but who were in favor of it, indicated over the course of the discussion that for safety reasons, they preferred a gynecological examination to self-HPV, as observed in previous studies.^{11,12} Women who were particularly resistant to the test feared that it could replace the gynecologist whose role they considered essential in health monitoring. Most participants were more confident in their gynecologist's ability than their own to collect cell samples, and preferred the gynecological visit even if the pelvic examination was uncomfortable and embarrassing.

Unscreened women, for whom the speculum intrusion was painful or traumatizing and time consuming, were the most enthusiastic and reported that they would immediately adopt self-screening if they could. However, in the focus groups, not all unscreened women would have accepted it. Furthermore, among the women who had tested the swab, some said they would not use it again in the future, especially young women

who were anxious about hurting themselves and not using it accurately, and felt uneasy with the swab. This suggests that the method is likely to increase the participation of cervical screening mostly in specific groups of women.^{3,6,8,9}

However, although many women perceived benefits in self-sampling, most participants indicated they would not use the self-HPV method. Interestingly, self-HPV was considered by many as an acceptable method in addition to the Pap smear, rather than as a replacement to it. Women saw it as a way to gain more information by collecting cells more regularly than their visits to the gynecologist. This could paradoxically contribute to over-screening which could result in more harm than benefit.

Therefore, at this point, the self-HPV method does not seem likely to rapidly or substantially modify women's behaviors in regard to screening, especially among those who have a good relationship with a gynecologist. These women emphasized that the gynecologist remains the expert, and self-HPV appeared to be unacceptable or even dangerous to them. They claimed that the focus should not be on which test needs to be promoted to increase screening, but instead insisted on the importance of improving the gynecological examination and relationship with the doctor,¹⁸ as well as improving the dissemination of information.

This preference for encounters with gynecologists could reflect the permanence of trust in the medical profession. It can also be interpreted as an illustration of the dependency on medical expertise,^{3,19} especially in relation to female body issues, described in the literature on medicalization.²⁰⁻²² In conclusion, self-HPV could be situated within the philosophy promoted by the movement at the origin of "Our bodies, Ourselves" in the 1970s, by giving women the opportunity to develop a form of expertise through the checking of their own bodies. However, our findings suggest that the technical possibilities offered by self-HPV might not be sufficient to radically alter the distribution of roles between health care professionals and patients.

This study conducted with both Pap smear attendants and non-attendants emphasized women's concern about the reliability of the test and their confidence in sampling performed by the physician. This confirms that self-HPV is more likely to be adopted by women who do not regularly attend a gynecologist. In Switzerland, where screening is opportunistic, these results help to assess the possibility of opportunistic self-HPV. Future research and policy should thus focus on how to reach and inform women who are not regularly attending a gynecologist.

Limitations

This qualitative study covers the range of issues considered important by the participants; it does not describe the relative importance of the issues. Furthermore, assessing acceptability differs from assessing actual use of the method. While the format of focus groups was appreciated by the participating women, the flow of the discussions and the expressed opinions may have been influenced by leaders within the groups, despite the efforts of the moderator. Individual interviews would have provided complementary data, but would not be comparable in other respects.

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Author contributions

All authors contributed toward data analysis, drafting and critically revising the paper and agree to be accountable for all aspects of the work.

Disclosure

The authors declare that they have no competing interests.

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