Barriers to Acceptance of Self-sampling for Human Papillomavirus across Ethnolinguistic Groups of Women

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ABSTRACT

Objectives: Immigrant and low socio-economic (SES) women in North America underutilize Papanicolaou screening. Vaginal swab self-sampling for oncogenic human papillomavirus (HPV) has the potential to increase cervical cancer screening participation. The purpose of this qualitative study was to understand the perceptions of lower SES and immigrant women regarding self-sampling for HPV.

Methods: Eleven focus-group interviews were conducted: one with Canadian-born English-speaking lower SES women, and two groups each with Arabic, Cantonese, Dari (Afghani), Somali and Spanish (Latino)-speaking women (one group conducted in English, the other in the native language) recently immigrated to Canada. Five to nine women aged 35 to 65 years and married with children participated in each group.

Results: Themes included 1) who might use self-sampling and why; 2) aversion to self-sampling and reasons to prefer physician; 3) ways to improve the appeal of self-sampling. Women generally perceived benefits of self-sampling and a small number felt they might use the method, but all groups had some reservations. Reasons included: uncertainty over performing the sampling correctly; fear of hurting themselves; concern about obtaining appropriate material; and concerns about test accuracy. Women preferred testing by a health care professional because they were accustomed to pelvic examinations, it was more convenient, or they trusted the results.

Conclusions: Perceptions of self-sampling for HPV were similar across cultures and pertained to issues of confidence in self-sampling and need for physician involvement in care. These findings can inform programs and studies planning to employ self-sampling as a screening modality for cervical cancer.

Key words: Emigrants and immigrants; mass screening; human papillomavirus; qualitative research

La traduction du résumé se trouve à la fin de l'article.

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In 2002, there were an estimated 490,000 new cases of cervical cancer worldwide.¹ This incidence rate varies greatly across the world, with rates in some areas of the developing world six times higher than in North America. Even in developed countries with screening programs, approximately one third of women do not participate regularly or ever in Papanicolaou (Pap) smear screening, with women of lower socio-economic status and immigrants being particularly under-represented in screening.²⁻⁴ One common barrier to screening is the need for pelvic examination with speculum insertion.⁵ Self-obtained vaginal sampling for human papillomavirus (HPV) testing has been investigated as an alternative to physician-obtained Pap smears for cervical cancer prevention.^{6,7}

Studies of vaginal self-sampling perceptions have mainly been conducted in clinics among women attending for cervical screening or treatment, using quantitative questionnaires; these studies provide limited insight into understanding barriers to and enablers for screening. Several studies have found that women who have experienced both physician Pap testing and vaginal self-sampling reported a preference for self-sampling or stated no preference.^{8,9-11} However, results from studies on the acceptability of self-sampling may not be generalizable to all ethnic groups or to women who have not yet performed self-sampling.¹²

Theories of health behaviour change emphasize patients' perceptions of barriers to and benefits of preventive health screening.¹³ Perceptions among immigrant women regarding cervical screening may act as barriers, due to lack of exposure and education around preventive screening in their home countries, as well as cultural or religious barriers around pelvic examination.^{14,15} Therefore, the purpose of this study was to gain a detailed understanding of immigrant women's perceptions of

vaginal self-sampling for HPV, in order to inform culturally appropriate interventions. As part of a qualitative study of perceptions of cervical cancer screening among immigrant women from five different ethnolinguistic groups and a Canadian-born group of women, this paper reports on results pertaining to vaginal self-sampling.

METHODS

The study used a qualitative grounded theory approach to describe and explain the women's perception of cervical cancer, grounded in data.¹⁶ The overall goal of the full study was to derive an explanatory model of cervical cancer.¹⁷ In line with this approach, the intent of sampling was to obtain views from a focused sample of participants who could represent their ethnocultural groups, to create local understandings.¹⁸ Focus groups were used to create a safe environment for women to discuss these issues with women of the same background, and to ensure the experience was socially acceptable and relaxing. The study was conducted from 2004 to 2005 in Hamilton, Ontario, Canada, a city with a population of approximately 500,000 that includes about 125,000 new immigrants.¹⁹ Five ethnolinguistic groups representing the greatest recent increase in numbers in Canada participated: Cantonese and Arabic speakers, as

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Table 1. Characteristics of Focus Group Participants

	Age	No. Children	Years in Canada	Taken English Lessons	Have Family Doctor	Go for Well-visit Check-ups
	Median (Range)	Median (Range)	Median (Range)	n (%)	n (%)	n (%)
Canadian-born English-speaking (n=7)	40 (34-61)	2 (0-8)	NA	NA	7 (100)	6/7 (86)
Arabic-English speaking (n=6)	39 (34-47)	2 (0-8)	3.5 (1-11)	6 (100)	6 (100)	5 (83)
Arabic-Arabic speaking (n=7)	39 (35-49)	3 (1-5)	4 (4-6)	7 (100)	7 (100)	2 (29)
Chinese-English speaking (n=5)	35 (30-40)	1 (0-2)	4 (3-11)	5 (100)	3 (60)	3 (60)
Chinese-Cantonese speaking (n=5)		Demographic information not obtained due to an oversight during the focus group				
Somali-English speaking (n=8)	ND	6 (1-8)	10 (4-16)	ND	ND	ND
Somali-Somali speaking (n=7)	40 (26-66)	5 (1-13)	2 (1-3)	2 (29)	5 (71)	4 (57)
Afghani-English speaking (n=8)	35 (22-45)	3 (0-6)	2 (1-6)	8 (100)	8 (100)	6 (75)
Afghani-Dari speaking (n=8)	37.5 (33-49)	2 (1-5)	2 (1-4)	6 (75)	8 (100)	6 (86)
Hispanic-Spanish speaking (n=9)	32 (22-51)	2 (0-4)	4 (0.5-16)	9 (100)	8 (89)	5 (56)
Hispanic-English speaking (n=7)	35 (34-51)	2 (0-4)	3 (1-5)	6 (86)	6 (86)	7 (100)

Note: Demographics not available for the Chinese-Cantonese speaking group
 NA = Not applicable, ND = No data available

well as women from Afghanistan, Somalia, and Central America. A group of lower socio-economic status (SES) Canadian-born women were also recruited from a community health centre located in a socio-economically disadvantaged area of the city, as another group who underutilize Pap screening.

Eligible women were 35 to 69 years old, currently or previously married. Immigrant women living in Canada between 1 and 5 years were sought. Additionally, advice from fieldworkers belonging to two of the cultural groups indicated that it would be more culturally appropriate to discuss cervical screening among women who were married and had children, since they would have experience with health care encounters involving pelvic exam; therefore, having a child was an additional inclusion criteria for the immigrant women. Age 35 to 69 years is the age group for whom HPV infection is relevant for clinical care.²⁰

Immigrant participants were recruited with the help of SISO (Settlement and Integration Services Organization), a local agency used by immigrant and refugee families in Hamilton. Employees of this organization used lists of families who had used the organization, along with our age eligibility criteria, to approach women for permission to be contacted by the researchers.

The topics on the interview guide were selected based on literature on barriers to cervical cancer screening among immigrants, and the clinical experience of family physicians on the research team with extensive experience in the health care of immigrants and refugees. Topics included, in order: a) a group activity in which participants drew in reproductive organs on an outline of a woman's body; b) women's knowledge about cervical cancer and how to prevent it; c) their opinion of a video depicting a family physician explaining a Pap test to a patient; and d) their views about a vaginal self-sampling kit as an alternative to Pap smear tests.

To reduce the risk of embarrassment, questions were raised indirectly by asking participants to imagine the response of a fictive friend of the same ethnic background and similar characteristics. Later, the facilitator directly asked participants what they thought about self-sampling and what they would do if offered this as an alternative to Pap testing.

Participants were shown a Dacron cotton swab for vaginal sampling, a tube with fixative solution, and a diagram and written instructions for obtaining a sample. The facilitator explained why self-sampling could be an alternative to cervical cancer screening. Women were asked if the fictive friend would be likely to use this method of sampling at home, reasons for their answer, what her concerns might be, circumstances under which women might be likely to use the kit, and which method – self or clinician sam-

pling – the friend would prefer. They were then asked about their own thoughts and opinions.

The first focus group was conducted with the Canadian-born participants. The discussions conducted in the English language with the ethnolinguistic groups were led by an experienced qualitative researcher (LL), assisted by a fieldworker. The focus groups conducted in the native language of the ethnolinguistic groups (Cantonese, Arabic, Dari, Somali, or Spanish) were led by the fieldworker. The first session served as hands-on training for the fieldworker, in addition to prior individual training of approximately two hours to teach the concepts of question-asking and group facilitation, given by the experienced qualitative researcher. Each fieldworker also translated written information into her native language.

Each focus group session lasted 2-3 hours and included a group interview lasting 1.5-2 hours.

Focus groups were audiotaped and transcribed verbatim. Translation and transcription were done either by bilingual university students, the fieldworkers, or a bilingual research coordinator. Fieldworkers were not involved in analyses. Two authors (AL, MH) independently read a first set of transcripts to identify themes and concepts. An editing approach, as an organizational style, was used to extract themes and develop a coding template by sorting data according to an emerging template.²¹ The analysts met to create an exhaustive list of themes and concepts, then each independently coded all transcripts. They then exchanged coding to ensure consistency, and discussed differences until consensus was reached either by one analyst changing their coding, or by adding new themes when agreed. The final themes and concepts were organized by discussions and consensus, to provide a complete picture on perceptions and barriers, to inform recommendations for uptake of self-sampling. The focus group moderator (LL) who conducted all English-speaking groups and was present at all groups, read all transcripts and is a co-author on this manuscript, as a check of trustworthiness. All co-authors who were not directly involved in the analysis for this manuscript have also read all transcripts, and all agreed with the results.

The Hamilton Health Sciences/McMaster Faculty of Health Sciences research ethics board in Hamilton, Canada, approved the study.

RESULTS

Median ages for the groups ranged from 32-40 years (Table 1). Women in all but the Somali English-speaking group had been in Canada a median of 2 to 4 years. In the Arabic, the English-speaking Somali, the Dari-speaking Afghani, and the Spanish-speaking Central American groups, we experienced difficulty in recruiting, and accepted

Table 2. Themes and Concepts That Emerged from the Focus Group Interviews

Concept	Focus Group													
	Canadian	Arabic-English	Arabic-Arabic	Cantonese-	English	Chinese-	Cantonese	Somali-English*	Somali-Somali	Afghani-English	Afghani-Dari	Hispanic-English	Hispanic-Spanish	Total
Who might use / why?														
To avoid speculum exam	•		•						•					3
Women not comfortable with doctor	•	•	•						•					3
Women embarrassed to undergo Pap	•													1
Option to Pap smear	•													1
Easy to do			•											1
Women who prefer to do test at home										•				1
Women who live far from health care	•											•		2
Women who are busy		•			•									2
Teenage girls	•													1
Women who have had no children	•													1
Personally would use (but not preferred)		•												1
Easier			•						•	•			•	4
More convenient	•									•			•	3
If women afraid of male doctor			•						•					2
Saves time										•				1
Would personally do test									•					1
Preferred by none						•								1
Reason for aversion to self-test and reasons to prefer physician testing														
Prefer expert	•		•		•	•	•		•					6
Prefer expert (but expert must be female)			•											1
Need instrument to open vagina			•											1
Doctor can see what to test									•					1
Safer									•			•		2
Physician testing more convenient		•												1
May not be able to do self-test correctly	•	•	•		•	•	•	•	•	•	•	•		9
May not get correct self-test result	•		•		•	•		•	•					5
Incorrect self-test answer if close to period					•									1
May harm self	•		•		•	•			•	•				6
Can't reach cervix			•						•					2
Tube contents can spoil on transport to doctor									•					1
Don't have enough information about the self- test					•							•		2
Self-test inconvenient	•	•												2
Modesty issue of vaginal swabbing		•												1
Similar to tampon use: dislike of tampons							•	•						2
Inappropriate to self-sample vagina for ethnocultural/religious reasons						•						•		2
Self-test cannot be done at home									•					1
Children may find swab									•					1
Government way to save money	•													1
Suggestions to improve appeal of self-test														
Improve diagrams and instructions	•													1
Give contact number for help	•													1
Instruct where to send test	•													1
Make women confident										•				1

* Self-sampling was not discussed in this group as fully as in the other groups due to time constraints, and therefore the data from this group are limited.

women who had been in Canada for a longer time period. Women in two ethnolinguistic groups would only come to the focus group meeting if they were accompanied by a female friend or relative who could also take part in the group. We agreed to this request, even if the accompanying person did not meet the criteria we had initially set.

Table 2 shows the themes that arose from the data in the different groups.

Theme 1. Who might use the test and why

Women were generally interested in the self-test but had many reservations. It was common for each group to suggest it would be suitable for some women, such as those who could not go to their physician or were embarrassed about having the exam done by a physician. While the occasional woman said that she herself would do the test, most participants indicated they personally would not like to use the method. (Quote 1A in Table 3)

When discussing reasons why the test might be beneficial and who might use it, issues around modesty, prior negative

experience with pelvic exams, and the convenience of not having to travel to a health care clinic arose. For example, women thought the test might be the preferred option for a woman who had not yet had children if she had less experience with physician exams. In contrast, for women with children, physician testing seemed the obvious choice. (Quote 1B in Table 3)

Theme 2. Reasons for aversion to self-test and preference for physician testing

The main reason participants thought other women would be averse to self-sampling was the concern about obtaining accurate results. Women expressed concern about the fluid in the tube spilling, the effect of menstruation on test results, doing the test incorrectly, not being able to find the cervix (indicating a perception that the swab was required to sample the cervix rather than the vagina), and not knowing how far to insert the swab and so possibly causing themselves harm. For these reasons, some women

Table 3. Selected Quotes from Focus Groups

Group	Quote
Theme 1. Who might use the test and why	
1A: Canadian-born English-speaking	"I think this would be good. But for myself, I don't think I would use it."
1B: Canadian-born English-speaking	"...if somebody's embarrassed about having it, this might be a good way for them to do it. It's not so embarrassing." "...She's (fictive friend) had 3 kids, why wouldn't she go to the doctor?"
Theme 2. Reasons for aversion to self-test and preference for physician testing	
2A: Hispanic-Spanish speaking	"...she would need to be extremely careful, because she could, instead of taking out cells she could instead extract some other additional bacteria and put it in the bottle." "...it would need to be more professional because someone could easily make a mistake and not do it properly."
2B: Chinese-Cantonese speaking	"If we Chinese women don't even use tampons, I think we would not do this test. It's probably the issue of cultural differences."
2C: Chinese-Cantonese speaking	"As far as I know, back in [home country], tampons are still not very popular among young girls unless they're athletes or going swimming."
2D: Arabic-Arabic speaking	"... [I would] prefer [the] doctor because speculum would be used." "[it's] too difficult to open the vagina without this instrument to make sure the sample would be taken the right way." "...If there's a nurse who could do it in a woman's home and send the sample to the doctor's office or lab, that would be alright."
2E: Arabic-Arabic speaking	"...don't care if it's a doctor or nurse, but the person should be female."
2F: Canadian-born English-speaking	"I don't like that... it's a pain. Then you have to write on the tube. You gotta take it to a clinic. You know, one stop deal.....go to your doctor, get your pap smear done, she looks after it."
Theme 3. Suggestions to improve appeal of self-test	
3A: Hispanic-Spanish speaking	"so just by looking at this diagram, she would need a lot more information to do this."
3B: Hispanic-Spanish speaking	"is this test 100% reliable?"

strongly felt that such an important test should not be done by a woman unsupervised at home. (Quote 2A in Table 3)

Women in one group indicated that self-sampling may not be favourably received because of cultural norms. (Quotes 2B, 2C in Table 3)

Many groups strongly indicated a preference for this procedure to be done by a health care professional or at least with a health care professional present to offer assistance if needed. (Quote 2D in Table 3)

One group of Arabic women further stipulated that the health care professional should be a woman. (Quote 2E in Table 3)

Attitudes of Canadian-born women were generally similar to those of the women from other cultural groups in that they discussed how physically uncomfortable Pap tests are, but that for them, self-sampling was not an option. (Quote 2F in Table 3)

Theme 3. Suggestions to improve appeal of self-test

Women made recommendations for improving the information and instructions about self-sampling, including providing step-by-step diagrams and instructions, having a version comprised of only diagrams, and information on how long the container can be kept in the home. (Quotes 3A, 3B in Table 3)

DISCUSSION

This study found that immigrant women from several ethnolinguistic groups, as well as Canadian-born women, were hesitant about the idea of vaginal self-sampling for HPV. They had many concerns about the accuracy and safety of this method, even after receiving an explanation and a diagram with instructions. Other studies have documented similar barriers to self-sampling – specifically, concerns about not doing self-collection of vaginal samples correctly and the perception that such tests should be conducted by health care professionals.^{6,22,23} Focus groups conducted among rural women in China found that women would be willing to pay up to the equivalent of US\$2.50 for a Pap smear done by a health care provider but less than US\$1.25 for vaginal self-sampling.²⁴

We expected, given the knowledge that immigrant women are less likely to use Pap screening, that there would be cultural issues around

self-sampling. Only Chinese women linked the lack of acceptance of self-sampling to a cultural issue in relation to their lack of tampon use. No other groups specifically mentioned culture as a barrier.

Despite concerns, women who participated in the present study saw benefit in having a self-sampling option in some situations for some women, but most participants indicated they were not interested in using this sampling method themselves. Some participants indicated they had undergone pelvic examinations before, and that having a health professional do a test "right" was more important than avoiding a speculum examination. It is possible that the women who participated in our focus groups may have been more like the mainstream "Canadian" women, the majority of whom do undergo Pap smear screening.

A good number of studies have reported that women find self-sampling acceptable,^{6,8,9} in contrast to the predominant findings in our study. In our study, a focus group led by a non-health professional may have allowed women to raise concerns that other studies asking a single question on acceptability or preference would not identify. In many studies, women who stated that self-sampling was acceptable or preferable were those who were questioned after they had performed the test, often in a clinic, and possibly with the help or supervision of a health care professional. In our study, women had not had prior experience with the method. Women in our study may also not have been accepting of self-sampling because our explanation and information about the self-sampling may have been inadequate, in that they did not *a priori* address women's concerns. Based on the concerns raised in this study, information on self-sampling should include the information outlined in Table 4.

There were several limitations in this study. The sample was restricted to women older than 35 and married with children and results may not be generalizable to younger single women. Only one focus group per ethnic and language group was conducted, and the particular group recruited may not have reflected views of the larger cultural group. However, results were very similar within each ethnic group, regardless of language, suggesting saturation of information. The interview guide and processes

Table 4. Recommendations Based on Immigrant and Canadian-born Women's Comments on HPV Self-sampling Kits

1. Explain the accuracy of the test
2. Explain testing appropriateness at the time of menses
3. Clarify how far the swab has to be inserted, perhaps by marking the point on the swab that should touch the introitus
4. Clarify the simplicity of the test: that the swab of the vagina itself is what is needed
5. Clarify that the cervix itself does not need to be sampled
6. Clarify that bacterial contamination, if any, will not affect test results
7. Address the issue of whether there is potential to hurt oneself
8. Address concerns about spilling the transport fluid and assure that the fluid is not harmful, or consider a dry swab method
9. Address concerns about the effect of transport on test accuracy and the expiry time on the test
10. Present step-by-step diagrams
11. Consider an instructional DVD

were not pilot tested for each cultural group separately due to a limited number of participants available, therefore we cannot be certain of comprehension and cultural relevance. However, the fieldworkers – members of the cultural groups themselves – conducted the groups, translated interview materials and provided input on appropriateness of materials.

Although not currently in standard use in Canada,²⁵ sampling for HPV may become an accepted screening method in the future. This study suggests that self-sampling may not be universally acceptable or preferable in several ethnolinguistic groups of immigrant women and also in Canadian-born women. Cultural issues may play some role, however there were concerns with self-sampling that were common across all groups. Any program proposing to use HPV self-sampling as a replacement or addition to cervical screening would need infrastructure to support women with information that addresses their specific concerns, and the education required is likely to be largely the same across different ethnocultural groups.

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RÉSUMÉ

Objectifs : Les immigrantes et les femmes de faible statut socioéconomique (SSE) en Amérique du Nord sous-utilisent le dépistage par frottis de Papanicolaou. L'autoprélèvement vaginal pour détecter le virus du papillome humain (VPH) oncogène pourrait accroître la participation au dépistage du cancer du col utérin. Notre étude qualitative visait à connaître les perceptions des femmes de faible SSE et des immigrantes sur l'autoprélèvement pour dépister le VPH.

Méthode : Nous avons mené 11 entretiens en profondeur auprès de différents groupes : un premier composé de femmes anglophones de faible SSE nées au Canada et deux groupes composés de femmes récemment immigrées au Canada; l'un de ces groupes a eu lieu en anglais et l'autre dans la langue maternelle des femmes, soit l'arabe, le cantonais, le dari (l'afghan), le somali et l'espagnol (latinophones). Chaque groupe comptait entre cinq et neuf femmes de 35 à 65 ans mariées et mères de famille.

Résultats : Nous avons abordé les thèmes suivants : 1) qui est susceptible d'utiliser l'autoprélèvement et pourquoi; 2) l'aversion à l'autoprélèvement et les raisons pour lesquelles on préfère qu'un médecin s'en charge; et 3) les moyens d'améliorer l'attrait de l'autoprélèvement. Les femmes percevaient en général les avantages de l'autoprélèvement, et un petit nombre d'entre elles sentaient qu'elles pourraient y avoir recours, mais tous les groupes ont exprimé des réserves. Raisons évoquées : la crainte de ne pas prélever correctement l'échantillon; la peur de se faire mal; la difficulté possible de se procurer le matériel nécessaire; et les craintes quant à l'exactitude du test. Si les femmes préfèrent se faire tester par un professionnel de la santé, c'est parce qu'elles sont habituées aux examens pelviens, qu'elles les trouvent plus pratiques ou qu'elles ont plus confiance en leurs résultats.

Conclusion : Les perceptions interculturelles de l'autoprélèvement pour dépister le VPH sont semblables; elles ont trait au manque de confiance en l'autoprélèvement et au besoin d'une intervention du médecin dans les soins. Ces constatations pourraient étayer la planification de programmes et d'études portant sur l'autoprélèvement comme méthode de dépistage du cancer du col utérin.

Mots clés : émigrantes et immigrantes; dépistage de masse; virus du papillome humain; recherche qualitative