'Before You Teach Me, I Cannot Know': Immigrant Women's Barriers and Enablers With Regard to Cervical Cancer Screening Among Different Ethnolinguistic Groups in Canada

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ABSTRACT

Objective: To describe the similarities and differences among multiple groups of immigrant women and Canadian-born women of low socio-economic status regarding barriers and enablers associated with cervical cancer screening, in order to inform core elements of a strategy that would be acceptable across multiple underscreened groups.

Method: Within a health behaviour framework, we used a qualitative explanatory multiple-case study approach consisting of focus group interviews (n=11) in Hamilton, Canada. Participants were newly immigrated (1-5 years) women and a group of Canadian-born women of low socio-economic status; all participants were in the age range 35-69 years and married. Language groups were Arabic, Cantonese, Somali, Dari (Afghanistan) and Spanish (Latin America). Two separate focus groups for each ethnolinguistic group were conducted; one in English and one in the native language. A template approach to analysis was used.

Results: All groups indicated a strong need for information on necessity of screening and on how the procedure is done. Use of a video and a group discussion format were desired strategies. Women had positive feelings about being proactive for their health even if prevention had not been the norm in their home countries. There were differences between groups with respect to preferring a female clinician, which was a higher priority than language congruence with the provider. Only Chinese and Arabic groups discussed embarrassment and modesty as barriers.

Conclusion: Addressing key knowledge gaps around cervical cancer screening through personal approaches, educational videos and invitations may be useful core strategies to remove stigma and fear around screening and improve uptake across multiple ethnic groups and in women of lower socio-economic status.

Key words: Immigrants; uterine cervical cancer; health behavior; focus groups

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

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Regular cervical cancer screening is an effective way to prevent cervical cancer in women.^{1,2} Despite its availability in Canada, immigrant women continue to be underscreened, leading to delayed diagnosis and a higher morbidity and mortality from cervical cancer.³⁻⁵

According to theories of health behaviour change, the perceived barriers to and benefits of preventive health screening likely influence patients' screening involvement.⁶ Barriers to cervical cancer screening in ethnocultural groups and women of lower socio-economic status have been described, and include lack of exposure and education around preventive screening, as well as cultural or religious barriers around pelvic examination.^{3,7-9} A 2008 systematic review of US studies examined socio-cultural factors influencing cervical cancer screening but reported that it was difficult to draw conclusions across studies due to heterogeneity of study design.¹⁰ In addition, the studies available for review were conducted primarily in Asian and Hispanic women. Given the diversity of ethnolinguistic groups in North America, it is important to understand the similarities and differences between groups in order to create public health interventions that will be relevant across multiple

groups, to use resources efficiently and to target the most women with a single program or strategy.

Thus the objective of this study was to understand and describe the similarities and differences among multiple groups of immigrant women and Canadian-born women of low socio-economic status with regard to barriers and enablers associated with cervical cancer screening, in order to inform culturally appropriate strategies for improving uptake of screening in the specific underscreened groups in our multicultural country.

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Table 1. Focus Group Characteristics

Group	Group Abbreviation (for text)	Median Age (Range)	No. Children Median (Range)	Years in Canada Median (Range)	Go for Well-visit Check-ups n (%)	Countries of Origin
Arabic; in English n=6	1 Ar/Eng	39 (34-47)	2 (0-8)	3.5 (1-11)	5 (83)	Iraq=2, Lebanon=1, Sudan=2, Bulgaria=1
Arabic; in Arabic n=7	2 Ar/Ar	39 (35-49)	3 (1-5)	4 (4-6)	2 (29)	Iraq=4, Jordan=1, Syria=1, Sudan=1
Cantonese; in English n=5	3 Ca/Eng	35 (30-40)	1 (0-2)	4 (3-11)	3 (60)	Hong Kong=2, China=1, Malaysia=1, not recorded=1
Cantonese; in Cantonese n=5	4 Ca/Ca	NA*				
Dari; in English n=8	5 Da/Eng	35 (22-45)	3 (0-6)	2 (1-6)	6 (75)	All Afghanistan
Dari; in Dari n=8	6 Da/Da	37.5 (33-49)	2 (1-5)	2 (1-4)	6 (86)	All Afghanistan
English (low SES) n=7	7 Eng	40 (34-61)	2 (0-8)	n/a†	6 (86)	Not asked
Somali; in English n=8	8 So/Eng	NA	6 (1-8)	10 (4-16)	NA	All Somalia
Somali; in Somali n=7	9 So/So	40 (26-66)	5 (1-13)	2 (1-3)	4 (57)	All Somalia
Spanish; in English n=7	10 Sp/Eng	35 (34-51)	2 (0-4)	3 (1-5)	7 (100)	Nicaragua=4, Guatemala=2, Costa Rica=1
Spanish; in Spanish n=9	11 Sp/Sp	32 (22-51)	2 (0-4)	4 (0.5-16)	5 (56)	Guatemala=3, El Salvador=1, Colombia=1, not recorded=4

Adapted from Howard et al.¹²

* NA=not available

† n/a=not applicable; all born in Canada

METHODS

Qualitative focus group methodology was chosen in order to encourage an interaction and richness in the discussion of women's perceptions that could not be elicited from a survey. An explanatory multiple-case study approach consisting of focus group (FG) interviews was used. This method was chosen because we wished to explain why women participate in cervical cancer screening as a function of the perceived associated barriers and enablers, and we considered each ethnolinguistic group as a case, bounded by the shared cultural understandings of each group. Per the description by Yin (2003),¹¹ the case study approach seemed appropriate because we wished to answer 'why' within the contextual conditions of language and culture. Detailed methods have been published previously.^{12,13} Twelve FGs were conducted between October 2003 and October 2005, with new immigrant women to Hamilton, Canada, after conducting one group with Canadian-born women of lower socio-economic status (SES) (Table 1). Inclusion criteria were: age 35-69, married and arrival in Canada within the previous five years. Groups were selected to include women from those regions of the world whose language and culture were predominant in Hamilton. Approximately 25% of Hamilton's population is comprised of immigrants.¹⁴ The top countries of birth for immigrants to Hamilton in the 1990s were the former Yugoslavia, Poland, India, China, the Philippines, and Iraq.

Recruitment

We used purposeful and snowball sampling through the local settlement agency, whose staff assisted with identifying and contacting potential participants for permission to be contacted by us, and recruiting a fieldworker from each ethnolinguistic group. The first women recruited were subsequently used for snowball sampling to reach additional women.

Two focus groups were conducted for each ethnolinguistic group, one in English and the other in the native language. Women who met the inclusion criteria were approached consecutively until we attained 6-8 willing participants in each group. One of the authors approached those Canadian-born lower SES women from her practice who were likely to be willing to discuss cervical cancer screening in a group. This clinician was not involved in the focus group; none of the researchers had any relationship with the participants. Seventy-seven women participated in total.

Interview guide

An interview guide was developed by the team (including fieldworkers) to ensure language and cultural appropriateness of the questions and exercises. It was translated and modified slightly by the fieldworkers. The interview started with general questions about perceptions of health and preventive health care for women in the given culture, and then moved on to the women's understanding of cervical cancer, their perceptions of Pap screening, and what would make it easier or more difficult for women to attend Pap screening. The questions were based on literature of immigrant women's views of cervical cancer, with an emphasis on knowledge and enablers with regard to participation, in line with the theoretical model.

Written consent was obtained from each participant before FG interviews started. An experienced FG facilitator and the fieldworker co-facilitated the groups and also took independent notes during the FG. Methods to facilitate discussion included: having a fictional case discussion about a 'friend in her community'; a videotaped interaction of doctor and immigrant woman patient regarding Pap smear (in the native language); a group anatomy drawing exercise and discussion about vaginal self-sampling.¹² Each FG lasted 90-120 minutes. At the end of each FG, in response to a need for information identified after the pilot focus group was conducted, one or the other of our two female family physician authors provided a 'doc talk' where women could ask medically related questions about Pap screening.

FGs were audiotaped and translated and transcribed by the fieldworker, or (for Arabic and Cantonese groups) bilingual university students. Data collection and analysis were iterative. A template approach to analysis was used, in which three analysts worked together to carefully read the transcripts, identify themes and create a codebook (template).¹⁵ Through multiple iterations of the template, the explanations of the data were refined. Identified themes were based on questions asked in the focus groups. NVivo software was used for data management. Regular group debriefs after each FG revealed that themes were well saturated by the 12th FG. Notes taken by the two facilitators during the FGs were compared to the transcribed results to ensure that no information was missed from the transcripts. Triangulation was achieved by having three analysts code the data and reach consensus.

As a check for rigour of analyses, themes were presented to the fieldworkers from each group to ensure that the findings represented what they heard from the groups.

The study was approved by the McMaster Faculty of Health Sciences/Hamilton Health Sciences research ethics board.

RESULTS

Results are presented under the major themes of knowledge gaps and needs, attitudes that prevent or enable screening, role of health care providers and system, and culturally specific barriers to screening.

Knowledge gaps and needs

Women indicated the strong feeling of need for information on the necessity of cervical cancer screening, how the procedure is done and the implications of test findings. The video and the format of the focus group itself were seen as solutions.

*"Before you teach me I cannot know." (Ar/Eng)**

"I think that making a programme like this one for woman... invite them and explain further about this, this is very important... so maybe that is a recommendation to actually form groups... as a group as a community." (Ar/Eng)

"I think it would help lots of women to do the test especially who are not educated, who can not read or does not have courage to discuss this type of issue with somebody." (Da/Da)

"Sharing everything, sharing ideas... we didn't just talk seriously about this problem but instead there were a lot of funny people... we were able to relax and leave our kids at home for a bit." (Sp/Sp)

Misconceptions about cervical cancer causes that could lead to low risk perception and non-participation in screening were mentioned, such as birth control pills, diet and weight.

Participants felt that information should be 'pushed' to them by health care providers and government (for example, by reminder letters):

"Why, I think, if the government decide to, like, this is something serious.....Like a check-up for everyone,... every family doctor.....send a letter for a woman, you know. To invite them." (Da/Eng)

"I just came out with an idea.....send out a letter every year to tell them they should take a test yearly. And which place you can take a test." (Ca/Eng)

Attitudes

Women had positive feelings about taking care of their health and being proactive even if check-ups were not the norm in their home country. The preventive health care emphasis in Canada was seen as empowering, to counter the usual fatalism about cancer:

"God didn't say stay at home and die."... "So even very religious people would say that..., there are things that I can do anyways to stay healthy." (So/Eng)

"Just the cancer alone, the word cancer, it has great impact on people, makes them really shocked and scared... but the doctor could explain it to her." (Sp/Eng)

"...for me, in Canada, it is something new, every year to be check up for the doctor, you know?" (Sp/Eng)

Clinician characteristics – Gender and language

There were differences between ethnolinguistic groups in their preference for a female clinician and in the priority of language spoken versus gender of the clinician. All groups expressed a preference for female clinicians but it was negotiable for most groups. The issue of physician gender was most important for Muslim women:

"The most important thing is the lady doctor for Muslim people. I don't care about the Afghani doctor. Just the lady." "I have a family doctor,.....he said 'I can do it for you'. And I told him, 'No, I'm not comfortable with you, I'm comfortable with woman.'" (Da/Eng)

Women not able to speak English expressed much stronger views on the role of language as the priority barrier:

"...and besides there are also the language barrier in this country right?how will I make the appointment? ... and then when I have the appointment I don't have someone who will translate for me, and I go looking and there are all these barriers... so someone really needs to have the desire to get it (Pap) done and realize that it's necessary for her to do so." (Sp/Sp)

Culturally specific feelings

Embarrassment and modesty were issues that arose in the focus groups with Chinese and Arabic women but not in other groups:

"It's embarrassing. (Paps) Chinese people mostly won't even use tampons,.....difference in cultural background. I think we're just very reserved as Chinese." (Ca/Ca)

"My opinion, we as our culture... don't talk with our daughters.... I still shy even after marry until now." (Ar/Eng)

"Some cultural things affected,...big difference here. Back home, culturally...women is not married, she can't talk about it like this." (Ar/Eng)

DISCUSSION

We found that there were more similarities than differences between the ethnolinguistic groups with respect to cervical cancer screening barriers and enablers. The main findings across all groups included a need for accurate knowledge in various formats, such as discussions; the usefulness of external influences promoting screening; and a desire to take care of one's health.

Many of the specific barriers and enablers identified in this study are consistent with those cited in a 2008 systematic review, including lack of knowledge about cervical screening and the belief that screening is unnecessary without symptoms of illness.¹⁰ Our study suggests that this particular belief is widespread across numerous groups from different areas of the world. An interesting difference in our study compared to previous studies^{8,16} was the absence of discussion of cancer fatalism (defined as "inability to change one's

* See Table 1 for explanation of abbreviations following quotes.

fate"). Women in our study conveyed a positive attitude about participating in prevention activities to stay healthy.

A 2010 systematic review of interventions to improve cervical cancer screening uptake in immigrant women, mostly in the US, found that access-enhancing strategies had the largest effect.¹⁷ Most Canadians have a family physician, and there are few other opportunities for screening. Thus the findings of the importance of language and gender of provider are very relevant to family practice. Since more family physicians in Ontario and parts of Canada are practicing in group practices, or in primary care networks with other health professionals, group education led by nursing staff could be a successful strategy. Nursing literature supports this concept.¹⁸

Using a language-specific video as a method to inform women about 'what to expect' before screening was acceptable in all groups of our study. Specific suggestions included providing the video to watch privately in a doctor's office and using the video for women new to screening or getting married. Previous research in Chinese women found that a video and pamphlets covering cervical cancer risk factors and Pap testing procedures; logistic information such as a list of Chinese health care facilities; addressing barriers to screening through the testimony of other women (e.g., encouragement for Pap testing from both a herbalist and a daughter); and culturally familiar scenes doubled the uptake of screening compared to a control group.¹⁹ Our results suggest that many of these same strategies would be appropriate across numerous cultural groups.

Discussing the topic in a safe environment of women from the same culture seemed to have made women comfortable with the idea of screening. In our study, the focus group itself seemed to be an intervention that promoted the acceptability of screening. The group may have had a similar impact as peer health educators, another promising strategy cited in the literature.²⁰

A challenge for cervical cancer screening in immigrant women is the approach to take with regard to women who are unmarried or adolescent. A strong recommendation by all of our ethnolinguistic fieldworkers was *not* to include unmarried women in our FGs because of cultural acceptability issues in discussing Pap smears among women expected not to be sexually active. The same reasoning would apply to the video's appropriateness for adolescent girls. However, this is a very important group of women who need to be included in cervical cancer screening.

There were several limitations in this study. The women who participated may have represented a more acculturated group than the community in general and therefore they may have had more favourable attitudes towards screening. The group format may have hindered some women from expressing opposite views from the majority, however individual interviews with a non-minority researcher on this sensitive topic may not have been appealing. 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 ethnic group regardless of language, suggesting saturation of information. On the advice of the fieldworkers, for purposes of cultural sensitivity, we only attempted to recruit women aged 35 and older who were married, therefore the results may not apply to younger women who may be more acculturated and have more knowledge on the topic.

CONCLUSIONS

In this study, there were more similarities than differences between ethnolinguistic groups of immigrant women regarding barriers and enablers associated with cervical cancer screening, suggesting that strategies to promote screening can use similar resources across many groups. There were some differences between groups around gender of health care provider that should be taken into consideration for Chinese and Arabic women. To mitigate fear of testing, the main components of cervical cancer health messages should emphasize the asymptomatic nature of the disease as well as reassurance that early detection is successful.

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RÉSUMÉ

Objectif : Décrire les ressemblances et les différences entre plusieurs groupes d'immigrantes et de femmes de faible statut socioéconomique nées au Canada en ce qui a trait aux obstacles et aux incitateurs associés au dépistage du cancer du col utérin, afin d'étayer les éléments de base d'une stratégie qui serait acceptable pour divers groupes de femmes sous-dépistées.

Méthode : Dans un cadre de comportements liés à la santé, nous avons mené une étude de cas à la fois qualitative et explicative axée sur des groupes de discussion (N=11) à Hamilton, au Canada. Les participantes étaient des femmes nouvellement immigrées (depuis 1 à 5 ans) et un groupe de femmes de faible statut socioéconomique nées au Canada; les participantes étaient toutes dans la plage d'âge de 35 à 69 ans et mariées. Les groupes linguistiques étaient l'arabe, le cantonais, le somali, le dari (Afghanistan) et l'espagnol (Amérique latine). Nous avons créé deux groupes de discussion distincts pour chaque groupe ethnolinguistique : l'un en anglais et l'autre dans la langue maternelle des participantes. Nous avons utilisé une analyse matricielle.

Résultats : Tous les groupes ont fait état d'un profond besoin d'information sur la nécessité du dépistage et sur la procédure. L'utilisation d'une vidéo et de la formule de discussion en groupe étaient les stratégies souhaitées. Les femmes avaient des sentiments positifs à l'idée de jouer un rôle proactif dans l'optimisation de leur santé, et ce, même si la prévention n'était pas la norme dans leur pays d'origine. Nous avons observé des différences entre les groupes en ce qui a trait à la préférence pour une clinicienne plutôt qu'un clinicien : c'était une plus haute priorité que le fait que le fournisseur parle la même langue que la patiente. Seuls les groupes de femmes d'origine chinoise et arabe ont cité la gêne et la modestie comme étant des obstacles au dépistage.

Conclusion : Comblar les principales lacunes du dépistage du cancer du col utérin au moyen d'approches individualisées, de vidéos éducatives et d'invitations pourrait être une bonne stratégie de base pour effacer la stigmatisation et la peur qui peuvent entourer le dépistage et pour améliorer l'acceptation de cet outil à l'échelle de divers groupes ethniques et chez les femmes de faible statut socioéconomique.

Mots clés : émigrants et immigrants; tumeurs du col de l'utérus; attitude envers la santé; groupes de discussion

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