

**« À l'intérieur et à l'extérieur » :
perspectives de femmes sikhes en matière
de dépistage du cancer du col de l'utérus**

Nelly D. Oelke et Ardene Robinson Vollman

Des tests de dépistage effectués régulièrement permettent de détecter le cancer du col de l'utérus à un stade précoce. La documentation suggère que le taux de dépistage de ce type de cancer chez les femmes immigrantes, une population croissante au Canada, est inférieur à celui recensé chez la population générale, puisque les immigrantes sont moins nombreuses à subir le test. Il existe peu de services de dépistage culturellement sensibles à l'intention des immigrantes. Une étude qualitative descriptive a été réalisée auprès des femmes appartenant à la communauté sikhe urbaine vivant au Canada, afin d'explorer leurs perspectives sur le dépistage de cette maladie. Des entrevues approfondies (13) et des groupes de discussion (3) ont été menés en vue de cerner les défis inhérents au dépistage de ce type de cancer. Les chercheuses ont identifié un thème prédominant, celui du concept « d'intérieur et d'extérieur ». Selon cette notion, les femmes se sentent emprisonnées dans leur communauté et éprouvent de la difficulté à aller « à l'extérieur », dans la société canadienne, pour bénéficier d'un test de dépistage. Le manque de connaissances concernant l'importance de la prévention, l'influence de la famille et de la communauté, et les problématiques liées aux professionnels soignants influent sur leur accès au dépistage. Les résultats aideront le personnel infirmier à mieux planifier et dispenser des services de dépistage auprès des femmes sikhes.

Mots clés : dépistage du cancer du col de l'utérus, dépistage du cancer, la santé des femmes

“Inside and Outside”: Sikh Women’s Perspectives on Cervical Cancer Screening

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Cervical cancer can be detected at an early stage through regular screening. The literature suggests that cervical cancer in immigrant women, a growing population in Canada, is less likely to be detected early than it is in the general population, as immigrant women tend not to take advantage of screening. Culturally appropriate screening services for immigrant women are few. A qualitative descriptive study was conducted with female members of an urban Sikh community in Canada to explore perspectives on cervical cancer screening. In-depth interviews (13) and focus groups (3) were carried out to uncover challenges to cervical cancer screening. The researchers identified a prevailing theme of “inside/outside” whereby the women felt confined to their community, finding it difficult to move “outside” into Canadian society in order to participate in screening. Lack of knowledge about the importance of prevention, influence of family and community, and health-provider issues affected the women’s access to screening. The results will be helpful for nurses planning and delivering screening services to Sikh women.

Keywords: Cervical cancer screening, cancer screening, women’s health, South Asian

Cervical cancer is an important woman’s health issue; it is a disease that can be detected in its early stages when women participate in regular screening. The immigrant population in Canada has increased in recent years and the trend is predicted to continue. The South Asian immigrant population, which includes the Sikh community, is no exception. Cervical cancer is less likely to be detected early in immigrant women than in the general population, as immigrants tend not to take advantage of screening opportunities and there is a paucity of culturally congruent screening services. The literature includes little information on the screening behaviours of Sikh women, particularly with regard to cervical cancer. Such information is critical for program development and outreach strategies targeting Sikh women living in urban areas.

Literature Review

Canada’s population is changing, with an immigration increase of 14.5% between 1991 and 1996 (Statistics Canada, 2002). The South Asian community accounts for 2.3% of Canada’s total population and Punjabi

is one of the country's fastest-growing second languages (Statistics Canada). The health of immigrant groups, including the Sikh community, is an important focus for health professionals. Barriers, such as language difficulties or cultural factors, affect immigrants' access to health services.

Most cases of cervical cancer can be detected early with regular screening (Health Canada, 1998); best practice guidelines recommend annual Pap testing for all women between the ages of 18 and 69 who have ever been sexually active (Alberta Clinical Practice Guidelines Program, 2000). Nevertheless, it was estimated that in 2005 in Canada 1,350 new cases of invasive cervical cancer would be diagnosed and the disease would result in 400 deaths (National Cancer Institute of Canada, 2005). In the province of Alberta in the year 2000, 154 women were diagnosed with invasive cancer and 38 women died of the disease (Alberta Cancer Board, 2004).

Of the women who participated in the Canadian National Population Health Survey, 13% had never had a Pap test and 28% had not been screened in the preceding 3 years (Maxwell, Bancej, Snider, & Vik, 2001). Groups at highest risk for non-participation in screening included women who were single, older, born outside Canada, and non-English-speaking; had low levels of education; and did not routinely participate in prevention activities.

Hislop, Deschamps, Band, Smith, and Clarke (1992) compared South Asian women and the general population of women in the province of British Columbia for incidence of cervical cancer. Rates for South Asian women were 1.8 times higher than those for the general population, and in some age groups as much as 4.5 times higher. The authors speculate that the higher rates were due to South Asian women's inadequate participation in screening and inadequate follow-up of abnormal Pap tests. Choudhry, Srivastava, and Fitch (1998) and Bottorff et al. (1998), in their respective studies, found that South Asian women's level of proficiency in English and length of residency in Canada were significantly related to their breast cancer screening behaviours. The role of women in the family and society, modesty, and screening in the absence of symptoms were factors in their screening behaviours. Clearly, there are challenges in screening access among South Asian women as an immigrant group. What is unknown is the extent to which information about breast cancer screening practice applies to cervical cancer screening as well.

Research Purpose

The purpose of this qualitative study was to explore the knowledge, understanding, and perceptions of cervical cancer screening on the part

of Sikh women, a subgroup of South Asian women, living in a large Canadian city. Data collection and analysis were guided by the question *What are Sikh women's perspectives on cervical cancer screening and Pap testing?*

Methods

As little is known about Sikh women and their perspectives on cervical cancer screening, naturalistic inquiry (Lincoln & Guba, 1985) was considered an appropriate approach for the study. Purposive, maximum-variation sampling (Polit & Hungler, 1999) was used to ensure broad representation of urban Sikh women. Inductive analysis was employed to negotiate interpretations between participant and researcher (Lincoln & Guba). Study protocols were approved by the University of Calgary Conjoint Health Review and Ethics Board.

Participants

A varied group of Sikh women were recruited to participate in the study ($n = 53$): women in different age groups with different lengths of stay in Canada (< 10 years and 10+ years) and different screening practices. This mix of participants was based on evidence that screening behaviour varies according to age group (Maxwell et al., 2001) and that recent immigrants have lower screening rates (Goel, 1994). Both screeners and non-screeners were included in the study.

Phase 1: Interviews

Posters in English and Punjabi calling for participation in the study were placed in various locations in the community: the *gurdawara* (Sikh temple), a community agency, public health clinics, and a breast cancer screening venue. In addition, posters were distributed to key contacts in the community and the study was publicized on Punjabi radio. A presentation was made to a senior women's group to specifically recruit women aged 50 and over. The snowball method was also used (Polit & Hungler, 1999): referrals by participants in earlier interviews or by key members of the community. Recruitment continued until a fairly balanced representation was achieved with regard to age groups, length of residency in Canada, and screeners versus non-screeners.

Women volunteering to participate from various recruitment sources were telephoned by the researcher or the interpreter, who then described the study and established eligibility. Informed consent was obtained at the initial interview. Consent forms were available in both English and Punjabi. Most of the women using the Punjabi consent form were able to read the information. If they had difficulty understanding it, the interpreter helped them to complete the form. In-depth interviews were

conducted in the woman's home, *gurdawara*, or place of work. The women were asked about themselves (age, length of time in Canada, their own and their family's screening practices), the purpose of the Pap test, the benefits of screening, barriers to screening in their community, influence of family members on screening, and reasons why they had not had a Pap test. For women who spoke little or no English, an interpreter was used. Most of the interviews were audiotaped; in other cases detailed notes were taken to capture the participant's responses. Field notes were taken during all interviews in order to summarize non-verbal communication and context.

Phase 2: Focus Groups

Once the interviews were nearing completion, focus groups were commenced in order to extend and validate the findings. Focus group participants were recruited through a community service agency and English classes. Focus group organizers contacted all potential participants, described the study, and solicited their participation. At the beginning of each focus group, the study was reviewed and a consent form (English or Punjabi) was completed by each woman. As with the interviews, participants who were unable to read or understand all parts of the form received assistance. The focus groups were led by a skilled Punjabi-speaking facilitator. The researcher observed all focus groups and took detailed notes on context and non-verbal communication.

The women were provided with key themes identified in the interviews. Discussion followed on the purpose and benefits of the Pap test for the participants themselves and for other women in their community as well as barriers to participation in screening. They were also asked how cervical screening resources and services might best be delivered to women in their community. Over and above validating the interview data, the focus groups served as an opportunity for triangulation of the study's data-collection methods (Polit & Hungler, 1999).

Confidentiality among women in a close-knit community can be an issue. The confidential nature of the subject matter in the study was discussed at the beginning and end of each focus group. Recruitment of participants for the focus groups was not a difficult process; in fact two of the three focus groups had as many as 16 participants. For the last focus group, held at the *gurdawara*, women were eager to participate. The women believed they had the right to receive information that could be beneficial for them. By attending focus groups and interviews in a public place, the women may have been afforded privacy that would be impossible in the home context.

Data Analysis

Audiotapes of English-language interviews were transcribed verbatim. Audiotapes of Punjabi-language interviews and focus groups were translated and transcribed verbatim. Detailed notes of non-taped interviews, focus group observation notes, and field notes were also transcribed.

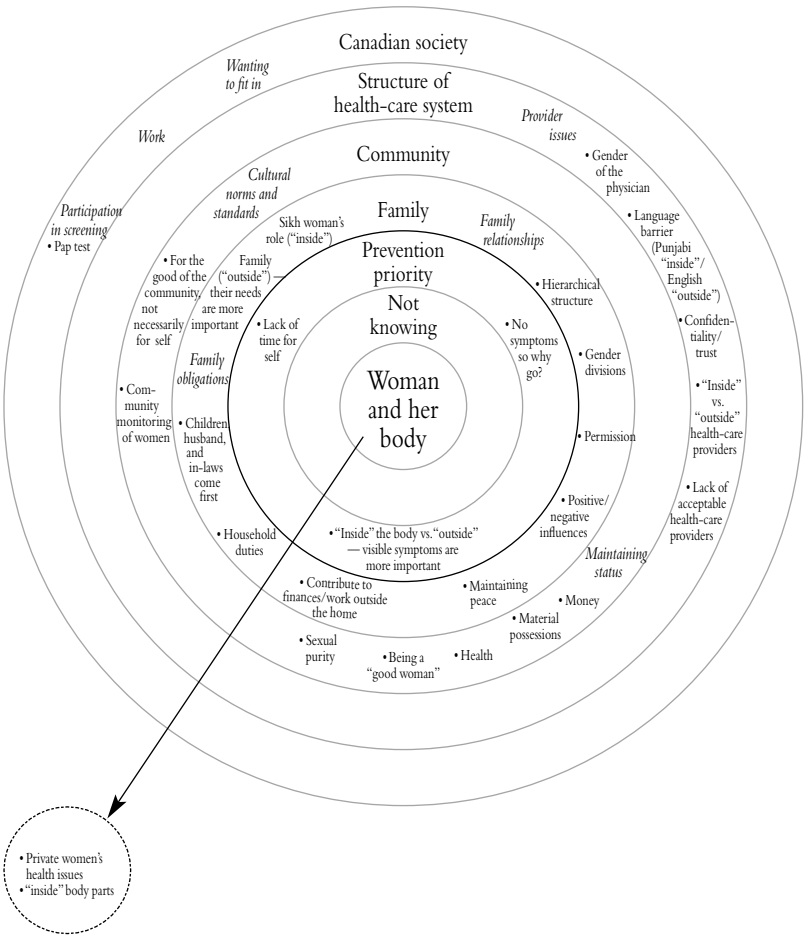
Inductive data analysis was used as a means of making sense of the data (Lincoln & Guba, 1985), facilitated by the N5TM computer program. Common themes with broad categories and patterns were identified and compared. This information helped to inform questions for further interviews and focus groups. Upon completion of all interviews and focus groups, a final round of data analysis was conducted. Trustworthiness of the results was ensured through member checking with three participants and by following audit methods outlined by Lincoln and Guba — that is, through process, confirmability, and dependability auditing.

Results

Thirteen interviews and three focus groups were conducted with a total of 53 women. Demographic information was collected for all participants. They ranged in age from 21 to > 65 years. Approximately two women from each 10-year age group (21–30 years, 31–40 years, etc.) participated in an interview. One participant was born in Canada. The others were born in India and had immigrated to Canada from 6 months to 32 years previous to the study. Most had been in Canada less than 15 years. All participants spoke Punjabi and had a range of abilities in English. They revealed a wide range of education levels, from Grade 9 to completion of postsecondary education.

Among the women who were interviewed, the overarching theme identified was the concept of “inside” and “outside.” The women’s screening behaviour was based on influences “inside” their own bodies, “inside” their personal sphere of influence, and “inside” their cultural norms and behaviours. The women faced numerous challenges to their moving “outside” into Canadian society in order to participate in cervical cancer screening. Figure 1 outlines a woman’s issues as an individual (her body, lack of knowledge about cervical cancer screening, lack of a focus on prevention), family and community influences, and health-system barriers. The process is layered from the “inside” to the “outside” in the same way that women negotiate the barriers to obtaining a Pap test. Details of the findings are presented below, followed by a discussion of the results.

Figure 1 *Issues for Sikh Women in Cervical Cancer Screening*



Individual Circle: "Inside" Our Bodies

For the interviewees, the cervix was an unseen or unknown part of the body: "It is for something you cannot see, a problem or anything inside." The participants often stated that they knew about cancer but were not aware that one could have cancer of the cervix. Most did not know what the cervix was or where it was located in the body.

The cervix was viewed as part of the "inside" of the body and thus as less important than the more visible "outside" parts. This speaks to the very private nature of women's health issues for Sikh women, particularly

those issues that concern sexual and reproductive health. The participants were strongly encouraged by family or community members to keep such matters to themselves, within their own bodies. This contrasts with Gadow's (1980) interpretation of women as seeking meaning of their bodies through its relationship to the "outside" world.

Knowledge Circle: "A Lot of the Time No One Knows"

Many of the interviewees had minimal knowledge of the Pap test and no ready access to information on it. Their lack of knowledge kept them from participating in "outside" screening activities and from fully participating in the "outside" world — Canadian society. Fewer than half the interviewees regularly screened; one had never had a Pap test, while others reported having one from time to time.

Focus group participants were not asked specifically about their personal screening behaviours but it was evident that many of them were not regular screeners: "I did not know anything about it till I came here [the focus group] and I have never had it done." Older women tended to know the least about the Pap test. Participants indicated that new immigrants were less likely to know about cervical cancer screening because women do not generally participate in screening in India. For those women who were aware of the test, their knowledge ranged from recently learning about it to not knowing its purpose despite having been screened.

Many of the interviewees also did not realize that annual screening is necessary: "I had it done and then I felt relaxed and I do not think about going again." The women believed that if they had the test once and it was normal they did not need to return.

These results indicate that there is limited knowledge within the Sikh community; for members of this community, knowledge about screening and the purpose of the Pap test exist in the "outside," external world. This finding is corroborated by those of other researchers. Gupta, Kumar, and Stewart (2002) found that among South Asian women lack of knowledge created a barrier to screening. Maxwell et al. (2001) and Goel (1994) found that age and length of stay in Canada were two consistent variables related to screening, with older women and new immigrants less familiar with the Pap test.

Prevention Circle: "My Body Is Perfect — Why Should I Go to the Doctor?"

The participants believed that seeking health care in the absence of symptoms is unnecessary and sometimes inappropriate. This lack of focus on prevention caused them to remain "on the inside," confined to their own community, and prevented them from readily participating in

routine screening: “You only have to go to the physician when you have [a] certain problem. If you’re fine, then you’re wasting your time.” Participants suggested that the cost of health care in India prohibited regular checkups and prescribed screening. Some women were confused about insurance coverage in Canada. Further, they were simply unaware of the Pap test and its recommended frequency.

As acknowledged by participants, India’s health-care system differs significantly from Canada’s. Private health-care spending in India is among the highest in the world, and the focus of the health-care system is curative as opposed to preventive and health promoting, as in Western countries (World Bank, 2001). This difference influences the health decisions and screening behaviours of Canadian Sikh women.

The interviewees stated that there was a lack of focus on health promotion in the Sikh community, posing another challenge with regard to cervical cancer screening. When they became aware of the need for Pap tests, participation was still minimal if no visible external (“outside”) symptoms were present. The results of this study confirm the finding of earlier research that lack of a focus on prevention is a barrier to both cervical and breast cancer screening in the South Asian community (Bottorff, Balneaves, Sent, Grewal, & Browne, 2001; Choudhry et al., 1998).

Family Circle: “Sacrifice for the Family”

The interviewees indicated that family structure and relationships can influence a Sikh woman’s ability to get to the “outside” to see a doctor for cervical screening. The Sikh woman’s role in the family (caring for family members, cooking, housekeeping) and family obligations are demanding and time-consuming. Male and elderly community members tend to dominate in the Sikh community: “It is a male-dominated society, and we accept that.” Likewise, decisions by senior family members must be respected: “All young people are actually dominated by the elderly of our society. We have to accept what they say... I can’t go against my parents’ wishes.” Participants often stated that permission for medical appointments may have to be granted by a husband, another male family member, or mother-in-law. For some women, their family was a positive influence for screening, encouraging them to see the doctor for an annual physical. For other women, their children, husband, in-laws, household duties, cultural obligations, and work outside the home came before their own needs: “My health...it’s not important”; “Women tend to ignore things and put her needs on the back burner.” For many of the women, time was also a factor, especially with regard to preventive practice in the absence of symptoms.

Cultural values and family expectations place considerable constraints on the behaviour of Sikh women and ultimately affect cervical cancer screening. The findings of this study confirm those of studies with the broader South Asian community (Bottorff et al., 1998; Choudhry et al., 1998).

Two significant themes were identified in the data regarding the family's influence on women: patriarchy and respect. The interviewees tended to live within a more traditional patriarchal society, with decisions generally being made by the head of the household. As suggested by other studies with South Asian women (Bottorff et al., 1998; Lynam, Gurm, & Dhari, 2000), the participants took care of others and fulfilled their other responsibilities before looking after themselves.

The second theme relates to respect for elders within the family and within the Sikh community. Sometimes a participant disagreed with a position taken by a respected elder but abided by the elder's guidelines in order to avoid conflict in the family and in the community. The relationship between mother-in-law and daughter-in-law is an important one in all families, particularly for extended families living within the same household. To avoid family conflict, this relationship was strongly protected, sometimes at great cost to the daughter-in-law. The custom of respect for elders and the hierarchical household structure is supported in the literature (Bottorff et al., 1998; Choudhry, 2001; Lynam et al., 2000). For many of the interviewees, the impact of family dynamics on cervical cancer screening was clear. The challenges posed by the "inside" (i.e., family) seemed not worth the effort required to reach the "outside," especially when "only" a checkup was at stake.

Community Circle: "Our Culture Is about Honour and Morals"

The interviewees stated that cervical cancer screening was a topic not to be discussed among women in the community. Such topics are kept "inside," in order to preserve the reputations of the woman and her family: "Nobody talks about this. Women don't tell each other." All participants, regardless of age or length of time in Canada, agreed that the Pap test is a private matter.

Lack of knowledge about the Pap test appeared to be closely connected to the lack of conversation about women's health concerns: "Maybe that's why people don't know...you just don't talk about [it]. How do you discuss something when nobody knows that it should be done?" Participants commented that in their families there was little intergenerational conversation, between mothers and daughters and mothers-in-law and daughters-in-law. Lacking knowledge about the disease and appropriate screening, they were unable to pass along important information to family members and other women in the

community: "The lack of knowledge and the shyness...go hand in hand...it is a vicious circle."

Participants often spoke of the Pap test and cervical cancer in terms of sexuality and therefore as an inappropriate topic for discussion: "I was not allowed to talk about sex, and this is all about having babies or inner parts of [a] woman. That is not appropriate"; "It is a shame on you to be talking about these things in public...you don't want people to have wrong thoughts so you keep your mouth shut." Women's health issues were discussed only with relatives or very close friends and then only if necessary.

The participants indicated that Sikh women live "inside" their community, their activities and actions monitored by others. A number of issues emerged related to preserving the honour and status of both the individual and the family within the Sikh community, ensuring that life was normal, at least in appearance.

The women had few opportunities for dialogue about female reproductive health, particularly issues linked to sexuality. They were strongly discouraged from talking about such issues for fear of bringing dishonour or shame upon the family. This lack of discussion resulted in large gaps in knowledge and considerable misinformation. Other researchers have similarly found that modesty and the preservation of family honour play a critical role in breast health practices (Bottorff et al., 1998) and that difficulty discussing such issues can serve to compromise women's health (Gerrish, 2001).

Health-Care System Circle: Health-Practitioner Issues

The health-care system presented a number of challenges for the Sikh women who sought to move "outside" their community to obtain screening, particularly for those women who were unfamiliar with the system or spoke minimal English. These challenges included the sex of the physician, language barriers, trust, confidentiality, and a dearth of acceptable health practitioners.

Provider issues were of particular concern. Many participants had not been made aware of the Pap test and its importance by their family physician. They may have seen the physician for another problem but were seldom advised to have an annual physical, including a Pap test. "Why do the women not know about this?" said one participant. "I feel this is the responsibility of the doctors." Participants felt that some Punjabi-speaking physicians did not take enough time with women, who therefore did not receive information or have a Pap test. Participants stated that embarrassment about this topic was apparent both for the health practitioner and for the woman.

There were differences of opinion about the importance of the sex of the physician. Some women believed that the main criterion was a qualified, competent doctor. Nevertheless, most of the participants felt more comfortable with a female health practitioner and, if given the choice, would select a female physician. Privacy and embarrassment were often cited as barriers for women seeing a male physician.

Language was a concern for many of the women. Most of the interviewees suggested that a female, Punjabi-speaking physician was the ideal choice although few such physicians were available: "They want to go to their physician, their own community people... They want to speak the language." The participants indicated that use of an interpreter when discussing private health matters could cause problems within the family or the community. The interviewees were divided on whether an Indian physician was preferable to a physician from outside the community. The women were concerned about trust and confidentiality. Many did not truly believe that their medical data would be held in confidence within the Sikh community. They described the Sikh community as small and close-knit.

When asked for suggestions on how to reach women in the Sikh community for cervical screening, many participants recommended the use of trained Punjabi-speaking nurses to carry out Pap tests. This would address health-practitioner issues to do with language and gender.

The interviewees reported that their physicians were not informing them about the Pap test and its importance. This is a common barrier to cervical cancer screening; the literature shows that the main reason why women do not obtain screening is that their doctor never recommended it (Fox, Siu, & Stein, 1994) and that a physician's recommendation of mammography is a cue for action in the South Asian community (Choudhry et al., 1998).

The participants' expressed preference for a female health-care provider when dealing with women's health issues is not unique to this population subgroup. Women in general prefer to have a Pap test conducted by a woman (Ahmad, Gupta, Rawlins, & Stewart, 2002). Many participants found it difficult to ask a physician, whether male or female, for a Pap test. Some Punjabi-speaking Indian doctors were themselves uncomfortable talking to women from their own community about Pap tests. Thus cervical cancer screening remains hidden "inside" the community and women are not being screened.

Difficulty with the English language made seeing a physician "outside" the Sikh community an additional challenge. Several researchers (Bottorff et al., 2001; Freeman et al., 2002) have reported on the advantages of having available first-language health practitioners

who possess cultural knowledge. However, the participants balanced these advantages with their concerns about confidentiality.

Discussion

Due to lack of participation in cervical cancer screening, the threat of cervical cancer appeared to be hidden both in the bodies of the Sikh women and in the Sikh community. The participants revealed layers of challenges to their becoming involved in screening activities. They frequently referred to the concepts of “inside/outside,” having to negotiate many obstacles in order to fully participate in the “outside” Canadian society and be screened for cervical cancer. For these women there remained a tension between themselves as individuals and their family and cultural traditions.

Participants in the study were “insiders” in their own community, wishing to be accepted into the larger Canadian society and to participate in health screening. The desire of immigrant women to belong and to have a connection with Canadians is also described by Lynam (1985), while Abouguendia and Noels (2001) found that, despite the strong desire of South Asian immigrants to participate more fully in Canadian society, there are still many factors preventing them from doing so.

What do the results of this study mean for cervical cancer prevention in Sikh women? The interviewees did not feel free to discuss the need for screening and many did not know about Pap testing. They preferred to have female health practitioners for sexual and reproductive health services. Yet few such practitioners are available and those who are available may be inaccessible to Sikh women because of language barriers. There is an urgent need for nurses to rethink the types of services that are available to Sikh women, how they are delivered and by whom, and how Sikh women can become participants in the decisions about these services. The present findings may help to familiarize nurses with the sexual and reproductive health practices of Sikh women, particularly the factors that affect their cervical cancer screening behaviours. Nurses can use this knowledge to increase participation in and access to culturally congruent screening services by planning and implementing educational and screening services for Sikh women. More specifically, those nurses who work directly with Sikh women have a role to play in welcoming the women, informing them about Pap testing, and encouraging them to participate in screening. Those nurses who are involved in community development could gather specific information from particular groups in order to effect policy, protocol, and process changes that address the issues in cervical cancer screening raised in this study.

Limitations

Ethnocultural communities are not homogeneous and there is often as much variation within groups as there is between groups. Efforts were made to recruit a sample with maximum variation in age and length of stay in Canada. Despite these efforts, caution is recommended in generalizing the results to all Sikh women living in Canada.

There are often issues entailed in conducting research in another language. The same interpreter and facilitator were used for all interviews and focus groups in order to ensure consistency of data. Consent forms were back translated; interview and focus group questions were reviewed by several Punjabi-speaking women; audiotapes of the Punjabi interviews and the focus groups were carefully translated and transcribed. Audits were conducted at various points in the process. Since language interpreters do not necessarily interpret culture, other means, beyond the words of the participants, were used to understand the Sikh culture.

Conclusion

The concepts of “inside” and “outside” referred to throughout this article require further study before we can fully understand them and their relationship to Sikh women and to cervical cancer screening. Although this study was intended to explore the perspectives of Sikh women on cervical cancer screening, throughout data collection and analysis it became apparent that it was about much more. The challenges and influences that emerged paint a picture of the Sikh woman’s response to many different aspects of health. The wide range of perspectives on cervical cancer screening revealed by the participants offer much-needed information, for nurses and other health practitioners, with regard to developing programs for cervical cancer screening for Sikh women and possibly other South Asian populations or other health-care programs.

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Authors' Note

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