

Concept Mapping with South Asian Immigrant Women: Barriers to Mammography and Solutions

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Abstract Despite benefits of screening mammography, many South Asian (SA) immigrant women in Canada remain under screened. We aimed to elicit their experiences and beliefs about barriers to mammography and possible solutions. SA immigrant women aged 50 years or over were eligible if they never had a mammogram or had one more than 3 years ago. We employed the participatory mixed-method approach of Concept Mapping. Sixty women participated with a mean age of 58 years. Participants brainstormed 150 items which were consolidated into 67 items. After sorting and rating, cluster analysis revealed eight clusters of barriers on knowledge, fear, language and transportation, access to mammogram center, access to doctor, beliefs and practices, self-care, and family dependence. Participants discussed possible solutions, and emphasized out-reach models to address knowledge gaps and issues of language and transportation. One example was a community-based shuttle bus to screening centres,

hosted by trained co-ethnic workers. The results are discussed to enhance the socio-cultural sensitivity of breast screening programs.

Keywords Breast cancer screening · South Asian · Immigrant · Qualitative · Canada

Introduction

In North America, breast cancer is the most frequently diagnosed cancer in women and is the second most common cause of deaths from cancer [1]. While deaths rates from breast cancer are declining over the last two decades due to improvements in treatments and screening [2, 3], the rates of breast screening uptake have stalled in several countries including Canada. The recommended procedures for breast cancer screening in Canada include screening mammography every 2 years for women 50–69 years of age [1]. In Ontario, only 66% of eligible women aged 50–69 participated in regular breast cancer screening in 2009 [4].

Evidence indicates that immigrant and ethnic minority women are vulnerable to low rates of breast cancer screening. In 2001, Maxwell et al. analyzed the National Population Health Survey of 1994/95, and found that Canadian women born in Asia were two times *less* likely to have a mammogram during their lifetime, compared to the Canadian-born women (age adjusted odds ratio of 2.3) [5]. In 1998, Choudhry et al. reported that 49% of South Asian (SA) immigrant women ever had at least one clinical breast examination (CBE) [6]. In 2005, Ahmad found even lower rates for CBE (i.e., 33%) for the same population [7]. Despite these few studies on CBE among SA immigrant women, there is a significant gap in knowledge about their

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uptake of screening mammography. This is also evident in an integrative review of 2009 by Hanson et al. for Canadian studies on facilitators and barriers to mammography [8]. Out of 52 selected studies, only nine included ethnic minorities and three of them were with SA women [6, 9, 10]. However, none of the three studies focused exclusively on mammography. Considering the increasing population diversity of Canada, it is salient to develop a deeper understanding about mammography among under-screened women.

SA immigrants form one of the fastest growing immigrant groups in North America. The number of SA immigrants in Canada rose by 37% between 1996 and 2002 [11]. For the first time in Canadian history, the national census of 2006 revealed that SA-Canadian ranked number one as a visible minority group [12]. In today's era of global migration, a socio-historical understanding of the issues faced by a vulnerable subgroup such as immigrant women from South Asia is essential in order to address their needs in a timely manner. Meaningful insights can be gained by focusing on metropolitan areas, such as Toronto, Ontario with a significant number of SA immigrants.

Using the participatory approach of Concept Mapping, we aimed to directly engage SA immigrant women to elicit: (1) their experiences and beliefs about barriers to screening mammography, and (2) their perspective on ways to increase mammography uptake and retention. As SA immigrants do not represent a homogenous group, we also explored the importance of these barriers by the language groups and the number-of-years lived in Canada.

Methods

Study Design

We used semi-structured qualitative method of Concept Mapping (CM) which has community-based participatory nature with three activities of Brainstorming, Sorting and Rating and Interpretation [13, 14]. The aim of group brainstorming is to collect a wide range of participant-generated ideas regarding the phenomenon under research (e.g., barriers to access mammography). The synthesized statements are then sorted by participants in an unstructured style followed by rating for one or more variables of interest (e.g., relative importance and feasibility). The techniques of brainstorming and unstructured sorting are well established in research [15, 16]. For the Interpretation activity of CM, the collected data is analyzed using quantitative techniques of multidimensional scaling [17] and cluster analyses [18] through a specific statistical package. The statistical analyses add rigor and credibility to qualitative data while generating coherent pictorial

views (concept maps) which are easy to understand and interpret by the participants. These maps can also be used with policy makers and program developers to identify future actions for change. The CM method has been extensively used in planning and evaluation [14] and more recently, in studies related to mental health [19, 20], violence [21, 22], gambling [23], child welfare [24], youth development [25], tobacco control [26] and health care models [27, 28].

Study Setting and Participants

In the metropolitan area of Toronto, almost 50% of the residents are immigrants compared to 20% nationally [29]. Nearly 700,000 Toronto residents identify themselves as SA regardless of immigration status, accounting for 54% of all SA in Canada. The majority of SA immigrants in Canada come from India (48.8%), Pakistan (14.6%), Sri Lanka (11.7%) and Bangladesh (3.6%) [12].

This study was conducted in 2009 in collaboration with a community-based agency serving immigrants in Brampton, which is a rapidly growing area of the metropolitan Toronto. This was a purposeful selection because of the high proportion of SA residents. Further, the collaborating agency had staff fluent in dominant SA languages. These staff members worked closely with the research team in the development of the study protocol, distribution of the flyers, advising on translation of the study materials, and organization of the group sessions.

SA immigrant women were eligible to participate if they were at least 50 years of age, could speak and read Urdu, Hindi, Punjabi or the English language, and *never* had a screening mammogram or had one more than 3 years ago. Participants of the concept mapping activities serve as cultural experts and their opinions are valid due to their membership in the populations of interest. Thus, we aimed for a *purposive* sample of approximately 60 eligible women.

The study protocol was approved by the research ethics board of the University of Toronto.

Data Collection and Analysis

We organized three groups for the Brainstorming activity ($n = 28$), three groups for the Sorting and Rating activity ($n = 26$), and one group for the Interpretation activity with women proficient in English language because the visual maps are produced in English. We recruited additional women for the Rating activity on one-to-one basis to power the statistical analysis of the mean rating scores (discussed below). Each participant provided an informed consent, completed a demographic survey, and received honorarium of \$30 for each activity. In the following section, data

collection procedures are described for each type of the activity.

Brainstorming

Participants in the Brainstorming activity responded to an open-ended central question on “reasons why you have not had a screening mammogram”. Prior to this activity, participants were debriefed about the symptoms of breast cancer. The list of brainstormed statements was recorded by the group facilitator (F.A.) on a flip chart. In total 150 statements were brainstormed in three groups. The research team and community collaborators translated the statements into English, and the master list was consolidated to eliminate duplicate or irrelevant statements. A refined list of 67 statements was produced and translated back into three SA languages to be used in the Sorting and Rating activity.

Sorting and Rating

Participants in the Sorting activity received individual packs of 67 printed cards with one statement per card. Each participant individually reviewed the statements, sorted them into groups or piles having similar meanings, and labeled each pile. Participants in the Rating activity completed a paper-and-pencil survey to rate each statement on a scale of 1 (not at all important) to 5 (extremely important) for its “importance in facilitating use of screening mammography every 2 years”.

Visual Maps and Interpretation

The data was quantitatively analyzed to create the visual maps. Through multidimensional scaling, all of the sorted data generated simple Point Maps where each item is represented as a point on the map. Points which were closer to each other indicated that many people sorted them in similar piles. The stress value for our data set was low (0.259) demonstrating overall good fit; lower value indicates better fit. Through hierarchical cluster analysis, the data in point maps was then used to create Cluster Maps. The research team prepared multiple cluster solutions. These were shared with the participants through the Interpretation group, during which the participants evaluated the cluster content, discussed moving some of the statements to other clusters, and assessed or modified the name of each cluster. Finally, participants were asked to suggest possible solutions to the identified clusters of barriers. This discussion was audio taped and detailed notes were taken for subsequent analysis of emerging key ideas.

For additional descriptive and correlation analysis, the data was entered in the Statistical Package for Social Sciences (version 17). The cluster mean scores were examined by three language groups and the number-of-years lived in Canada using ANOVA test.

Results

Participants

In total, 60 women (Punjabi 27%, Urdu 43% and Hindi 30%) participated (Table 1). Sixty-five percent had lived in Canada for about 5 years and the majority were currently married (73%) and had children (95%). Seventy percent reported having at least high school education but a minority was employed (10%). Participants rated their self-perceived health, level of social support, and English language proficiency on a scale of one (poor) to 5 (excellent). On average, health was rated as “good” (mean 3), English language as “fair” (mean 1.9) and social support as nearly “good” (mean 2.7). Seventy-five percent had a regular family physician. Eighty-five percent never had a screening mammogram and 15% had one more than three years ago. Almost 13% reported having a family member with diagnosis of breast cancer.

Cluster Map and Content

For 67 participant-generated statements, the final cluster solution comprised of 8 clusters (Fig. 1). Sample statements, also referred as items, are presented in Table 2. For more details, please see “Appendix”.

Cluster Ratings

Across 8 clusters of barriers, the mean scores for ‘importance’ in facilitating the future regular use of screening mammogram ranged from 3.0 to 3.6 (Table 2). The clusters of *Lack of Knowledge* (mean = 3.6), *Fear of Cancer* (mean = 3.6), and *Language and Transportation* (mean = 3.5) were rated as the most important.

The clusters were compared between participants who were in Canada for ‘up to 2 years’ (Group 1), ‘>2 to 5 years’ (Group 2), ‘> 5 to 10 years’ (Group 3), and ‘> 10 years’ (Group 4). The clusters of *Dependence on Family*, *Ease of Access to Mammogram Center*, *Language and Transportation*, *Fear of Cancer*, and *Self-care* differed significantly by the number-of-years lived in Canada. On post-hoc analysis, most of these significant differences were due to higher scores of Group 2 (Fig. 2). On comparing the three language groups, the cluster scores did not vary significantly.

Table 1 Socio-demographics of South immigrant women ($n = 60$)

Variable	Percentage or mean
Age, mean (SD)	58.2 (6.4)
Birth country, %	
India	61.7 (37/60)
Pakistan	38.3 (23/60)
First language	
Punjabi	26.7 (16/60)
Urdu	43.3 (26/60)
Hindi	30.0 (18/60)
Years lived in Canada, %	
Up to 2	45.0 (27/60)
2.1–5	20.0 (12/60)
5.1–10	13.3 (8/60)
More than 10	21.7 (13/60)
Marital status, %	
Married	73.3 (44/60)
Widowed	23.3 (14/60)
Separated/divorced/single	3.3 (2/60)
Highest level of education, %	
Less than high school	30.0 (18/60)
High school complete	28.3 (17/60)
College, some or complete	8.3 (5/60)
University/Post-graduation, some or complete	33.3 (20/60)
English language, mean (SD) ^a	1.85 (0.9)
Current employment status, %	
Not employed	81.7 (49/60)
Part-time or full-time employed	10.0 (6/60)
Retired/on disability	8.3 (5/60)
Social support, mean (SD) ^a	2.7 (1.27)
Had family physician (FP), %	75 (45/60)
FP was female	31.1 (14/45)
FP spoke same 1st language	77.8 (35/45)
Overall experience with FP, mean (SD) ^a	3.3 (0.8)
Self-perceived health, mean (SD) ^a	3.0 (1.0)
Had family member with breast cancer	13.3 (8/60)
Breast cancer screening status, %	
Heard of CBE	31.7 (19/60)
Ever had CBE	15.0 (9/60)
Heard of mammogram	56.7 (34/60)
Ever had a mammogram	15.0 (9/60)

^a Scale of 1–5: poor; fair; good; very good; excellent

Discussed Solutions

Participants had the opportunity to discuss possible solutions to address the barriers to mammography. Most of the discussion focused on the clusters of *Knowledge, Language and Transportation, Dependence on Family and Fear of Cancer* in an intertwined manner. Representative statements are presented in Table 3. Participants emphasized

avenues to increase knowledge and reduce fear and, thus dependency on their families. Others added that improved knowledge empowers women by building up confidence and ability to communicate with family. To increase knowledge, suggestions included educational seminars, word-of-mouth by peer-outreach or story telling, targeting youth as knowledge brokers for parents or grandparents, greater emphasis by family physicians, and local media coverage. A preference was also expressed for group based activities organized at places often visited by women because these were perceived as fostering more “confidence”, “comfort” and “assurance” in participants’ words.

Addressing the barriers of transportation and language, participants proposed a shuttle service from community agencies to mammography centers (Table 3), and recommended that shuttle users should be accompanied by someone fluent in their language, such as female volunteers from the Language Instructions for New Comers (LINC) classes. The shuttle service was also perceived to reduce the time burden on families.

Discussion

The study findings advance our knowledge about barriers to screening mammography among South Asian immigrant women, and raise possible solutions from the target population of under-screened or never-screened SA women. Participants identified eight clusters of barriers, and rated Lack of Knowledge, Fear of Cancer, and Language and Transportation as very important to address the low uptake of screening mammography within this community.

Several of the barriers we identified are consistent with previous research, albeit limited, with SA women [6, 9, 10, 30]. However, it begs some critical questions. For example, why is there such persistence of multiple barriers to breast cancer screening among SA immigrant women? What is the efficacy of cancer screening health promotion programs for this community? As two-thirds of the participants in our study had a regular family physician, these concerns become even more important. A recent literature review by Hanson et al. demonstrated that, while some research exists on the interventions to improve mammography among Canadian women [8], none of these studies examined the success of programs for ethnic minority women. In this light, the solutions proposed by our study participants address a significant knowledge gap and sets direction for future program development and evaluation.

From the perspective of our study participants, the first step forward will be to address knowledge gaps about breast cancer, screening and mammography, in order to empower SA immigrant women by overcoming their fears, misperceptions, and dependency on family. Participants

Fig. 1 Clusters of barriers: concept map

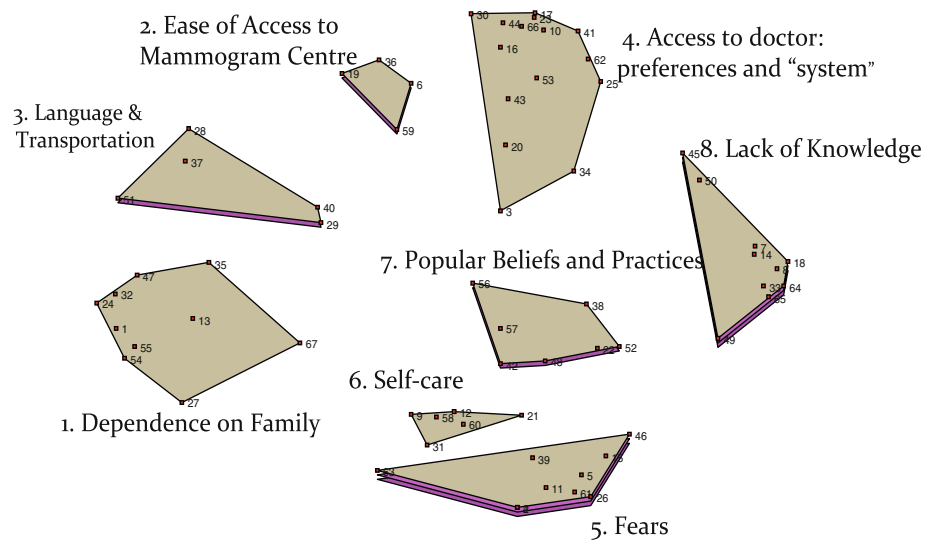


Table 2 Cluster of barriers by South Asian immigrant women (n = 60)

Clusters with sample statements	Mean score (SD) ^a				
	Overall (n = 56)	Years lived in Canada			
		≤2 (n = 24)	>2–5 (n = 12)	>5–10 (n = 8)	>10 (n = 12)
<i>Dependence on family</i> My children are newcomers, so I don't want to trouble them more by taking me for a mammogram I do not want my children to have the financial burden (e.g., arranging transportation, buying medicines)	3.02 (1.1)	2.95 (1.0)	3.75 (0.9)	3.13 (0.6)	2.35 (1.1)
<i>Ease of access, mammogram centre</i> Only a few of the staff at the mammogram centres know my language All mammogram services are available during the daytime	3.30 (1.1)	3.09 (1.1)	4.04 (0.8)	2.94 (0.8)	3.23 (1.3)
<i>Language and transportation</i> Bus routes are complicated and I have to change several buses Transportation is a big issue because I do not know how to drive	3.49 (1.1)	3.31 (1.1)	4.20 (0.8)	3.70 (0.9)	2.98 (1.2)
<i>Access to Dr: preferences and 'system'</i> I do not like to be touched by a male doctor because of cultural or religious beliefs Doctors are overloaded with patients and do not have time to give proper advice	3.30 (0.8)	3.12 (0.8)	3.69 (0.6)	3.32 (0.6)	3.26 (0.8)
<i>Fear of cancer</i> I think the chances of survival are very low after being diagnosed with breast cancer I am scared of the word "cancer"	3.58 (0.9)	3.33 (0.9)	4.14 (0.7)	3.85 (0.7)	3.33 (1.1)
<i>Self-care</i> I do not have enough time for myself because I am very occupied with my work Generally, I hide the physical complaints or signs	3.17 (0.8)	2.99 (0.6)	3.54 (0.7)	2.75 (0.8)	3.46 (0.9)
<i>Popular beliefs and practices</i> Until there is a problem, I do not go to a doctor I do not think it is necessary to get a mammogram because I perform breast self-examination	3.40 (0.9)	3.24 (0.9)	3.89 (0.6)	3.41 (1.2)	3.24 (1.1)
<i>Lack of knowledge</i> I am not sure about the benefits of a mammogram I have little knowledge about breast cancer and screening	3.60 (0.9)	3.43 (0.9)	4.18 (.05)	3.41 (0.5)	3.48 (0.9)

^a Scale of 1–5: not at all important; somewhat important; important; very important; extremely important

proposed multiple community-based avenues to engage SA women and their families, while emphasizing group activities and story-telling to create hope and counteract

fears. Such community approaches have been effectively used to increase knowledge of and screening for cervical and breast cancer among SA women in Bradford, a

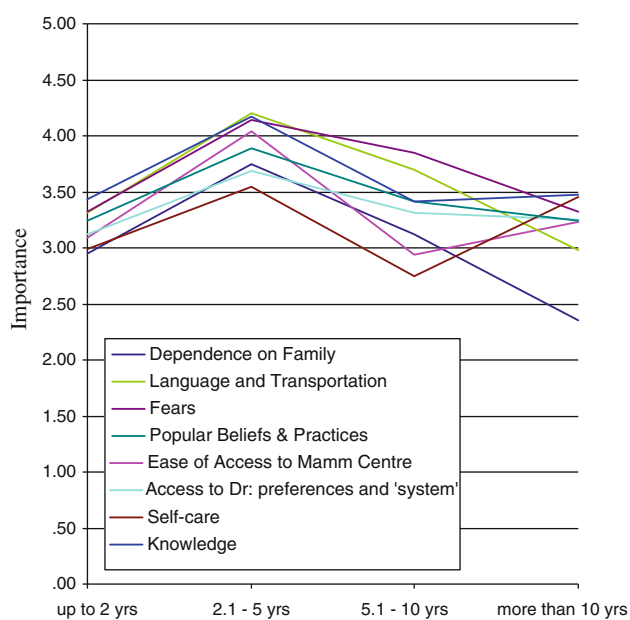


Fig. 2 Cluster of barriers: rating for “Importance”. Importance scale: 1 (not at all important) to 5 (extremely important)

community with the second highest proportion of SA migrants in the UK [31]. In light of our findings, it is worthy to examine its effectiveness in Canadian SA migrant communities. Some promising pilot work has begun but needs systematic wider application and evaluation [32].

For meaningful knowledge enhancement, socio-cultural tailoring of the educational materials for public dissemination and workshops is essential. In 2005, Ahmad et al. used socio-culturally tailored breast health articles in ethnic newspapers and revealed its effectiveness in improving the knowledge, attitudes and uptake of clinical breast examination among SA immigrant in a pre-post study [7]. Others have tailored educational tool kits to train the lay health educators or peers from the community. For

example, the Joy Luck Women’s Project for Chinese immigrant women in Toronto developed such tool kit and reported that 38% of the participants requested for mammography appointment after the workshops [32]. In an recent review of 61 pan-Canadian projects with never or seldom screened women, the authors suggest that tailoring of messages should include plain language, community photographs, preferred and accessible media, visual formats for oral-based cultures, periodic reminders, success stories, and positive framing of messages to reduce fear and anxiety [32].

Women in our study suggested a community-based program with shuttle buses hosted by trained link-workers to accompany women visiting the mammogram centre. The term link-worker refers to a bilingual person from the ethnic community who could help members navigate the use of health services, like mammogram centers. Women in our study suggested a community-based program with shuttle buses hosted by link-workers to accompany women visiting the mammogram centre. This type of model has been used in South East Wales, UK to link SA women with their General Practitioners [33]. In this previous work, the participation rate was 51% but the screening uptake significantly increased across three sites from 35 to 51%. Although there was no control group, the use of shuttle buses is a promising model which warrants further study. We propose that this type of intervention should be developed and evaluated through collaboration between social and health sectors, to make it cost-effective and sustainable. Such multi-sector approaches should also enhance the socio-cultural competency of health care providers.

Our study findings also highlight the need to broaden the focus of outreach by considering the role of family in SA women’s decisions to participate in health-seeking behaviours. The cluster of Dependence on Family is novel in understanding screening barriers encountered by elderly,

Table 3 Discussed solutions

Solution to barrier cluster	Representative statements
Lack of knowledge and dependence on family and fear of cancer	Increasing knowledge about health is the first thing that needs to be addressed... The more awareness women have, the more power they have to convince their families about their health needs and concerns When I did it [screening mammogram], I then went to the park and told two other ladies and they both then had a mammogram done.... They thought it would be a lot of pain but I told them I did it and they should try it and see it reduced their fear. So by telling them this, they find out more
Language and transportation and ease of access to mammogram centre and dependence on family	After 3 or 6 months, whichever you feel is better, there should be a special bus, such as that for seniors [who need mobility assistance]. This way it could pick up a group of people from one location, 10–15 people, and bring them to their mammography appointment on time. Family doctors should know about this, what time the patient has an appointment for this and where That way there wouldn’t be any tension for kids and husbands [to accompany and take time off from work] if we went on our own. That would be the easiest [many women nodding]... You can reduce your dependence on your family. I think at least 80% will be reduced

financially-dependent SA immigrant women with language difficulties. Women's perceptions of family dependency led to their concerns about becoming a burden on children by asking them to accompany for their health care visits. These concerns were captured in the cluster Self-Care. Perhaps, the issue of self-care is augmented by gender-based role of women in SA families. Such deep concern about others and sacrifice of one's personal needs is consistent with the collectivistic orientation of the SA culture [34]. In Eastern collectivistic cultures, the self is interdependent; personal and communal goals are closely aligned; social behaviour is guided by obligations, duties, and communal goals; and emphasis is placed on maintenance of relationship and harmony even when personally disadvantageous. This is in contrast to the individualistic cultures of the West where the self is independent; personal goals have priority over group goals; social behaviour is guided by attitudes, personal needs, rights and contracts; and relationship maintenance is critically analyzed for advantages and disadvantages. Thus, active engagement of family members is highly important when planning outreach programs for SA women. Similar insights were recently reported by Grewal [35]. In 2007, Tanjasiri et al. examined the effectiveness of workshops on breast cancer with immigrant women and men in separate sessions. The results showed an increase in men's belief that they should support women's screening visits [36]. This is an emerging area and needs further exploration for immigrant SA populations.

The health-seeking patterns of immigrants are influenced by not only culture-based norms and values (e.g., modesty, family harmony and gender roles) but also resources available to them at the individual (e.g., language and income) and community (e.g., social support and services) levels to adjust or acculturate in the adopted country. In this study, we did not measure the level of acculturation among our participants. However, the number-of-years lived by participants in Canada impacted their level of importance for the clusters of barriers to access mammography. Participants who had lived 2–5 years in Canada gave more importance to these clusters than very recent or established immigrant participants. Perhaps, there is a specific time period in which immigrants begin to pay more attention to health after overcoming initial settlement issues of employment and housing. Future research should examine variations in the effectiveness of health promotion programs among recent and established immigrants whom may need different approaches for optimal success [37]. Several studies with Asian migrant communities also signify the role of acculturation style on illness behaviour and health-seeking pathways [38]. A larger follow-up study is needed to explore the influence of acculturation on mammography use.

There are some limitations to our study. While our findings provide insights about the perceptions of SA immigrant women in relation to their breast screening behaviours, we cannot make casual links. Therefore, the interpretation of our findings warrants caution in extrapolating to SA immigrant communities in other countries due to variations in health care services and immigration policies creating differences in cohorts. Likewise, the perceptions of our study participants may not be congruent with those of their daughters or with other SA immigrant women who are working and are fluent in English language or with SA women who were born or raised in Canada. Nevertheless, the community-based participatory nature of our study led to active engagement of women who then proposed promising solutions to enhance their uptake of screening mammography. The empowering impact of the participatory approach became evident during the course of study in two dominant ways. First, several of the participant women disclosed to the study coordinator that they went for a screening mammogram after joining the study. Second, the collaborating agency is launching the shuttle-bus program.

In conclusion, a proactive engagement with the community of interest can lead to unique and context specific promising solutions. Participant women in our study identified multiple intertwined barriers to mammography which calls for a multi-pronged approach involving social and health agencies to facilitate uptake of screening mammography.

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Appendix: Description of Cluster Content

The cluster *Lack of Knowledge* (10 items) had statements on: knowledge about breast cancer, risk factors, screening methods, and intervals; the process to obtain a mammogram appointment; benefits and side effects of mammograms; and details of the procedure. Other statements were about having no screening advice from providers in the countries of origin and limited access to translated information in Canada.

The cluster *Fears of Cancer* (10 items) included participants' worries about the disease (e.g., poor prognosis, essential death, cancer recurrence), mammogram experience (e.g., pain, cancer diagnosis), outcomes of cancer

diagnosis (e.g., psychological stress, access to counsellors, social isolation), and consequences of treatment (e.g., post-surgical spread, harm to physical beauty).

The cluster *Language and Transportation* (5 items) reflected women's difficulties to travel independently to the mammogram centre, for reasons which included not knowing how to drive, complexity of public transit system, language difficulties and financial dependence on family precluding taxis as a mean to commute.

The cluster of *Self-care* (6 items) comprised of statements about women's tendency to minimize one's health care due to perceived competing demands which were either practical in nature (e.g., work) or cultural norms (e.g., modesty, preference for quality of life over quantity, self sacrifice).

The cluster *Popular Beliefs and Practices* (7 items) had statements about risk misperception (e.g., low susceptibility to breast cancer), preference for alternative care and limited understanding of preventive health care. The cluster with largest number of statements was *Access to Doctor: preferences and 'systems'* (15 items). Some of the statements in this cluster were participants' socio-culturally based preferences (e.g., wish to have a female physician or visiting a doctor only when sick) and others were system-level pressures on providers or their communication skills (e.g., waiting time, short visits, ability to listen and explain). The cluster on *Ease to Access Mammogram Centres* (4 items) was on the distance and timings of centres and interpretation services.

In the cluster *Dependence on Family* (10 items), participant-generated statements primarily showing their concerns about giving "trouble" to their children by asking them to accompany for visits to mammogram centres. They felt this could compromise children's work or add financial pressure on their children who were themselves immigrants and had employment insecurity and limited income. Other statements reflect worries about familial sanction to seek health care (e.g., husband's permission, social restriction by children) or generational gap (e.g., risk of losing respect for elders or transfer to nursing home).

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