Gender, letters, relatives, and God: mediating actors in mammographic screening among Pakistani women in Norway

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Abstract

Background: Pakistani immigrant women in Norway have lower attendance rates in the national breast cancer screening program (BreastScreen Norway) compared to non-immigrants and immigrants from most other countries.

Purpose: To identify and explore human and non-human actors that play a role for Pakistani immigrant women's attendance in the program.

Material and Methods: Qualitative interviews with 16 Norwegian-Pakistani women in 2017 and 2018. Inspired by Latour, we explored how human and non-human actors act and interact when Pakistani immigrant women consider attendance in BreastScreen Norway.

Results: Among the actors found to play a significant role in the relationship between Pakistani immigrant women and the screening program were trust in the healthcare system and breast cancer screening, the gender of the screening radiographer, the written information received from the screening program, family life, daughters, general practitioners, non-governmental organizations, religious beliefs, private service providers, monetary expenses, accessibility, worries, and digital tools.

Conclusion: Many human and non-human actors work to shape and influence Pakistani immigrant women's screening attendance, or lack thereof, for instance by creating thoughts, promoting opportunities, raising doubts and generating worries, thus variously encouraging, enabling, facilitating, discouraging or preventing attendance in organized breast cancer screening.

Keywords

Breast cancer, emigrants and immigrants, minority health, mammography, screening

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Introduction

Based on qualitative interviews, this paper aims to identify and explore human and non-human actors that play a role for attendance in the national breast cancer screening program in Norway (BreastScreen Norway) among immigrant women from Pakistan. Who and what are these actors, and how do they act when women consider attending the program and when they go for their examinations?

Women who do not attend have a higher risk of being diagnosed with advanced stage disease than women who do, and improvements in breast cancerspecific survival are probably due to a combination of mammographic screening and improved treatment (1). From a public health perspective, mammographic screening attendance should be as high as possible to reduce disease-specific mortality (2).

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Norwegian studies have shown that low screening attendance rates are associated with certain sociodemographic factors, such as earning a low income, residing in Oslo, and being an immigrant (3,4). Among immigrants with particularly low attendance are those with a background from Pakistan. Only 59% of the 2978 Pakistani immigrant women who were invited to BreastScreen Norway between 1996 and 2015 had ever attended, compared to 86% of non-immigrants. When comparing mammographic screening attendance among immigrants from 71 different countries, women from Pakistan ranked 51st in terms of ever having attended (5). Moreover, women receive 10 invitations over 20 years and only one-third (34%) of all invitations sent to Pakistani women resulted in attendance. This proportion was more than twice as high (78%) among non-immigrants; when comparing immigrant groups with different country backgrounds, Pakistani women ranked third lowest (69th out of 71).

A recent study has shown that South Asian immigrant women in Norway had lower incidence rates of breast cancer than non-immigrants between 1990 and 2012 (6). This could indicate that they have a lower risk of breast cancer than non-immigrants. The lower incidence could also potentially be influenced by early stage tumors remaining undiagnosed due to lower mammographic screening attendance. While Asian immigrants in Europe and North America have been shown to have lower incidence rates of breast cancer than non-immigrants, their descendants are found to have similar rates of breast cancer as other nonimmigrants, indicating risk-adaptation among descendants of immigrants (7,8). Studies have also shown that South Asian immigrant women in Norway have had more advanced breast cancer, had lower survival from the disease, and been younger at diagnosis than non-immigrant women (9,10). From a public health perspective, low screening rates are of concern among Pakistani immigrant women despite lower incidence rates of breast cancer due to the risk of more advanced disease and consequently lower survival.

As far as we know, no previous study has explored Pakistani immigrant women's attendance in BreastScreen Norway. In Denmark, a study that included Pakistani immigrants revealed that major life stressors and competing priorities often left little room for breast cancer screening, and this was so even among women who had knowledge both about the disease and about the screening program (11). In Canada, a study among women from Pakistan and other South Asian countries identified language difficulties, problems with transportation to the screening facility, reluctance to being touched by male health providers, and a lack of knowledge about breast cancer as barriers to screening (12).

The Norwegian-Pakistani community

There is a large Pakistani diaspora in Norway; women born in Pakistan make up the fifth largest immigrant group invited to organized breast cancer screening in the country (5). A majority of the immigration from Pakistan occurred > 20 years ago (13,14) and consisted mostly of labor migrants, whereas those who have arrived after 1975 have primarily come through family immigration (15). Pakistani immigrants and their descendants (hereafter called the Norwegian-Pakistani community) account for > 37,000 of the 5.3 million people living in Norway.

In some ways, the Norwegian-Pakistani community shows signs of being an integrated part of the Norwegian society and includes members of parliament, local politicians, cultural personalities, highprofiled journalists, and well-known medical doctors. The Norwegian-Pakistani community also differs from the overall population, for example in terms of residence pattern (67% of Norwegian-Pakistanis reside in Oslo, as compared to only 12% of the total population (15)) and with respect to religion (three-quarters of the overall population are members of the Church of Norway, whereas the vast majority of Norwegian-Pakistanis are Muslims (16)). Moreover, while 69% of all women aged 15-74 years had paid work in 2008, this was the case for only 31% of Pakistani women who had come to Norway through family immigration (17). As factors possibly contributing to this, Statistics Norway suggests traditional division of work in Norwegian-Pakistani households and low educational status (17). They also point out that many Norwegian-Pakistani women have difficulties with the Norwegian language.

Accessing BreastScreen Norway

BreastScreen Norway invites all women in Norway aged 50-69 years to biennial mammographic screening as a secondary preventive tool against breast cancer (18). Women due for screening receive a letter (in Norwegian) offering mammography at a specific (but changeable) time and date. The letter is accompanied by an information sheet (also in Norwegian) about breast cancer and breast cancer screening. In total, the information package consists of four pages of text (see reference (19) for the invitation letter and information sheet). Two short paragraphs about mammographic screening are available in Urdu after navigating through subpages on the screening program's website. In Oslo, where the fieldwork for this study was carried out, there is a single screening facility operated by BreastScreen Norway, located 6 km from the city center and up to 1 h away from major

residential areas by public transport. The screening examination requires payment of a user fee of 250 NOK (about €26).

Material and Methods

This paper draws on qualitative research carried out in and around Oslo in 2017 and 2018. The study was part of a larger research project using several different approaches to investigate breast cancer and breast cancer screening attendance among immigrant women. So far, the project has demonstrated that immigrant and minority women have lower attendance rates than other women across the world (20), that this is the case also in Norway, both overall and for all levels of all sociodemographic factors studied (3,5), and that mammographic screening performance measures differ between immigrants and non-immigrants in Norway (21).

Identifying and exploring "actors"

Several theoretical models have been used in attempts to understand breast cancer screening attendance, and lack of such, among Asian women. Some studies have approached these topics through the identification of barriers preventing attendance and facilitators promoting attendance (12,22). Another framework that has been used is the health belief model, through which attempts are made to predict health-related behavior on the basis of personal beliefs (23). Roughly put, the idea would be that women will attend breast cancer screening if they believe breast cancer is a sufficiently serious illness, to which they feel sufficiently susceptible, and for which they perceive mammographic screening to be a reasonably effective preventive measure. Yet other frameworks, such as social cognitive theory (23), focus on women's self-efficacy.

While these frameworks have provided useful perspectives on screening attendance and non-attendance, they also seem to have their limitations. Among them may be that they propose fairly linear relations between cause and effect and, as a result, could come to give rise to rather simplistic ideas about interventions to promote screening attendance. If women merely had (or acquired) the right beliefs, or if obstructive barriers were simply removed, screening coverage would improve.

In this article, we draw inspiration from Latour's theorizing of action in an attempt to understand why women act as they do in relation to organized mammographic screening in Norway. We take as our starting point Latour's (24) view that action is normally multiple and dislocated rather than single and situated.

In other words, a whole range of agents typically play a role in shaping people's actions.

To come to grips with this insight, Latour suggests that we reconsider the concept of "actors." Rather than understanding an actor as a "pure and unproblematic source of action" (p. 46), we should—quite to the contrary—conceive of actors as entities that are made to act (p. 46) and acknowledge that what makes us act are normally many agents (as opposed to one). Let us offer a simple example to illustrate these points. If someone wanted to understand how we, the authors, came to write this paper, we imagine Latour would have encouraged them to try and identify the range of entities that contributed to make us act to have it written. Among candidate actors would probably be a few teachers who have taught us different skills, some family members who permitted us to work on the manuscript instead of contributing to household chores, and the policy makers who decided to make our academic careers dependent on active publication, along with many others. For each identified agent, one could in turn explore what made them act in the ways they did. A whole network of actors contributing to make others act could be envisioned in this way.

In addition to human actors, Latour would also be likely to prompt us to take into consideration the things that contributed to make the authors prepare the article. While objects may not have the same type of agency as humans, Latour argues that they can still meaningfully be conceived of as entities that make other agents do things. As examples of what things can do, he mentions to "authorize, allow, afford, encourage, permit, suggest, influence, block, render possible, forbid, and so on" (p. 72). As we are writing up this article, for example, several tables, chairs, and computers are among the things that permit us to work on the manuscript, while the electricity supply keep our offices lit and our computers running and thus render our writing possible.

In short, Latour defines an actor as anyone or anything that is made to act by other agents so that they come to modify "a state of affairs by making a difference" (p. 71). To identify an actor, the question he wants us to ask is therefore: "Does it make a difference in the course of some other agent's action or not?" (p. 71). Inspired by this, the first question we try to answer in this paper is: who are the agents, broadly understood, that contribute to make Norwegian-Pakistani women act in various ways in relation to organized mammographic screening? Which human and non-human actors are involved? For each identified actor we then go on to explore the ways in which they may make women act. In other words: what do they do?

Asking women for advice

In this paper, we also bring forward Norwegian-Pakistani women's advice on issues related to breast cancer screening and the different agents that contribute to shape the women's relations with it. There are currently widespread calls for patient and public involvement in research (e.g. Greenhalgh et al. (25)) as well as in care (e.g. Greenhalgh (26)). Among other things, situated, lived experience is thought to be crucial if one is to succeed in developing services that cater meaningfully to patients' perceived needs and circumstances. In the context of a paper which deals with low participation in cancer screening, it would seem to be particularly important to take into consideration advice provided by the very people the screening program is intended to benefit.

Qualitative interviews

A convenience sample of 16 women with a Pakistani family background participated in qualitative interviews. Despite being a convenience sample, the study population included women with different backgrounds with respect to age, education, work, time in Norway, and screening participation (Table 1). Thirteen of the women, all born in Pakistan, were in the target age group for BreastScreen Norway (age range = 50-64 years; mean age = 56 years). The most recent immigrants had arrived in Norway the last few years preceding the study, while others had immigrated as early as in the 1970s. Because several key informants and interviewees suggested that daughters could or should play a role in getting more women to attend screening, we also sought the perspectives of three younger women (mean age = 31 years) with a Pakistani family background who had mothers in the target age range for breast cancer screening. One of them was born in Pakistan, another grew up in Pakistan, and the third was born and raised in Norway.

Six of the 16 interviewees were not employed at the time of the interview, whereas 10 had paid work. The latter group included both unskilled laborers and women who had jobs that required higher education. Two were medical doctors (they did not have work related to breast cancer). Four women did not have any higher education; three of them could not read or write.

Among the interviewees who were in the target age group for BreastScreen Norway, 10 had attended screening at least once, two had not yet had their first appointment, and one had never participated despite being invited several times (she had, however, had an opportunistic examination before she reached the age group targeted by the program). The women who had

Table I. Overview of interviewees

	n (%)
Age (years)	
< 50	3 (19)
50–59	10 (63)
> 59	3 (19)
Ability to read and write	
Yes	13 (81)
No	3 (19)
Higher education	
Yes	4 (25)
No	12 (75)
Attended screening at least once	
Yes	10 (63)
No	6 (38)
Resided in Norway for at least 5 years	
Yes	13 (81)
No	3 (19)
Repeat interview	
Yes	4 (25)
No	12 (75)

attended had been screened either regularly (i.e. they had always attended after receiving an invitation) or irregularly (i.e. they had attended at least once, but not always).

The interviewees were recruited through people involved in the larger research project, key informants, Norwegian classes for adult immigrants in a suburb of Oslo, and a multicultural non-governmental organization (NGO) promoting participation in Norwegian society among immigrants in an area of Oslo with a high proportion of immigrants.

Interviews were semi-structured. A topic guide was prepared before fieldwork started in order to remind the interviewer about issues we had conceived of as potentially relevant on the basis of literature review and conversations with key informants. Importantly, however, the topic guide was not intended to be a tool that should fully steer the interviews, nor was the idea to ask questions in any particular order or to exclude topics women felt were relevant. On the contrary, a main strategy was to allow interviewees opportunities to bring up issues they felt were important and to lead the conversations in directions that made sense from their points of view. The topic guide covered breast cancer and attendance in breast cancer screening, as well as contextualizing topics related to sickness and health, breast lumps and breast cancer treatment, and consisted of a list of themes (rather than readyformulated questions), as well as brief descriptions of situations and statements the women were asked to comment on, and a word map with key words allowing the interviewer to have an overview of the guide on one page. All interviews were audio recorded.

We aimed for repeat interviews when possible to allow opportunities for greater in-depth exploration of salient topics. Most women agreed in principle to take part in repeat interviews. However, only four women agreed to participate when contacted for scheduling of follow-up interviews.

Twenty interviews were conducted face-to-face (at times and places proposed by the interviewees or at a venue close to the interviewees' homes as proposed by the interviewer) or by telephone. Some women strongly preferred telephone conversations and some only agreed to take part in interviews conducted over the phone; thus, eight interviews were conducted by telephone. The duration of conversations was in the range of 30–75 min.

The interview guides were dynamic in the sense that they were updated after each interview to reflect emerging insight and remind ourselves of themes that we still needed to understand better. Initial interview guides focused on broad topics, such as what women knew about breast cancer and mammographic screening, what they wanted to know more about, how they would go about gaining more information, and how they felt about mammographic screening. The interview guides for follow-up interviews were prepared based on the initial interviews and our preliminary analyses of them. During early interviews, we identified several actors, and among the aims of follow-up interviews was to explore these actors further in order to understand their actions in relation to breast cancer and breast cancer screening attendance.

Most interviews were conducted in Norwegian. However, seven women were interviewed in Urdu, either because they preferred this, because they did not speak Norwegian, because they had difficulties understanding the first author's Norwegian dialect, or because they only agreed to participate in the study if they could speak Urdu. In interviews conducted mainly in Norwegian, the women at times also expressed themselves in Urdu, and in interviews conducted mainly in Urdu, women now and again also used Norwegian words and expressions. Further, the interviewees also used English words and phrases, as is quite common among Urdu speakers.

Key informant interviews

In preparation for the interviews proper, the first author consulted nine key informants, i.e. persons with experience and/or positions of relevance to the topic of the study. The key informants, all of whom were women, had prior experience from immigrant health work and included health professionals, researchers, and persons working for NGOs. Six of them had been involved in projects aiming to increase

cancer screening attendance among immigrants. Four had a Pakistani family background, while five did not. The key informants were asked about experiences and opinions regarding breast cancer and breast cancer screening among Pakistani women and for advice on how to get in touch with potential study participants. Some of them were also asked to comment on the findings in the ongoing data analysis, for instance regarding the importance attached to the gender of radiographer.

The first author's position

The first author conducted the fieldwork and carried out all interviews. He is a man in his 30s, which means he had a different gender and age than most interviewees. His professional and academic backgrounds (a medical doctor specializing in oncology and a cancer-screening researcher), moreover, clearly rendered him an outsider with respect to women's perspectives on cancer screening.

With respect to the Norwegian-Pakistani cultural context, on the other hand, the first author was arguably both an insider and an outsider. Born in Norway to parents who emigrated from India to Norway about 40 years ago, he may be considered a desi (a loose term used by people from the Indian subcontinent to refer to its people, its diaspora, and the culture and languages they have in common). As a desi, the first author was familiar with aspects of the Norwegian-Pakistani community with which most non-desis are unacquainted. However, as a non-Pakistani, he continually ran the risk of overlooking aspects that that may be more common among Pakistanis than among Indians, and taking for granted that perspectives familiar to him because of his Indian background were also relevant for Pakistanis.

The first author is fluent in Norwegian and English and speaks and understands Hindi/Urdu (spoken Hindi and Urdu are interchangeably understandable).

As always in research, the researchers' preconceived assumptions and knowledge undoubtedly played a role for their understanding of the interviewees' perspectives. The first author is a doctoral fellow at BreastScreen Norway, supervised by the other authors. The second author is an epidemiologist and the head of BreastScreen Norway, whereas the last author is a medical doctor and social anthropologist who has been involved in public health research, including studies about cervical and breast cancer screening. The authors were therefore well-informed by medical and public health perspectives, while they lacked personal experience with the lived lives of Norwegian-Pakistani women. Striving to transcend preconceptions, the first author strove to allow time for the interviewees' stories

to unfold, and continuously attempted to identify information that could challenge or disconfirm what the authors took for granted. Assumptions and analyses were moreover continuously challenged in the ongoing dialogue between the authors and between the first author and key informants.

Ethical considerations

The study was approved by the Norwegian Data Protection Authority (case no. 2017/2727). All interviewees provided informed consent to participate. Most consent was provided in writing, but oral consent was obtained from women participating in telephone interviews and from women who could not read or write. Transcripts did not include directly personidentifying information and were stored on an encrypted server at the Cancer Registry of Norway. The audio recorder and consent forms were stored in a locked cabinet in the same institution and recordings were deleted after transcription. We have given study participants pseudonyms in this paper to protect their identity.

Data management and analysis

The analytical process was considered a continuous activity throughout the study, from preparation of the study protocol, via the interviews and thematic content analysis, to submission of the final manuscript. All interviews were written out sentence by sentence. This was done by the first author within a day of each interview. In the process, some conversations had to be translated to Norwegian. The first author (the only author who understood Urdu) did this by listening to the conversations sentence by sentence, translating to Norwegian, and then listening to the conversations again with the aim of identifying and correcting errors. Where the first author felt that the meaning was lost in translation, he wrote out the text at verbatim in Urdu (with Latin letters).

Transcripts and field notes were read through several times to develop overall familiarity with the material. As part of the thematic content analysis, the first author thereafter went through the material sentence by sentence, intensely examining the texts and generating codes to categorize the content. Terms that had been used in vivo were often used as code labels. Numerous themes were identified based on these codes and analytic notes were written for these themes. In this paper, inspired by Latour's theorizing of actors, we focus on the human and non-human actors that played a role in women's actions towards and interactions with the breast cancer screening program. We attempted to find out how these actors acted,

for instance how they authorized, encouraged, or forbade screening attendance. While the initial coding process was open and mostly inductive, we later took a more deductive approach informed by theory and focused on core categories given the actor perspective (27,28).

Results

Trust in healthcare and breast cancer screening

The interviewees clearly had a high degree of trust in Norwegian public healthcare services. As an example of how strongly articulated their trust could be, consider Shabana's response when she was asked to elaborate on why she thought women should attend breast cancer screening. Without a flinch, she answered:

The government and the doctors think about what is best for us. After all, it is our best they have in mind. If there is a problem, it will be investigated.

Other women used different terms, but the tone was rather similar across the group of interviewees. They were all confident that breast cancer screening was important and they enthusiastically offered reasons for why one should attend.

Related to this, there was often a sense of urgency among the interviewees to contribute to get others to participate in breast cancer screening. One of them recommended that screening attendance among immigrants be promoted through dedicated screening days at NGOs, during which women would attend lectures about breast cancer before being offered transport to a screening facility for the examination. Another recommendation was to stimulate attendance by removing user fees and possibly even by offering attending women a reward:

It should be free. No, not only free, but maybe there should be some kind of voucher if you attend. Maybe some kind of reward system. (Tahira)

Finally, a few interviewees argued that screening was so important that women should even be forced to attend. It was as if they wanted to remove screening from the list of things about which women needed to make active decisions by rendering attendance compulsory.

Gender of the radiographer

The second actor we will consider is gender, more specifically the gender of the radiographers working at one of the 26 stationary or four mobile screening units operated by BreastScreen Norway. Women clearly

found that the gender of this category of healthcare personnel played an important role in breast cancer screening.

While a few women were willing to attend screening even if the radiographer was a man, not one of them was comfortable with this scenario. Alone the possibility that one might encounter a male radiographer gave rise to negative emotions.

In some cases, this was linked to previous, selfexperienced, and upsetting incidents with male examiners. Rashida, for example, had experienced what she portrayed as highly inappropriate behavior by a male radiographer when she had a mammogram before reaching the target age range for the organized program and this had led her to not attend breast cancer screening for > 10 years. In most cases, however, the women had not had such experiences, but they were still uneasy with the idea of male radiographers. It created emotional distress and plans for or de facto nonattendance. Ifran may serve as an example. She had not thought of the possibility that the radiographer could be a man until she arrived at the screening center for her appointment, but it struck her as soon as she sat down in the waiting room. She decided that if it turned out that a man were to examine her, she would excuse herself, pay the user fee, and leave. For her, a male radiographer would have blocked her from getting the screening examination.

In discussions about why male examiners were undesirable, several interviewees explained how they were uncomfortable undressing in front of, or being touched by, men at the screening center. Others highlighted that some Norwegian-Pakistani women were not used to close interaction with men from outside of their most immediate social circles in the first place. Said Begum, one of the younger interviewees, with reference to women older than herself:

It's a bit like, women who never see men they don't already know. And then seeing a man, especially of another race - that would be a crisis. It's just a no-go (...) They don't have any male friends, they are not used to interacting with other men [other than family and friends of the family]. They are somewhat separated from they are children, and a lot is left there.

It was also taken for granted among the interviewees that some Pakistani husbands would block their wives from attending if they were not confident that it was a woman who conducted the examination. Ifran (whose husband had not interfered with her own screening attendance) explained:

If the husband thinks that the examination is conducted by a man, of course he will not allow it, but if the husband is ensured that this examination is conducted by a female, I don't think he will do any nonsense, because he will not be interested in losing his wife.

Importantly, some interviewees said that their religious beliefs explicitly forbade them being examined by a male. They explained that in Islam, women are not allowed to be naked in front of a man. As Tahira remarked:

It is our religion, we are Muslims. A man should not look at a woman's body.

Notwithstanding the importance placed on religion, women were adamant that male examiners in breast cancer screening was not a problematical issue only for Muslim women, but for many non-Muslims and non-immigrants as well. The point they wanted to get across was that having a Pakistani and/or Muslim background did not necessarily render them an "other" (29) with respect to this, but rather united them with women with various other backgrounds. In effect, they refused to be given the position of the problematic, ethnically different *other* in this question.

When asked for recommendations, several of the interviewees argued that more women would attend breast cancer screening if they knew they could be secured a female radiographer.

The written information received from BreastScreen Norway

The information material sent from the screening program to the women was another important actor in the screening venture. Interestingly, none of the interviewees said that the exclusive use of Norwegian in this material had blocked their own screening attendance. In fact, several women had attended despite not knowing Norwegian at all and, in some instances, even if they did not know how to read. In these cases, however, the letter from BreastScreen Norway had acted by putting several people to work. Some of the necessary labor was carried out by women themselves and typically consisted of contacting and interacting with family members who were able to read Norwegian. Additional work was carried out by these family members as they engaged with the task of translating and explaining the information. Alina, who did not speak Norwegian, outlined how this could occur:

If they get a letter, they get someone who knows Norwegian to read it for them. My sister knows some families where no one can read or write at all. There they call her and tell her on the phone that they have gotten a letter from the doctor or somewhere else, take a photo of

the letter, send it to her, and she calls them back and explains.

Some interviewees emphasized that women who did know Norwegian would find the information from the screening program more interesting and easier to engage with if it had been in Urdu. Begum drew a parallel to her mother to make this point. While she was not interested in health-related information in Norwegian, she went to health-focused seminars in Urdu and often enthusiastically shared with the rest of the family what she learnt.

Apart from language challenges, the interviewees drew attention to another way in which the information material from the national breast cancer screening program might work to hinder screening attendance. Several explained how they had been discouraged from reading the whole information package because they felt it was too complex and too comprehensive. At one point, Tahira exclaimed:

You know, the content of the letter, it is not right. It is not good! There is SO much information in the letter, long and broad. Who has a head where something that long and broad fits?

When asked for advice about the information material, interviewees recommended that information about mammographic screening be made available in Urdu. They argued that this would allow women with limited or lacking Norwegian language skills to understand the contents of the letter better and that this would encourage more women to attend screening.

Women also argued that the information should be more persuading in tone and content. Nasreen suggested the following:

That examination is good for your health and will cost you less than if you get the disease and receive treatment, something like that. A bit powerful; it has to be short, but powerful (...) Direct information in their own language.

Tahira suggested an even simpler message:

The information should be direct. (...) It should only say what time you have an appointment, and that's it!

Family life

A fourth actor of significance was women's family lives. Interviewees described how looking after their family and home was utterly important for them, and in many cases could and should be prioritized before looking after their own health. This meant that family

commitments at times interfered with the feasibility of attending mammographic screening. For instance, significant events in children's lives (such as exams, births, and driving tests) typically led to busy periods for mothers and could work to prevent screening participation. Zaynab, for example, narrated:

When I got the first invitation, that period was hectic. My husband was not that available, and some of my children had exams. It was busy around then, and I just did not have the time.

Some women felt that they would outrightly fail both themselves and their family members if they prioritized their own health before their responsibilities at home. Explained Azra:

The way we Pakistani women think is that we don't think so much about ourselves. We think more about our family, what are the benefits for them; we don't put ourselves first.

It was argued that from when they are young, many Pakistani women are not used to being prioritized and thus would not rank their own cancer screening needs over their commitments towards others. When asked what Pakistani women would choose before their own health, Nasreen was in no doubt:

[They will prioritize] being at home, cooking and cleaning!

Interviewees also pointed out that a subset of Pakistani women did not attend breast cancer screening because they were dependent on their husbands. When this was the case, women would not be able to go for screening alone but might have to be accompanied by their husband. In such cases they had to negotiate time for the examination versus their husband's schedule and responsibilities in addition to their own. Alina elaborated:

They only leave their house with their husbands; they don't want to go alone. The husband might not have time; he has to work and might not be finished in time for the examination. They can't go on their own, women who are uneducated.

While family life could thus in various ways supplant screening attendance for some women, the exact opposite was true for others – interestingly with the precise same rationale: that family life should come first. Some interviewees argued that their family commitments not only allowed, but almost commanded that they get screened for breast cancer, because if they were to get ill, they would not be able to contribute at home.

Umara, for example, asserted that if you do not go for screening and get ill from breast cancer as a result, your husband will leave you for a woman who is not ill.

Daughters

While children are of course part of family life, women portrayed their daughters as such important actors for screening participation that we have chosen to discuss them separately.

Several interviewees advised that to channel information about breast cancer screening through young women would help improve screening attendance in their mothers' generation. Children had a better grasp of the Norwegian language and knew better how to navigate public systems and could thus make information easier to understand and help with the practicalities of attending screening. Fatima, for example, recommended that children learn about breast cancer screening in school, so that they could inform their mothers about the need to attend.

Most interviewees did not problematize whether it was appropriate to inform women through their children, but rather took for granted that the daughters ought to play a role. As Azra pointed out:

Why else do we have children? We look after them, so they also need to look after us when we get older!

Daughters could aid by accompanying their mothers to the screening center, which some of the younger interviewees had indeed done. One of them, Hadia, explained how much Pakistani women wanted to be accompanied by their daughters:

They think it is super social and nice, when I follow my mother to the examinations where I drive, bring her, we have a cup of coffee on the way back, she thinks it's great. She thinks 'She [Hadia] takes part in everything. I get to spend time with my daughter'. What Pakistani woman would not want to be social like that?

However, there were both younger and older women who were opposed to relying on children to inform their mothers. Begum, for example, one of the younger women, pointed out:

I have so many other responsibilities, and I have already contributed lots and reminded [my mother] about appointments, but I have my own life now and don't live with them. It is like a never-ending upbringing, and I have already reminded her lots and know that she's been a few times, but I have no idea how often one should go. It is unfair to expect that I should be responsible for this.

Nasreen, one of the older interviewees, also rejected the idea that daughters should inform women in order to increase attendance. She argued that children were not supposed to teach their parents what is (right and) wrong; it should be the other way around.

Among those taking an intermediate position between these views was Shabana, who was reluctant to rely on information through children, but felt that if women did not understand health-related information, it was appropriate to use their daughters to inform them.

General practitioners (GPs)

A sixth actor was of significance mostly due to their marginalization in the screening venture: the GP. Women expected their primary care doctor to be involved in breast cancer screening and were surprised that this was not the case. Their analysis was that the exclusion of GPs from the breast cancer screening program acted to hinder screening uptake, as they saw GPs as actors excellently positioned to provide information about and promote the examination. As Tahira remarked:

The GP should have a connection to the mammography people, so when you have an appointment for mammography, the GP will know and can say 'you have got an appointment for this, and this is something you must attend'.

Interviewees pointed out that GPs have a high status in the Norwegian-Pakistani community and that they are thus particularly well positioned to promote and encourage screening attendance. They also noted that there are now many Urdu- and Hindi-speaking GPs, and that this is an asset with regards to health promotion among Pakistani women, including the provision of information about breast cancer screening.

Non-governmental organizations

A seventh actor of importance were the range of NGOs women knew of and interacted with. Some interviewees specifically mentioned that they had gained knowledge about breast cancer and mammographic screening from such NGOs; many saw NGOs as potentially important promoters of screening participation in the Norwegian-Pakistani community.

Among recommendations brought forward was that NGOs should be utilized to teach about screening. Ifran, who had attended an NGO lecture about breast cancer and breast cancer screening, explained:

What can be done is that one can cooperate with NGOs and mosques, right, because that's where people are. And that you get in touch with them [Pakistani women] in

another way, right, so you have access through NGOs and Norwegian classes, but you'll especially get in touch with many through NGOs.

Religious beliefs

Interviewees were adamant that their religion authorized and encouraged mammographic screening, even though it was Allah who decided the final outcome in cases of ill health. As long as the radiographer was a woman, none of the interviewees expressed religious views that prevented them from attending screening. Shabana, for example, argued to the contrary that her God had given her the right to have good health and the opportunity to go for screening examinations, and Ifran explained how God and science could very well act together:

I believe in prayer, right, you answer your calling, (...) but that is in addition to, not a replacement. There are things you have to do in parallel, but I'm a religious person, so I believe prayers are answered. So, I think, science has a great meaning in Islam too, and there is no conflict between science and religion, so one has to avail the offer [of breast cancer screening] and the possibility that exists, and at the same time have faith that your God will help you.

As mentioned above, some interviewees recommended that the screening program cooperate with mosques in order to reach Pakistani women. In 2009–2010, a collaborative project, which included participation from the Oslo Breast Centre, the Norwegian Cancer Society, and the Cancer Registry of Norway, ran campaigns aiming to increase screening attendance among immigrants, especially women from Pakistan (30). These campaigns featured Urdu-speaking doctors as "ambassadors" for screening, educational DVDs in Urdu, and one-off teaching events in Urdu at mosques in Oslo. While women praised such events as highly useful, they emphasized that they ought to be offered regularly. As Tahira explained:

There should be courses or seminars about breast cancer screening, and the mosque is a good place [for that]. There are different courses in the mosques... and tell about reasons and that it is important... as soon as you attend mammography you don't need to worry about whether you have a mass or not. And they [courses] have to be yearly or every six months.

There was some disagreement among study participants as to whether courses like these would lead to screening attendance. Among those who were in doubt

was Hadia, who argued that women are not all that interested in non-religious topics when going to the mosque. Nasreen, to the contrary, believed that women were very interested indeed in hearing about such topics in mosques.

Private service providers of mammography

An actor that was both appreciated and caused some confusion in the context of the organized screening program operated by BreastScreen Norway was private mammography providers.

Several women were not aware that there existed different providers of mammography (public and private). For instance, during a presentation at a class for immigrants learning Norwegian, when told that the user fee is about 250 NOK (about €26), a woman from Pakistan explained that she had paid 10 times as much. She had not reached the target age for BreastScreen Norway and had attended a private service provider.

Monetary expenses

Monetary expenses had not blocked attendance for any of the interviewees, but several were concerned that other Pakistani women might not have sufficient financial resources for the user fee. Ifran, who had experience from NGO work, explained that many Pakistani women live in households where only the husband has paid work. In such households, the need to prioritize food, rent, and medical appointments could limit the possibility to attend mammographic screening.

When asked about recommendations, women argued that the examination should be free in order to enable all women to attend. Tahira explained:

These things that will save lives should be free. I mean, if someone can pay for it, that's fine, but what should someone who does not have much income do?

Accessibility

Several of the interviewees explained how matters related to transportation could contribute to make attendance difficult. Women with a car could drive to the facility, but this involved driving to an unfamiliar destination and paying for toll and parking. For women who were working or who were dependent on their husbands to accompany them to the screening facility, the opening hours could also act to restrict their possibility to attend.

Among recommendations brought forward were to have more screening units in Oslo to bring screening

closer to where women live and to improve accessibility by keeping screening centers open on some weekends.

Worries

Various concerns and apprehensions could also influence screening attendance. Some interviewees were worried about pain and discomfort during the examination; for some, the expectation of pain brought forward thoughts about non-attendance. Noor was worried that radiographers paid too little consideration to how uncomfortable the examination was:

My own experience is that the people who take these X-rays, they do it at least 15–20 times every day, it becomes a routine for them, so they have become a bit too rough. They mean well, but it feels very uncomfortable. (...) It is very painful, very uncomfortable, and it's not a nice examination.

Rashida was worried about side-effects of radiation and about her registered data being accessed by other actors than BreastScreen Norway.

Digital tools

Google, YouTube, and mass media were actors providing women with information about breast cancer and mammographic screening. Umara, for example, had searched on YouTube to find out more about cancer, and Rashida's worries about radiation, mentioned just above, were influenced by a TV program about the risk from radiation from too many examinations.

BreastScreen Norway's website had not engaged with the interviewees. During the fieldwork, the first author made a video showing how to access information in Urdu on the screening program's website, but when showing it to study participants, they usually stopped following the video early on and explained that the information appeared too complicated to access.

Many interviewees were active users of social media platforms and recommended that such platforms be used both to reach out with information and to invite individual women for screening appointments. Some recommended the use of voice messages, for instance via WhatsApp, not least because voice messaging could also reach women who could not read. Several thought that webpages and group discussions and advertisements on Facebook could be used to inform women about mammographic screening.

A few of the study participants were not at all very computer literate; for some, even the menu-sign many websites currently use was confusing. Amina, one of the younger women, explained her experiences when helping women with other websites with the same menu sign:

The generation that was here before Internet, they would have trouble knowing that they should press there (the menu sign) and you have to tell them every time that that is a sign you have to press to get an overview.

Discussion

Through qualitative interviews with 16 Norwegian-Pakistani women, we identified and explored actors that variously enabled, encouraged, delayed, hindered, or blocked Pakistani immigrant women's breast cancer screening attendance. The actors we identified were trust in healthcare and breast cancer screening, the gender of the radiographer, the written information received from BreastScreen Norway, family life, daughters, GPs, NGOs, religious beliefs, private service providers of mammography, monetary expenses, accessibility, worries, and digital tools.

This is the first qualitative study exploring breast cancer screening attendance among Pakistani immigrant women in Norway. In a study with a partly overlapping study population (Somali and Pakistani immigrant women in the Oslo region aged 25-70 years), Gele et al. identified barriers and facilitators to cervical cancer screening (31). Some of their findings resonate well with the experiences of the women in this study, such as women being hesitant to male healthcare workers and having difficulties with the Norwegian language.

There were also differences, however. While the women in this study had a high degree of trust in the Norwegian healthcare system, the women in the study by Gele et al. were understood to express distrust towards the healthcare system. However, as in our study, women in a Danish study of immigrant women's mammographic screening attendance, that also included Pakistani immigrants, were found to show a high degree of trust in the national healthcare system (11). Grimen likens a trusting person to someone who is willing to leave something of value in another person's custody (32). He or she feels ensured that the entrusted person will not in any way harm his or her interests, but rather be protective of them. Understood in this way, trust would be a basic, but often immensely important, actor in terms of willingness to succumb to medical care. The considerable confidence women in this study had in their healthcare providers thus clearly seemed to work to promote participation in BreastScreen Norway.

The women in this study were utterly dedicated to their families and family-related responsibilities;

commitments at home at times blocked breast cancer screening attendance despite knowledge of the screening program and a strong belief in the importance of the examination. Shakari has documented the importance of family life in the Norwegian-Pakistani community (33). The well-developed care ethics (34) among the women we interviewed, along with the concern and compassion they articulated for the people with whom they were closely connected, worked to limit their possibility to attend breast cancer screening, at least in periods. In addition, the Danish study mentioned above found that major life stressors and home commitments often dominated immigrant women's daily lives and left little room for prioritizing breast cancer screening despite knowledge of breast cancer and the screening program (11). The flipside of the coin in the present study was that the importance attached to women's family roles also acted as a reason to take part in screening.

Postponing preventive health measures due to other commitments is not an issue limited to immigrants from far away. In a study of rationales for postponing cervical cancer screening among Norwegian and Danish immigrant women in Sweden, women described that competing needs related to immigration were overwhelming in the first years after immigration (35). This included the invitation for cervical cancer screening being just one of many offers to deal with, navigating a new healthcare system and considerable changes in life situation and routines.

As everyone else, care seekers must divide their energy and resources between the demands of care and everyday life. When the aim is to improve participation in preventive care, it is important to acknowledge the work people do when engaging with and utilizing health services. It would seem important that healthcare providers seek to reduce the work load they put on people they are entrusted to provide with services. Health personnel may indirectly see the result of the work people do, i.e. reading information from healthcare providers, getting it translated if needed, transportation to the screening facility, etc., but rarely the work itself (36). Some of the women in our study could not read Norwegian (or read at all) and relied on family members translating the invitation letter. This might be a common experience in many immigrant communities (for instance, a German study with Turkish women found that due to difficulties with the German language, the invitation letter was often read by family members (37)).

Interviewees who could read Norwegian often argued that the information material from the screening providers was too long and complicated. One reason why the text is as long as it is would seem to be that the information is intended to serve as a basis

for invitees to make an informed decision about screening participation. In the words of BreastScreen Norway (18), the four-page information package is supposed to provide women with "balanced, high quality information about mammographic screening to enable them to make an informed choice about whether to participate" and to "ensure that women have the practical information they need to make use of their screening invitation" (p. S10). The interviewees hardly perceived it to work this way and rather thought of it as an unnecessarily convoluted and dense text that discouraged attendance and needed to be shortened and made more to the point. A study about the information material from BreastScreen Norway has found that also non-immigrant women thought of the information as too comprehensive and detailed (38).

Further, the women pointed out what they perceived to be a confusing contradiction in the information they received. The screening program invited them to an examination that aimed to prevent them from dying from cancer, while at the same time seemingly downplaying the importance of that examination. This was perceived to be so because the information package emphasized that it was up to women themselves whether they wanted to avail themselves of the screening opportunity or not. Interviewees reasoned that it was illogical that the screening provider would leave women to draw their own conclusions in a question on which the provider was clearly the expert and where women's survival was in the balance. They argued that the program should send a clear message that breast cancer screening is an important preventative health measure which every woman of a certain age should avail themselves of.

BreastScreen Norway is a vertical program with centralized management and objectives (39). The program offers screening, operates its own screening centers, and informs attendees about screening results. When examinations turn out positive, women are referred for assessment at breast diagnostic centers in regional public hospitals. If diagnosed with cancer, they are thereafter referred for surgery. It may be first when a woman is discharged from hospital after surgery for breast cancer that her GP receives any information about the diagnosis. That GPs are thus in effect excluded from breast cancer screening in Norway was hard to understand among the women we interviewed. The GP was exactly the actor women would expect to take centerstage in a program of this kind. They argued that their permanent doctors were excellently positioned to provide information about screening, encourage screening participation, and communicate and follow up screening results. This may be read as a pointed critique of the vertical organization of BreastScreen Norway. Women were satisfied with their GPs and reasoned that GPs could and should be entrusted to bring

screening services closer to their daily lives and ordinary interactions with the health sector.

Strategies to increase attendance among immigrant women usually focus on improving delivery and uptake of information, for instance by educating women or translating the information to foreign languages (40). In Norway, time-limited information campaigns with written and oral information in Urdu have targeted the Norwegian-Pakistani community in attempts to increase attendance (30). Pakistani immigrant women had low mammographic screening attendance rates both before and after these campaigns (5). A systematic review of cancer screening interventions among Asian women argued that mailed translated education materials alone were not effective in increasing screening uptake among Asian minority women and that combining multiple strategies is more likely to increase attendance than single interventions (41). This study suggests that the low breast cancer screening rates among Pakistani immigrant women in Norway are not simply or overwhelmingly due to a lack of knowledge and information. Importantly, the women in this study had several recommendations about how the screening venture could fit better into Pakistani women's lives. These suggestions included cooperating with NGOs to facilitate screening, increasing accessibility by offering screening in weekends, and involving women's family members and GPs to encourage attendance. In addition, lectures at NGOs and mosques could allow for interactive learning situations where women could listen, ask questions and discuss emerging topics with each other and presenters, and also provided learning opportunities for women who could not read or write well.

In the following, we will discuss the study in terms of trustworthiness, which can be interpreted in terms of dependability, credibility, transferability, and confirmability (42).

To be dependable, researchers should ensure that the research process is traceable and clearly documented (43). We have striven to achieve this by securely storing all documentation produced throughout the study period, including various drafts of the study protocol and interview guides, and all transcripts, field notes, analytical notes, article drafts, and feedback received from key informants and reviewers. A factor limiting the dependability of the study is the different languages that were used (Urdu, Norwegian, and English). Few people understand all three languages and will thus not understand all written material produced in the research process. However, information in Urdu was translated to Norwegian, which all three authors understand. Further, some women only agreed to take part in interviews if they could speak Urdu; we would not have reached these women if we insisted that the interviews must be in English or Norwegian.

The credibility of a qualitative study can be understood as the degree to which the findings it presents are recognizable in the groups about which it aims to provide knowledge (42). Since this study draws on interviews with a limited number of women, and although they came from a variety of backgrounds and had variety of experiences, we could clearly have come to overlook actors and perspectives that are of relevance for Norwegian-Pakistani women's relationship with breast cancer screening. We would particularly have wanted to have included more perspectives from women who have never attended breast cancer screening. On the other hand, we are rather confident that the findings and actors we do present are recognizable and perceived as relevant among Pakistani women and professionals with experience relating to healthcare for immigrants. This impression is strengthened by the feedback received through discussions with study participants (especially with those who took part in repeat interviews), other community members, and a number of healthcare providers with relevant experience. Further, while additional interviewees and repeat interviews could potentially have brought new perspectives, we did not recruit more attenders to our study as few new actors or contradictory perspectives regarding identified actors emerged in the latter interviews. Towards the end of the analytical process, some interviewees and some women with a Pakistani family background not included in the study were offered and accepted to read the manuscript. Among other things that may contribute to strengthen the credibility of the study are also that we to a large degree let interviewees steer conversations, letting their stories unfold without interruption, that we did not set a time-limit for interviews, that women were allowed to speak their preferred language, and that we have used abundant quotations throughout the paper.

The interviews conducted by phone could potentially have limited our ability to explore and understand, among other reasons because we were not able to observe non-verbal cues and because it can be more difficult to establish trust over phone than face-toface. The reason why we nonetheless carried out some telephone interviews was that this was a preference among some interviewees (and also among some of the persons who functioned as recruiters for this study, among whom there were some who believed that Norwegian-Pakistani women would be reluctant to meet a male interviewer and only agreed to recruit women for phone interviews). If we had not allowed for phone interviews, the voice of some of these women would have been silenced. Let us add that although we had preferred to meet all interviewees in person, the telephone interviews turned out to become engaged

conversations that were rich in information and perspectives.

The transferability of a study refers to its potential ability to play a role in other contexts than the one in which it was carried out. It would seem likely that several of the perspectives and actors described would be recognizable and relevant for Norwegian-Pakistani immigrant women also outside of Oslo, where the study was conducted. Many of them have backgrounds similar to the women who were part of this study and they relate to the same, nationwide breast cancer screening program. We may not be in a position to judge to what extent the concrete actors identified and explored in this paper are relevant in other groups of immigrants, among women in general, and in other countries. However, if nothing else, it will be of value for screening programs to have the possibility for similarities on their radar. At that, we do hope that the actor perspective we have taken may raise this approach as a possibility for others.

In conclusion, many human and non-human actors acted on Pakistani women and influenced their mammographic screening attendance, for instance by raising doubt, giving worries, stirring confusion, promoting opportunities, encouraging actions and putting others to work, thus variously enabling, facilitating, discouraging, and blocking screening attendance. Among actors that were involved in the relationship between Pakistani immigrant women and the nationwide breast cancer screening program in Norway were women's trust in healthcare, the gender of radiographers, the written material sent to women before screening, several aspects of Norwegian-Pakistani family life, GPs, NGOs, religious beliefs, and private service providers. If one were to listen to the women who took part in this study, a key to improved breast cancer screening attendance among Norwegian-Pakistani women would be to strike stronger partnerships with actors they identified as important, including NGOs, mosques and GPs. It is our hope that our findings might prove useful for politicians, legislators, the public health BreastScreen Norway, and - not least - for Norwegian-Pakistani women themselves.

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