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Factors contributing to the low participation rate of Turkish women to a breast cancer screening program in Antwerp, Belgium

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Summary

Objectives: To explore possible factors explaining a low participation rate to breast cancer screening for Turkish women living in Antwerp, Belgium, and to develop ways to increase participation rate. *Material and Methods:* The authors used focus group discussions with Turkish women to explore their reasons to participate or not to participate in breast cancer screening. Groups consisted of four to six women. Inclusion criteria were: being female, having a Turkish origin, and age between 50 and 69 years. For each focus group, one Turkish women was invited and asked to invite five other women meeting the inclusion criteria. *Results:* Three focus group discussions with in total 17 women have taken place. Six women had participated to all consecutive invitations for breast cancer screening. One woman had participated once, but not the next time she was invited. Ten women had never participated to screening mammography, although some of them had undergone diagnostic mammography. In all three focus groups, insufficient knowledge of the Dutch language, the unavailability of a professional interpreter, being careless about healthcare, and a negative influence of the husband, were the main reasons not to participate in breast cancer screening. Invitation letters are not read because they are in a language the woman does not understand. Less frequently mentioned obstacles were being on a holiday or being sick on the day of the scheduled mammography, fear of pain, considering an examination useless when not having any symptoms, being anxious for a positive result, and the physical distance to the screening center. Receiving an invitation in Turkish and knowing that a person speaking Turkish will be available at the screening center were proposed as possible measures to improve participation. *Conclusion:* The single most important reason why Turkish women living in Antwerp, Belgium, do not participate in breast cancer screening was a language problem; other reasons were a lack of knowledge concerning breast cancer screening and not worrying about breast cancer. The language barrier in this population of older women can possible be overcome by Turkish speaking personnel at the screening centers.

Key words: Breast cancer screening; Ethnic minorities; Migrants; Prevention; Participation (rate); Belgium; Turkish.

Introduction

Breast cancer is the most common cancer in women and constitutes the most frequent cause of cancer related death of women in Belgium. Since 2001 there is a national screening program in Flanders (the northern region of Belgium) for breast cancer. All women between 50 and 69 years of age are invited biannually for screening mammography. The over-all participation rate in Flanders in 2010-2011 was 50.2%. Some groups demonstrate a lower participation rate, specifically those from ethnic minorities.

Turkish women living in the Netherlands have been noted to participate in only 44%, whereas the general participation rate is over 80% [1]. The causes for this low participation rate are not completely understood. For this study Turkish women living in Antwerp, a city in Flanders with an important Turkish community, have been selected as these represent one of the major groups of ethnic minorities in Antwerp.

Materials and Methods

The authors performed focus group discussions, groups consisted of four to six women with a trained moderator who was also a native Turkish speaker with a medical background (TF). The methodology used was such as described by Morgan [2]. Before the actual discussion, a script had been prepared. Care was taken that at least all questions from the script had been addressed by the end of the discussion. The script included a general presentation of breast cancer screening, then the discussion was opened by informing whether women had, or had not, received the invitation letter from the screening centre and how they had reacted to this. Later it was asked why they did or did not participate in the screening and what had influenced this decision, furthermore questions about breast cancer in family or friends were posed. Finally the participants were stimulated to present solutions to eventual barriers to participation, before ending the focus group discussion an open question was asked offering the opportunity to give further comment. Discussions have been tape-recorded but have not been filmed. To document non-verbal communication, an observer noted all non-verbal communications during the focus group discussion.

Inclusion criteria for the selection of focus group members were: being female, aged between 50 and 69, and of Turkish origin. The

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Table 1. — *Participation rate of women to screening mammography*

Number FGD	FGD 1	FGD 2	FGD 3	Total
Always participation to screening mammography	3	1	2	6
Drop-out	0	0	1	1
Never participated to screening mammography (already had a diagnostic mammography)	4	3	3	10
Total amount of women	7	4	6	17

FGD: Focus Group Discussion.

age category is identical to the age women in Flanders receive an invitation for the breast cancer screening program. Women were considered of being of Turkish origin if Turkish was their mother language and they had been born in Turkey. All focus group discussions were performed in Turkish only. For each focus group, only one woman was contacted and she was asked to bring four to five other women with her at the moment of the focus group discussion.

All discussions have been completely transcribed and translated into Dutch as this is the mother language of the other members of the research group. Every reason for non-participation to the breast cancer screening program that was given by a woman, received a code.

Results

Three focus group discussions occurred. Saturation was reached after the second group discussion, but as a control, a third focus group discussion was held. In the first there were seven participants and the mean age was 57 years. The focus group discussion took 75 minutes and there were no participants with a history of breast cancer. The second group consisted of four women. The focus group discussion took 35 minutes, the mean age of the participants was 60 years and none of the participants had ever had breast cancer. The third focus group consisted of six participants, mean age was 56 years. The discussion took 64 minutes and one of the participants had been diagnosed with breast cancer five years before the discussion. Table 1 presents the participation of these women to screening mammography.

All reasons mentioned by the women not to participate in the breast cancer screening program were reduced to 19 codes and these are presented in Table 2. The most frequently mentioned reason by all three groups were problems with the language and translation. The language problem represented a barrier at the moment the invitation letter arrived. Often Turkish women were unable to read, let alone understand, this letter. Suggestions from the group were to make the letter in Turkish, but other women responded that this has no use as they are analphabetics. The problem with the language also disables the woman even when they finally understand the invitation letter to go to the screening mammography as they have fear not to understand what will be said or asked them They are also anxious as they think they will not be able to understand the results. All these women are first generation migrants with a very limited knowledge of the Dutch language as they have neither worked nor studied in Flanders. Another problem that was mentioned is that it is another member of the family that selects and reads letters that arrive at home, for instance, the husband or one of the children, and as they are not themselves concerned with this invitation, they immediately drop it. Women stated:

- Focus Group Discussion 1, participant 3 (FGD1,3): “we do not want to go to the doctor as we do not know the language”.
- FGD 3,1: “we are unable to go if there is not a helper that goes with us because we do not know the language”.
- FGD 3,4: “we all are the same, as we do not know the language we do not have the courage and we will not go”.
- FGD 1,3: “I have never seen such a letter, other people who live in the house can also have taken the letter”.

The problem of not having an interpreter is closely connected to the language problem. Usually it is not a professional interpreter but family members, such as daughters or husband or sons. If these family members are unable to take free time to go to the mammography unit, they will not go and the mammography will not be taken.

The interpreter also had to read, translate, and explain the invitation letter.

Women stated:

- FGD 1,4: “no we cannot read, there are daughters for that”.
- FGD 2,2: “why we will not go? Because there is no interpreter, we do not understand so we will not go”.

Table 2. — *Reasons for low participation rate of Turkish women.*

Code	FGD 1	FGD 2	FGD 3
Language problem	X	X	X
Interpreter problem	X	X	X
Carelessness	X	X	X
Negative influence husband	X	X	X
Being already sick	X		X
Being on a holidays	X		X
Not worry about	X		X
Hospital phobia	X		X
Not seen the letter	X		X
Laziness		X	X
Analphabetism		X	X
Transport		X	X
Fear for pain	X		
Not having any symptoms	X		
Do not care	X		
Anxious for positive result	X		
Having a good mood	X		
Distance too far	X		
Already underwent diagnostic mammography		X	

FGD: Focus Group Discussion.

– FGD 3,5: "because we are lazy and we do not know the language, we do not have an interpreter, so I never went".
– FGD 3,6: "if there was an interpreter that would be normal for Turkish women, then they should write you are obliged to come and then we would come, if they write that there is an interpreter I think we will go".

The availability of transport to the mammography unit also seemed to be an obstacle to go to the screening. When the husband, who usually has a minimal but sufficient daily life knowledge of Dutch, is unable to bring them and stay with them, they will not take part in the breast cancer screening program. Some women also noted that they want to be brought to the unit as they have problems with walking and need help with the transportation. Only in one focus group discussion women mentioned that the mammography unit was too far from their home. In all three focus groups, a negative influence from the husband was mentioned as a reason not to take part. The husband sometimes finds that his wife should not show her breasts to other people, so screening mammography is not important enough.

Some statements:

– FGD 2,4: "I will once again be unable to go, who shall bring me? If someone could bring me I would like to go".
– FGD 2,2: "Yes I did receive the letter and I showed it to my daughter. She explained to me that it was about a breast examination, and then my husband he did not bring me, so I did not go there. We do not know the language. My husband knows it a little bit, I do not know anything. Once you are there you need someone to talk to, if they talk to me I do not understand. My husband did not go, he said: what use is it? You look so enthusiastic to show your body there, so that was what happened".

There were four repeated expressions in Turkish that where often mentioned: "*ihmalkarlık"* which is to be translated as *"*carelessness", "*önemsememek"*, which means "not to worry", "*eringeçlik"*, being "lazy" and "*umursamamak"*, just "do not care" about it.

Women who did give these explanations confess that it is purely their own fault they just do not worry about breast cancer, because they think it will never happen to them.

Some citations

– FGD 1,1: "We never talk about it, it is just because of carelessness, what else?".
– FGD 3,6: "We are the Turkish people, that is what we do, we do not worry about it, do we care for our health? No, we do not worry about health".
– FGD 3,1: "I did not go because I am unable to, I am just too lazy to do it".

Some other reasons that were mentioned included being on holiday or pilgrimage to Turkey or just being sick on the day the screening mammography had been planned, or being to afraid of the hospital, and giving a hospital phobia as a reason not to go. One important reason is that women state they do not want to have a mammography when they have no symptoms, like feeling a tumor or pain in the breasts. They believe that when they do not have symptoms there is no breast cancer, so there is no reason to participate in the screening program. A few women mention that they had diagnostic mammographies before the invitation and that is why they do no longer participate in the screening.

Discussion

For this study the authors chose a focus group discussion instead of a questionnaire, because, to gain information on this topic, they expected qualitative research to generate more in-depth and useful information on the often very complex reasons of non-attendance. First of all, because of the interaction in a FGD, more reasons will be thought and mentioned compared to the information collected by questionnaire. Moreover, not much is yet known regarding reasons and opinions of breast cancer screening participation in Turkish women in Flanders. FGD are a very good method to gain more insight into explorative research. As far as the authors know, this is the very first study in a population of Turkish migrant women on breast cancer screening participation. In FGD, questions are open and reasons originate from the women themselves and not from the examiner. Focus group discussions constitute qualitative research, hence this study does not provide quantitative data on the relative importance of each particular explanation for non-participation. Data from this study can be used to construct further quantitative analysis.

Women recruited in this study originated from seven different provinces of Turkey. It would be interesting to know the participation rate of Turkish women in Turkey as a comparator. There is no national breast cancer screening program in Turkey [3,4]. One pilot study in Balıkesir in the period 2004 to 2006 demonstrated a 74.2% participation rate [5]. This extremely high value can be explained because the women were first selected, then received an educational program on breast self examination, and the invitation for the mammography was individually delivered at home by a midwife. If the women did not arrive at the moment of mammography, the midwife visited her at home for a second time. Such a very intensive program is not likely to be organized for a complete region let alone a country.

In a Dutch study, the low participation rate for Turkish and Maroccan women was stated to be caused by poor knowledge on screening and on socio-cultural aspects [6]. In Turkey it has been shown that age, education, being married, and having breast cancer in the family were not related to the participation rate for mammography [7]. Women with a lower social economic status and a more traditional and religious view seem to accept disease and look at it as coming from God. In a Turkish study performed in Izmir, the same reasons as in the present study have been described: the lack of symptoms, being careless, and not needing screening as they do not perceive breast cancer as a personal risk [8]. Also

fear of poor diagnosis and pain from the mammography were present as was also noted by our focus groups. In a Turkish study the fear for pain was reduced by education and it was also shown that education can increase "breast awareness" [9-11]. In Flanders no data are known on the prevalence of breast cancer in Turkish migrants versus the autochthonous population. In a Dutch study, the standardized incidence rate for Turkish women as compared on autochthonous Dutch women was only 0.29 [12]. Similar results were obtained in Germany for Turkish women living in Hamburg [13]. A lower incidence of breast cancer in Turkish migrants has also been demonstrated in Australia [14]. Both studies suggesting that breast cancer risk is less in Turkish women. One bias in these numbers can be that women who become sick want to migrate back to their land of origin. Although the frequency of breast cancer in Turkish women seems to be lower, it still constitutes the most frequent cancer in women in Turkey, up to 24% of cancers in Turkish women. A higher incidence of breast cancer is seen in second and third generation migrants. Contrary to the older generations of Turkish migrants who want to return to Turkey when diagnosed with cancer, as they want to die in their own country, the younger generation does not make this move and remains in the country they live in. It has also been suggested that the younger generation has taken over a Western lifestyle that negatively influences the incidence of breast cancer [15-17].

Reasons for not participating in breast cancer screening can be reduced to two major components. The first one is the language problem and all difficulties caused by a language barrier, such as reading the letter and needing an interpreter at the moment of the mammography. The second problem is the lack of knowledge on the disease and on the process of screening, not realizing the differences between screening mammography and diagnostic mammography.

A solution for the language problem is not easy to find. The law in Belgium does not allow any other language than Dutch in the Flemish region to be used for any official document such as an invitation for breast cancer screening. Trying to adapt the language laws has been known to result in major political crisis in the recent past. Even if another language could be used, there is no official list of who is member of the Turkish community or speaks and understands only Turkish. This is difficult because some women from Turkish origin, unable to communicate in Dutch, do have Belgian nationality, while others have only Turkish nationality. In the future this problem will diminish as the younger generation has been working and studying in Dutch. However even then for recently migrated women the problem will persist. At the moment an obligatory language course for newcomers has been introduced and the effect of this is still yet to be seen. Another part of the non-participation could be improved by education, given in small groups in their own language or by their individual family physician. Actually FGDs themselves were educational moments and at the end of the discussion all participants stated that they will take part in the screening the next time. Of course this does not mean that they actually will do this.

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References

[1] Visser O, van Peppen AM, Ory FG, van Leeuwen F.E.: "Result of breast cancer screening in first generation in Nothwest Netherlands". *Eur. J. Cancer Prev.*, 2005, *14*, 251.
[2] Morgan D.L.: "The Focus Group Guidebook". Thousand Oaks, California: Sage Publications, 1998, Kit 1-5.
[3] Dundar P.E., Ozmen D., Ozturt B., Haspolat G., Akyildiz F., Coban S., Cakiroglu G.: "The knowledge and attitudes of breast self-examination and mammography in a group women in a rural area in western Turkey". *BMC Cancer*, 2006, *6*, 43.
[4] Vahit O.: "Breast Cancer in the world and Turkey". *Meme sagligi dergisi*, 2008, *4*, 2.
[5] Balikesir D.H. Ketem, Bir Tarama Ornegi: balikesir meme kanseri tarama program, In: Tuncer A.M., *Türkiyede kanser kontrolü*. Ankara: Saglik bakanligi yayinlari, 2007, 707, 345.
[6] Hartman E., Van den Muijsenbergh M.E., Haneveld R.W.: "Breast cancer screening participation among Turks and Maroccans in the Netherlands: exploring respons for nonattendance". *Eur. J. Cancer Prev.*, 2009, *18*, 349.
[7] Avci I.A, Kurt H.: "Health beliefs and Mammography rates of Turkish women living in rural areas". *J. Nurs. Scholarsh.*, 2008, *40*, 170.
[8] Cam O., Gümüs A.B.: "Breast cancer screening behavior in Turkish women: relationships with healt beliefs and self-esteem, body perception and hopelessness". *Asian Pac. J. Cancer Prev.*, 2009, *10*, 49.
[9] Gözüm S., Karayurt O., Kac S., Platin N.: "Effectiveness of peer education for breast cancer screening and health beliefs in eastern Turkey". *Cancer Nurs.*, 2010, *33*, 213.
[10] Secginli S., Nahcivan N.O.: "Factors associates with breast cancer screening behaviours in a sample of Turkish women: a questionnaire survey". *Int. J. Nurs. Stud.*, 2006, *43*, 161.
[11] Alimoğlu E., Alimoğlu M.K., Kabaalioğlu A., Ceken K., Apaydin A., Lüleci E.: "Mammography-related pain and anxiety". *Tani girisim Radyol.*, 2004, *10*, 217.
[12] Visser O., Van der Kooy K., Van Peppen A.M., Ory F.G., van Leeuwen F.E.: "Breast cancer risk among Firs-generation migrants in Netherlands". *Br. J. Cancer*, 2004, *90*, 2135.
[13] Spallek J., Arnold M., Hentschel S, Razum O.: "Cancer incidence rate ratios of Turkish immigrants in Hamburg, Germany: a registry based study". Cancer Epidemiol., 2009, *33*, 413.
[14] McCredie M., Coates M., Grulich A.: "Cancer incidence in migrants to New South Wales (Australia) from the Middle East, 1972-91". *Cancer Causes Control*, 1994, *5*, 414.
[15] Ziegler R.G., Hoover R.N., Pike M.C., Hildesheim A., Nomura A.M. West J.W., *et al.*: "Migration patterns and breast cancer risk in Asian-American women". *J. Natl. Cancer Inst.*, 1993, *85*, 1819.
[16] Zeeb H, Razum O, Blettner M., Steigmaier G.: "Transition in cancer patterns among Turks residing Germany". *Eur. J. Cancer*, 2002, *38* 705.
[17] Raymond L., Fischer B., Fioretta G., Bouchardy G.: "Migration bias in cancer survival rates". *J. Epidemiol. Biostatist.*, 1999, *1*, 167.

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