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An exploration of attitudes towards breast cancer screening in orthodox Jewish women in Antwerp – Belgium

E. Bruwiere[1], S. Van Roosbroeck[2], G. Van Hal[2], J. Muys[1], Y. Jacquemyn[1]

[1] *Department of Obstetrics and Gynaecology, Antwerp University Hospital UZA, Edegem*
[2] *Department of Social Medicine and Epidemiology, Antwerp University, Wilrijk (Belgium)*

Summary

Objective: To explore determinants of participation in breast cancer screening in orthodox Jewish women living in Antwerp, Belgium, and to uncover their opinions and attitudes towards screening, and thereby to detect ways to optimize participation. *Study design:* Focus group discussions were performed during the last months of 2011 and the first half of 2012 to explore motivation to participate or not in breast cancer screening. Groups consisted of five to seven women. Inclusion criteria were: being female, considering oneself as orthodox Jewish, aged between 50 and 69 years. *Results:* Three focus group discussions with in a total of 20 women had taken place. All participants in the focus group discussions had a screening mammography taken on a regular base. All participants agreed that the social cohesion between Jewish orthodox women and the importance that is given to healthcare within the Jewish tradition are important contributors to their participation in a breast cancer screening program. Pain, lack of information during the exam, lack of confidence in the quality of the exam, perceived problems when the examining doctor/technician is male, and fear of the results are mentioned as barriers. The participants, however, state that these were not important enough to result in non-participation. Barriers could be diminished by information sessions specifically aimed at orthodox Jewish women. Conclusion: This qualitative research demonstrates a generally positive attitude of orthodox Jewish women living in Antwerp, Belgium, towards mammographic breast cancer screening. Increased and repeated structured information sessions are likely to improve breast cancer awareness in this population.

Key words: Breast cancer screening; Ethnic minorities; Prevention; Jewish.

Introduction

Cultural and religious traditions are important to consider in health promotion, especially in so called cultural "insular communities" (communities defined by religious or ethnic orientation that effectively places them outside mainstream sources of information on health promotion) [1].

Breast cancer is the most common form of cancer affecting women in Europe and is the most frequent cause of female cancer-related death in Belgium. In 2001 a screening program was set up in Flanders (the northern region of Belgium) offering a free mammography every two years to all females between 50 and 69 years of age. The overall participation rate in Flanders in the period 2010 to 2011 totalled 50.2 %. Participation rate was lower in some groups, especially in ethnic minorities.

Approximately 20,000 orthodox Jews live in the city of Antwerp, but not much is known about the health behaviour in this group. In Israel significantly more orthodox Jewish females participate in breast cancer screening by mammography as compared to Arab women [2]. Orthodox Jewish religious women seem to demonstrate better health behaviour as compared to non-religious women. Researchers found a lower prevalence of stress and smoking among religious persons, as well as a healthier diet. On the other hand, religious women are less likely to undergo breast examinations and mammography [3].

This qualitative research was set up to further explore the views, visions, and possible problems with mammographic breast cancer screening in the orthodox Jewish community in Antwerp.

Materials and Methods

The study was reviewed and approved by the Antwerp University Ethics Committee UA A11-05. Participants provided written informed consent before taking part in the focus group discussions. The focus groups discussions consisted of five to seven women and were led by a trained moderator. Discussions were held in Dutch. In general, Jewish women living in Antwerp speak fluent Dutch. The moderator was non-Jewish and did not speak Hebrew or Yiddish. The authors followed the methodology as described by Morgan [4]. A questionnaire was scripted beforehand and meticulously checked off during the discussion. The discussions were recorded on audio tape. An observer noted all non-verbal communication during the focus group discussion.

Inclusion criteria for the selection of focus group members included being a female between 50 and 69 years old and considering oneself as a member of the orthodox Jewish community in Antwerp.

The age category is identical to the age in which women in Flanders are invited for the breast cancer screening program. One

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Table 1. — *Comments on barriers for breast cancer screening.*

Pain:
1. For me it is really a barrier that it hurts very much. If I have the choice between an injection and a mammography, then I prefer the mammography. I am not saying it is really agreeable but anyhow.
2. It is part of the unpleasant things of life, it is logical but …
3. All that stuff is very annoying but it has to be done.
4. Having to do a bicycle test, being attached to all these wires, that's much worse than having to show your naked breasts.
Technical quality:
1. You need some luck that the reading is done right. I know a person who went to the lab and they told her it was just a cyst. They did not do any puncture and eight months later she felt a nodule. She returned and it was cancer. One centimeter and six millimeters already. Then there you are, how do you screen? Can screening be so important when it is not 100% safe?
2. I had a screening and then I received the result and then I had to wait for two years, I don't feel that as being very safe!
Physician's gender:
1. It is not that we really and absolutely want a woman but...
2. I am used to being examined by a man.
3. It is easier when it is a woman who does it.
4. If you need to talk it is easier to talk with a female than with a male doctor.

Table 2. — *Comments on the personalised letter.*

1. The fact that the letter is personally addressed to you makes you think more about it. If it is just one of these forms they put in every postal box... but the fact that it is personal and on a list.
2. Seriously, I know my name is on it, printed on it, I like that very much, the date and the doctor I had to see was mentioned and I don't read the rest.

Jewish woman was contacted and asked to bring four or five others meeting the inclusion criteria to the focus group discussion. She also requested two other women to do the same.

The three samples thus composed can be considered as convenience samples. Because data on this topic are scarce, the qualitative research method of focus group discussions is an appropriate method for which selection bias is less important. In qualitative research, saturation of the data is much more important than representativeness. Saturation of the data is reached when similar information is gathered in following focus group discussion, making new focus group discussions redundant.

The main aim of this explorative study was to uncover the opinions and attitudes of orthodox Jewish women on the topic under study in an in-depth way. Afterwards, the results of the focus group discussions could be used to construct a questionnaire for a quantitative, more representative study. The participants were told that their contribution to the study was voluntarily and that all data would be analysed and reported in an anonymous way. The focus group discussion was completely transcribed within three weeks after the session in order to maximise the inclusion of context and details.

Each reason mentioned for participation or non-participation in the breast cancer screening program was numbered with a code. The first transcript was independently coded by two researchers (BE and VRS). The codes of the two researchers were then compared and a consensus was reached which was used by BE for coding the following transcripts.

Results

Three focus group discussions were held, totalling 20 orthodox Jewish women between 50 and 69 years old. The first focus group discussion consisted of eight women, the second of seven women, and the third of five women. Every participant confirmed that she was already taking part in screening mammography. They all had a mammography taken every two years through the national screening program, or as prescribed by their family physician or gynaecologist. In general the participants were highly motivated to take part in the screening program.

Most women mentioned that they participated following an invitation from the health authorities. Taking care of one's health is considered as very important in the orthodox Jewish community. Several barriers to participation were mentioned, but none of these was considered important enough not to participate. The most frequently mentioned barrier was (fear of) pain during the exam, mentioned by five women. The second most frequently cited barrier was receiving insufficient information during the exam (n=4) or lack of confidence in the quality of the exam (n=4) because it is offered free of charge by the regional authorities. Some women were less comfortable with the male gender of the examining physician or technician (n=4). Two respondents mentioned anxiety for a possible bad result. Table 1 shows some comments of the participants on the most frequently mentioned barriers.

None of the participants had had breast cancer. All women mentioned that the invitation letter they received was clear, well written, and did not cause any language problems. They specifically appreciated that the letter was personalised and included the date, time, and the name of the doctor who is going to perform the exam. Table 2 shows some statements on this personalised letter. Only five out of the 20 women mentioned explicitly that they preferred a letter from their family physician or gynaecologist.

In every group it was asked whether Jewish culture or religion plays a role in participating in preventive breast cancer screening. All agreed that the closeness of the community of which they are part of is an important determinant. In addition, the women mentioned some social factors having an influence as well. Table 3 shows some insights of our participants.

At the end of each focus group the authors asked whether the participants had any recommendations to suggest for family physicians and gynaecologists. In all three groups it was mentioned that encouraging breast examination is something very important for these healthcare workers to

Table 3. — *Comments on the importance of a close community and social cohesion.*

1. I have the impression that it all has to do with us living in a very small circle, we always meet the same people, and if one says I am going to do that, then the other says I am going to do that as well.
2. It is just by coming together and then everyone telling how important it is that you do it and that is not just for the mammography. We do a lot of things together, that is perhaps why people talk about this more easily.
3. It is more a social than a religious aspect. In our community we talk quite a lot with each other.
4. If in our community someone has cancer, everyone knows it immediately. You don't need to know that person yourself; you just become aware of it.
5. We all have many children and it is important to stay alive and to stay healthy for them".
6. Yes I think that all doctors, gynaecologists, and family physicians, play a very important role; they should really emphasise breast self examination.

Table 4.

Comments on information sharing:
1. If such information sessions could be organised, a lot of people would come, for sure.
2. There we could learn in a practical way how to perform breast self-examination.
Comments on the influence of the environment:
1. My mother died from cancer a few years ago. Just after that I had myself examined.
2. It always gives you more strength after a personal history.
3. More anxiety is caused by other people having breast cancer.

do. In all groups the idea of information sessions was supported in order to further increase breast awareness within the orthodox Jewish community. Finally it was noted that being confronted with someone with breast cancer plays a role in becoming aware of one's own health. Comments on this issue can be found in Table 4.

Discussion

Recruitment of women of the orthodox Jewish community by a non-Jewish research group proved to be not an easy task. It took some time to find one enthusiastic ambassador who was able to mobilise other women from her community. This could have had an influence on the composition of the present discussion groups and hence on the results. The authors cannot exclude that those with a more negative view regarding breast cancer screening did not participate. Some bias is probably introduced as all participants in the focus group discussions actually had regular mammography's performed. Although the majority of Jewish people in Antwerp speak fluent Dutch, the fact that the present moderator only spoke Dutch could also have caused a bias in the present recruitment. After these three focus group discussions, saturation had been reached, which suggests that the present information gathering is complete.

The present study group seemed to be very much aware of the problem of breast cancer and they all presented themselves for regular mammography. The majority felt happy about the way the screening was organised and made use of the free preventive mammography as offered by the government. A small group preferred a personal prescription by their family physician or gynaecologist.

Social cohesion in a group of orthodox Jewish women seems to be an important determinant of health behaviour. The groups even advised to further activate this social cohesion by starting information sessions to spread useful information and to eliminate misconceptions, such as the limited value of mammography or free-of-charge mammography being of lower quality. None of the barriers to participation that the women mentioned did actually prevent them from taking part in screening mammography. In a cohesive and close community, chances are high to know that someone has cancer. A personal history (including family or friends with breast cancer) can strengthen the motivation to have a breast exam.

For this study the authors have chosen focus group discussions instead of a questionnaire because in a questionnaire reasons, barriers and explanations are stated beforehand. In focus group discussions, the questions are open and answers are collected until no new answers come and saturation is reached. Data from this kind of qualitative studies can be used to construct further quantitative analysis.

As far as the present authors' are aware, this is the very first study in a population of orthodox Jewish women on breast cancer screening participation in Europe. Neither in Flanders nor any other part of Western Europe as far as they know, data on the prevalence or incidence of breast cancer in orthodox Jewish women are known. Recently Tkatch *et al.* have tried to calculate the breast cancer incidence rates among orthodox Jewish women by using geo-coding; in neighbourhoods with a high estimated Jewish population, a higher breast cancer rate was noted. It is also known that an elevated rate of BRCA1/BRCA2 founder mutation has been documented among Ashkenazi Jews [5]. In 2004, Albert *et al.* examined the differences in the use of prevention services such as mammography between women in a densely populated, low-income area in New York (primarily populated by ultra-orthodox Jews) and New York city women (matched for age, geographic residence, and race-ethnicity). In the case of breast cancer screening, they reported no difference for women aged 50-69 between the two groups with respect to having mammograms and clinical breast exams. Indicators of socio-demographic status, such as education and financial means, were not related to the likelihood of breast cancer screening. In addition, being

diagnosed with cancer or having a family history of breast cancer was not related to reports of cancer screening. A lower likelihood of screening was mainly associated with low exposure to mainstream media, such as a less than daily exposure to English newspapers and television [1]. Baron-Epel *et al.* used a random telephone survey to compare four different cultural and ethnic groups in Israel including veteran, ultra orthodox, and immigrant Jewish and Arab women [2, 6]. In some populations subjective norms, fatalism, fear of breast cancer, and perceived (lack of) effectiveness were associated with participating or not participating in mammography screening and it was concluded that beliefs and attitudes should be studied in sub-populations before planning interventions.

In conclusion this qualitative research has demonstrated a generally positive attitude of orthodox Jewish women living in Antwerp, Belgium, towards mammographic breast cancer screening. Increased and repeated structured information sessions could probably even improve breast awareness in this population. There is a need to study the breast cancer incidence in this and other sub-populations. Only in this way further optimisation of targeted screening in sub-populations and cultural insular communities can be obtained.

Conclusions

One of the strengths of the present study was that it has tackled a topic that is barely touched on in scientific research. The authors succeeded in conducting three focus group discussions after which saturation of the data was reached. In order to gather information on this topic in a representative way, more research has to be done, more specifically in a quantitative way. The results of the present study, however, could be used to create a quantitative questionnaire.

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Address reprint requests to:
Y. JACQUEMYN, M.D.
Department Of Obstetrics and Gynaecology
Antwerp University Hospital UZA
Wilrijkstraat 10, 2650 Edegem (Belgium)
e-mail: yves.jacquemyn@uza.be