

How to reach a higher participation rate for breast cancer screening in Flanders?

by

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Abstract

Objectives: *To know more about the reasons why women participate or do not participate in the official screening programme for breast cancer in Flanders. This might enable us to intervene in such a way that the participation rate could be raised.*

Methods: *A survey in women who participated and depth interviews in women who did not participate in the official screening programme in the province of Antwerp, Flanders.*

Results: *Where the participants is concerned, more than 40.0% of the questionnaires was filled out and sent back (n=807). The invitation letter is the way by which most participants get into contact with the screening programme (88.0%), followed by television (47.0%) and the general practitioner (24.0%). This actual situation is, however, not entirely congruent with the women's preferences. Many more women want the GP to be the channel by which they get into contact with the screening programme. The interviewed non participants all had a*

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diagnostic mammography performed. On the other hand, they have a very limited knowledge of the official screening programme. They do not know about the quality of a screening mammography. Moreover, the fact that their GP does not stimulate them to attend the screening, is a major barrier to have a screening mammography performed.

Conclusion: *To achieve higher participation rates for the breast cancer screening programme in Flanders, the existing measures to lower the threshold for participation must be combined with more concrete and background information and a more active role of the GP.*

Introduction

As in other Western European countries, breast cancer is a major health problem in Flanders (Belgium). In the period 2000-2001, 10,240 Flemish women were diagnosed with invasive breast cancer. This means 35.3% of all cancers in Flemish women (1). According to the registration of the Flemish Cancer Registry Network (VLK), breast cancer is diagnosed in more than 1 out of 9 women before the age of 75. The risk increases with age. Three out of four cancers occur in women older than 50. Compared to other European countries, Flanders scores highest where the age standardised incidence rate for invasive breast cancer is concerned (1).

In 2001, 1,367 Flemish women died because of breast cancer and this at a relative low age. From the age category of 30-34 on, breast cancer is the most important cause of death amongst all cancers (2). In 2001, the total number of potential years of life lost due to breast cancer compared to life expectancy at birth, was 8.2 years/1,000 person years (2). This means that, at least in theory, there is still room for health gain by decreasing the number of early deaths because of breast cancer.

Since primary prevention of breast cancer is practically not possible, secondary prevention becomes more important. Several randomised controlled trials have shown that early detection and therapy of breast cancer, can be effective. Women who participate in a breast cancer screening programme, reduce their risk of dying from breast cancer with over 50.0% (3). Nyström et al. and Otto et al. found out that a breast cancer screening programme can succeed in reducing cause specific mortality in time (4-5). The European Union recommends that its member states offer mammographic screening every 2 years to all women between the ages of 50 and 70 (6).

In 2001, a breast cancer screening programme was implemented in Flanders, Belgium. Unlike the Flemish health target of a 75.0% participation rate, only one third of all eligible women take part in the official programme.

Knowing the reasons why women participate or do not participate in the official screening programme might enable us to intervene in such a way that the participation rate could be raised. Moreover, when trying to increase the participation rate, it seemed very important to us to take into account the experiences of the participants in the time before, during and after the screening.

Women participating in the screening programme might also be confronted with psychological side-effects at different moments. This can be caused by receiving the invitation letter, by waiting for the results or by receiving bad results. Also these aspects should be taken into account.

Methods

Two kinds of methods have been used to answer the research question: How to reach a higher participation rate for breast cancer screening in Flanders?

- a) A survey in women who participated in the official screening programme;
- b) Depth interviews in women who did not participate in the official screening programme.

a) Survey in participants

Two thousand women who participated in the official screening programme and were living in the province of Antwerp, Flanders, were randomly selected. Half of the selected participants were townswomen, while the other half were villagers. The townswomen lived in Antwerp and the villagers were inhabitants of a village with less than 16,000 inhabitants and a surface smaller than 500 km². Six villages were randomly selected out of the list of villages with above-mentioned characteristics. With the assistance of the 'Regionaal Screeningscentrum Antwerpen' (Regional Screening Centre Antwerp) some thousand addresses of participants living in one of these six villages have been randomly selected. Both groups, townswomen and villagers, received a questionnaire on several topics concerning breast cancer screening:

knowledge of the test, reasons to participate, evaluation of the programme and suggestions for improvement. We were interested in the opinion of the participants. Participating in the survey was voluntary and completely anonymous.

A cover letter was added with the following information: identity of the research team, the goal of the study, the fact that there are no good or false answers, the guarantee that the data would be handled anonymously and some instructions for filling out the questionnaire properly. The different questions can be divided into three main groups: questions regarding affective components, questions regarding knowledge and questions regarding reasons for participation.

Questions regarding affective components

When some time ago Flemish women who participated in a breast cancer screening programme were asked which were the positive feelings associated with their participation, the principal answers were: reassurance, relief and having certainty. On the other hand, when asked which negative feelings occurred, the fact that the mammographic examination was painful, unpleasant or annoying were mentioned. Other negative experiences concerned the waiting time before getting the result, fear of having cancer diagnosed or doubts about the benefit of the mammographic examination (7).

Others found that women who were rather afraid of participating in any kind of research and screening (for example because of fear of pain, radiation or bad result) are less inclined to participate in breast cancer screening (8). Therefore we found it important to include questions regarding affective components of participation.

Questions regarding knowledge

A second type of questions, also included in the survey, are questions about knowledge. Women who know that breast cancer is the most frequent cancer in Western-European women and also know that older women have a higher risk of getting breast cancer, have a much bigger chance of being mammographically examined (7).

Questions regarding reasons for participation

The third type of questions are questions about the reason why women participate or not, which aspects encourage them to participate and which act as barriers. There was also a focus on the different channels that influenced and convinced women to participate.

b) Depth interviews

Few non-participants could be motivated to talk about the subject. Therefore, a specific method has been chosen to find non-participants to talk about breast cancer screening, mammography and why they did not participate. This method included also that only women who did not participate in the official screening programme, but who already had been participating in the *diagnostic circuit* were contacted. Apparently engagement towards breast examination was present by these women, and they were motivated to talk about it. Ten depth interviews took place, five with townswomen and five with villagers (inhabitants of the village of Sint-Amands). The ideal method would have been an 'at random' selection of the respondents. Because of the few women who were prepared to be interviewed, the selection was on an arbitrary base (i.e. friends and acquaintances) which resulted in the fact that only women who already participated at the diagnostic circuit could be reached. Throughout the ten depth interviews the researchers used the same script so that conversations could be compared. A first global analysis of the interviews has been realised by using the programme Atlas-ti. This analysis made it possible to assess the frequency, intensity and specificity of the most relevant aspects brought up during the interviews, which is a key feature in qualitative research.

Results

Analysis of the results of the survey in participants in the official screening programme

More than 40.0% of the questionnaires was filled out and sent back (n=807). The number of villagers that responded is markedly higher than the number of townswomen that returned the questionnaires (n=437 and n=358 respectively)¹. This difference is statistically significant ($p < 0.01$). Besides, women older than sixty and especially older than sixty-five are underrepresented in this survey. This has to be taken into account when interpreting the results.

Most of the respondents are concerned about their health situation: they make sure that they eat healthy food² (60.5%, n=488), they are

¹ Twelve respondents or 1.5% did not answer the question concerning the place of residence.

² The health pattern of the respondent is measured subjectively. These women judged their food pattern as healthy or unhealthy on a scale from one to five. This applies also for the other variables related to the profile of the respondent.

TABLE 1:
Profile of the respondents

Food Pattern	Healthy	60.5% (n = 488)
	Less healthy	39.5% (n = 319)
Smoking Pattern	Non-Smokers	79.3% (n = 640)
	Smokers	20.7% (n = 167)
Exercise Pattern	More than two hours a week	52.8% (n = 426)
	Less than two hours a week	47.2% (n = 381)
Marital Status	Married	73.0% (n = 589)
	Not Married, Divorced, ...	27.0% (n = 218)
Education	Till 15 to school	56.8% (n = 458)
	Till 18 to school	14.1% (n = 114)
	Higher education (college and university)	29.1% (n = 335)
Occupation	Unemployed	66.2% (n = 534)
	Employed	33.8% (n = 273)

non-smokers (79.3%, n=640) and they are exercising more than two hours a week (52.8%, n=426). These women are married (73.0%, n=589), less educated (56.8%, n=458) and 66.2% is un-employed (n=534).

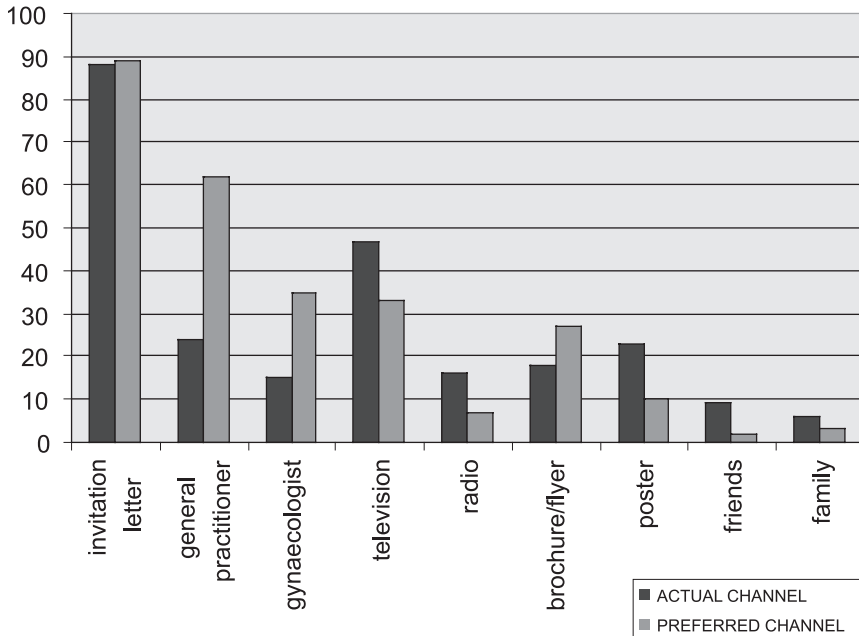
Communication channels

The invitation letter is the way by which most participants get into contact with the screening programme (88.0%, n=713), followed by television (47.0%, n=377) and the general practitioner (24.0%, n=190). The latter is mentioned relatively more frequently by women older than sixty: 30.3% (n=70) by women aged sixty and older versus 21.0% (n=120) by women younger than sixty.

This actual situation is not entirely congruent with the women's preferences. 24.0% (n=190) Of the respondents say they get into contact with the programme by means of a general practitioner, whereas 61.4% (n=495) prefers this way of contact. Moreover, only 15.2% (n=123) gets information about the programme via the gynaecologist while 35.6% (n=287) of the women choose the gynaecologist as the preferred communication channel. On the other hand, 88.0% (n=713) gets into contact with the screening programme by the invitation letter while 89.2% (n=719) of the respondents prefers this letter. The following graph supports these findings visually.

Women who prefer the invitation letter mainly do so because it is a personal way of invitation, they would forget the screening otherwise and because of the straightforwardness and easiness of the invitation

Figure 1:
The actual channel in comparison with the preferred channel for getting into contact with the breast cancer screening programme



letter. Still, the respondents have some recommendations on this means of inviting people. A minority of women (4.0%, $n=32$) perceives the invitation letter as distant, they judge the language as too difficult and they miss the motive of the invitation in this letter.

Another important point is the way by which participants want to obtain the result of the screening. The desired way for obtaining the result of the screening mammography seems to be related to the outcome of the examination, the age of the woman and the preferred way of invitation. When a lesion is observed ('positive' result), the majority of women (61.8%, $n=499$) prefers the general practitioner as communication channel whereas 32.0% ($n=256$) favours a letter from the screening centre. This outcome is completely different when the result is negative. In that case 62.1% ($n=501$) of the respondents give preference to the letter as communication channel for obtaining the result. This finding differs according to the respondent's age. 70.0% ($n=379$) Of women in their fifties prefer a letter to be informed compared to only 50.0% ($n=119$) of the respondents being 60 years or older. Furthermore the majority of women who prefers the invitation letter to get into contact

with the screening programme also prefers a letter from the screening centre for the result. On the other hand, women who like the general practitioner or the gynaecologist as invitation channel, also more like to get the result by means of their GP or gynaecologist.

Knowledge

46.8% Of the respondents (n=378) could not give any cause of breast cancer. This result is related to the education level of these women. The more educated they are, the more they can give an answer to this question. The same applies to the item concerning the risk of getting breast cancer before the age of seventy-five. In general, four out of ten women value this risk correctly (6.0-15.0%). Of the women with a university education, 70.0% (n=16) has given the right answer. It is remarkable that our respondents, especially the younger ones, overestimate this risk. Moreover, most women do not make the distinction between a screening mammography and a diagnostic mammography. Only 43.0% (n=351) has already heard about a screening mammography. The term diagnostic mammography is known even less (one out of three). Overall, there is a serious knowledge gap between higher and lower educated women.

Emotions

More than one third of our respondents experienced the screening mammography as painful. Nevertheless this will not keep them from participating. Moreover, 20.0% (n=28) of lower educated women link breast cancer with death but yet participate as well in the screening programme.

On the day of the mammography most of the women are satisfied and relaxed. Nevertheless, one out of five women was nervous, which is actually normal in that situation. Although the result is not statistically significant, it is remarkable that the majority of these anxious women is lower educated. Table 2 shows this finding. As mentioned above, lower educated women are less familiar with the screening programme and with cancer in general. In general women judge the personnel as friendly and sympathetically during the examination.

Depth interviews with non-participants

All interviewees have a positive attitude towards the screening programme, nevertheless they take part in the diagnostic circuit. Their limited knowledge (table 3) concerning the difference between a screening mammography and a diagnostic mammography might be a reason why they choose to have a diagnostic mammography performed. The

TABLE 2:
Nervousness on the day of the screening in relation to the education level

Education	Nervous	Not nervous	Missing data	Total
Lower education or less	n=28 19.0%	n=115 78.2%	n=4 2.8%	n=147 100.0%
Lower technical education	n=54 22.7%	n=173 72.7%	n=11 4.6%	n=238 100.0%
Secondary school (1 st -2 nd degree)	n=15 20.8%	n=53 73.6%	n=4 5.6%	n=72 100.0%
Secondary school (third degree)	n=15 13.2%	n=97 85.1%	n=2 1.7%	n=114 100.0%
Higher education (3 years)	n=16 11.3%	n=118 83.7%	n=7 5.0%	n=141 100.0%
Higher education (> 3 years)	n=2 11.8%	n=15 88.2%	n=17	n=0 100.0%
University degree	n=3 13.1%	n=19 82.6%	n=1 4.3%	n=23 100.0%
Missing data	n=8 14.5%	n=41 74.5%	n=6 11.0%	n=55 100.0%
Total	n=141 100.0%	n=631 100.0%	n=35 100.0%	n=807 100.0%

interviewed women hardly know what exactly happens during the examination (diagnostic mammography). Furthermore they are not aware of the high quality of the screening mammography, which meets the European quality guidelines. Moreover they experience the word 'screening' as too difficult because it originates from the English language.

Besides the lack of knowledge, the limited assistance from the general practitioner and the gynaecologist forms a second disturbing factor in persuading women to participate in the screening programme. The interviewed women mention explicitly that their general practitioner does not encourage them to participate and they also mention that if the GP would do so, it would be an enormous support for them to participate in the screening programme. Furthermore, according to the interviewees, it would give the screening programme a more personal character when the general practitioner acts as a link between the women and the screening programme.

Discussion

The quantitative and qualitative research show there is still a tremendous lack of knowledge in women belonging to the target group about

TABLE 3:
Knowledge about the official Flemish screening programme by non-participants

Interviewed women	Intrinsic meaning of the screening
R1	'That's some sort of examination, it's done approximately every two years by my gynaecologist.'
R2	'I think that that hmm, hmm according to me, it has some thing to do with statistics and so. Than hmm, yes obviously, why, why, why checking the breasts?'
R3	'... that, that, I don't know how this, hmm breast cancer screening of the government works,...'
R4	'Screening, than you are talking about this preventive examination, right?'
R5	'Having it done, I mean, having your breasts examined.'
R6	'Seeing or examining, but that is actually not quite the same as when you see it, right?'
R7	'Is that a synonym for test? A screening or an analysis?'
R8	'Yes, I have already heard about it. That is a mammography. That is a screening of the government. It is the second or third year that this kind of examination takes place.'
R9	'... tell me...'
R10	'How? Screening? A kind of examination, right?'

breast cancer in general and about the screening programme in particular. These shortcomings could be solved by communicating the strengths of the mammographic screening programme in the invitation letter. The media can also play an important role by not focusing solely on the emotional aspects, but as well by providing more concrete and background information. However, the main finding in recent research showed a substantial variability in women's desire for information about mammography screening. 39.0% Did not want detailed information on limitations and drawbacks, and 6.0% wished to receive no information at all (9). Hence, more effective and balanced information will not ensure that women will read and understand it. We also have to consider a lack of interest in the target group women.

Furthermore, our findings show a positive link between the educational level and the knowledge level of women as well as a link between the educational level and the emotional situation on the day of the screening: the majority of anxious women was lower educated. This is contradictory to other research, which found a negative correlation between anxiety and education (10). Education can perhaps be an explanatory variable, but we have to put this variable into perspective and look for other intermediary variables in the meantime. Anyhow, all

efforts to reduce the gap concerning educational level are more than welcome.

The main finding of the depth interviews in our study is the importance of the role of the general practitioner in supporting women to participate in the screening programme. The GP can help women to overcome their fears and ignorance. The previously mentioned study of Chamot also suggests that women who refuse or feel oppressed by information on breast cancer screening within the framework of a mass programme, might be reached easier on the occasion of a private consultation with a health professional (9). The National Health Interview Survey of 2004, shows that 79.0% of the Belgian population visits at least once a year its general practitioner (11). This suggests that the general practitioner can indeed play an important role in improving the participation rate of the breast cancer screening programme.

A lot of efforts have already been implemented to lower the threshold and raise the participation rate (i.e.: mammography screening being free of charge, making use of mobile screening units, sending women personal invitation letters). When these measures can be combined with more concrete and background information that attracts the target population, a more active role of the GP and a reduction in the gap between different educational levels, it is to expect that this will result in higher participation rates for the breast cancer screening programme in Flanders.

Samenvatting

Doelstelling: *Meer te weten komen over de redenen waarom vrouwen al dan niet deelnemen aan het officiële programma voor borstkankerscreening in Vlaanderen. Dit moet ons toelaten om de gepaste maatregelen te nemen om de participatiegraad te verhogen.*

Methoden: *Een enquête bij deelnemers en diepte-interviews bij niet-deelnemers aan het officiële screeningsprogramma in de provincie Antwerpen, Vlaanderen.*

Resultaten: *Meer dan 40,0% van de participanten stuurde de vragenlijst ingevuld terug (n=807). De uitnodigingsbrief is het kanaal waardoor de meeste participanten in contact komen met het screeningsprogramma (88,0%), gevolgd door televisie (47,0%) en de huisarts (24,0%). Deze feitelijke situatie weerspiegelt echter niet volledig de voorkeuren van de vrouwen. Er is een veel grotere groep vrouwen die de huisarts prefereren als kanaal om in contact te komen met het screeningsprogramma. De geïnterviewde niet-deelnemers hadden allemaal reeds een diagnostische mammografie laten uitvoeren. Anderzijds hebben ze een zeer beperkte kennis van het officiële screeningsprogramma. Ze weten niets over de kwaliteit van een screeningsmammografie. Daarnaast vormt het feit dat de huisarts hen hier niet toe aanzet, een ernstige barrière om deel te nemen aan het officiële programma.*

Conclusie: *Om een hogere participatiegraad voor het borstkankerscreeningsprogramma in Vlaanderen te bereiken, moeten de bestaande drempelverlagende maatregelen worden aangevuld met concretere en achtergrondinformatie en een actievere rol van de huisarts.*

Résumé

Objectifs: *En savoir plus sur les raisons de participation ou de non-participation des femmes au programme officiel de dépistage du cancer du sein en Flandres. Ceci devra nous permettre d'établir des mesures adaptées pour augmenter le taux de participation. Méthodes:* *Une enquête chez les participantes et un interview plus approfondi de non-participantes au programme officiel de dépistage dans la province d'Anvers, Flandres.*

Résultats: *Plus de 40,0% des participantes ont renvoyé le questionnaire dûment rempli (n=807). La lettre d'invitation est le canal par lequel la majorité des participantes est mise en contact avec le programme de dépistage (88,0%), suivi de la télévision (47,0%) et du médecin généraliste (24,0%). Cet état de fait ne reflète cependant pas complètement les préférences des femmes. Il y a un beaucoup plus grand groupe de femmes qui préfèrent le médecin généraliste comme canal pour la mise en contact avec le programme de dépistage. Les non-participantes interviewées avaient déjà toutes effectuées une mammographie diagnostique. D'autre part elles ont très peu de connaissance sur le programme officiel de dépistage. Elles ne savent rien sur la qualité d'une mammographie de dépistage. En outre, le fait que le médecin généraliste ne les poussent pas dans ce sens, forme une barrière importante pour participer au programme officiel.*

Conclusion: *Pour obtenir un plus haut taux de participation au programme de dépistage du cancer du sein en Flandres, les mesures existantes pour diminuer le seuil doivent être complétées avec de l'information concrète et sur le fond et un rôle plus actif du médecin généraliste.*

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