

Information in practice

Presentation on websites of possible benefits and harms from screening for breast cancer: cross sectional study

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Abstract

Objective To investigate whether information on mammographic screening presented on websites by interest groups is balanced, is independent of source of funding, and reflects recent findings.

Design Cross sectional study using a checklist with 17 information items.

Setting 27 websites in Scandinavian and English speaking countries.

Results The 13 sites from advocacy groups and the 11 from governmental institutions all recommended mammographic screening, whereas the three from consumer organisations questioned screening ($P=0.0007$). All the advocacy groups accepted industry funding, apparently without restrictions. In contrast the three consumer organisations acknowledged the risk of bias related to industry funding, and two of them did not accept such funding at all. Advocacy groups and governmental organisations favoured information items that shed positive light on screening. The major harms of screening, overdiagnosis and overtreatment, were mentioned by only four of these groups, but by all three sites from consumer organisations ($P=0.02$). In addition, the chosen information was often misleading or erroneous. The selection of information items for websites did not reflect recent findings, apart from the consumer sites, which were much more balanced and comprehensive than other sites (median of 9 information items *v* 3 items, $P=0.03$).

Conclusions The information material provided by professional advocacy groups and governmental organisations is information poor and severely biased in favour of screening. Few websites live up to accepted standards for informed consent such as those stated in the General Medical Council's guidelines.

Introduction

Women can get information about the possible benefits and harms of mammographic screening from governmental institutions and professional advocacy groups. This information could be biased, however, since the success of a screening programme depends on the participation rate. Another potential conflict of interest is industry funding of advocacy groups.

A review of 58 Australian pamphlets in 1998 showed that the information presented to women invited for breast cancer screening was biased and insufficient and did not allow fully informed consent.¹ Another Australian study, of 54 publications used to inform about screening mammography in New South Wales, showed that only 18% of the publications gave any information on false positive and false negative results, and only 48% gave any information on adverse effects.²

In the European Union an average of 23% of the population use the internet to find information about health issues; Denmark has the highest rate, at 47%.³ If the information about screening on the internet is biased, women's status as autonomous individuals could be violated.⁴ The importance of balanced information is underlined by a study which found that 61% of women decided for themselves whether to have a screening mammogram, and a further 26% made the decision together with their doctor.⁵

In 2001 the quality of the randomised trials of mammographic screening was criticised in a comprehensive Cochrane review that questioned the benefit of screening.⁶ In addition, important harms related to overdiagnosis and overtreatment were demonstrated.^{7,8} We therefore decided to study whether the current information on the internet was balanced and reflected the recent findings.

Materials and methods

We studied whether the information presented on the internet by major interest groups gave a balanced account of the possible benefits and harms of mammographic screening; whether funding of interest groups was related to type of information; and whether the information was different from what was previously provided in pamphlets.¹

We located websites produced by professional advocacy groups (such as cancer charities), government institutions, and consumer organisations from Australia, Canada, Denmark, New Zealand, Norway, Sweden, the United Kingdom, and the United States. All of these countries have screening programmes, although so far only regionally in Denmark and Norway. We searched for "breast cancer" and



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“mammography” and “screening” and one of the included countries, primarily with the search engines Google and Yahoo (see bmj.com for details).

The relevant information on each website was evaluated independently by each author, and any disagreements were settled by discussion. We used a data sheet that contained the same 10 information items as in the review of pamphlets¹ and seven additional relevant items.⁹ When information on funding was unclear, we contacted the organisations.

We divided the websites into three groups: governmental institutions, advocacy groups (promoting the interests of patients and their relatives), and consumer organisations (assessing the quality of the healthcare services).

Results

Recommendations on websites

We located 27 websites, 13 from professional advocacy groups, 11 from governmental institutions, and three from consumer organisations (see bmj.com). The governmental and advocacy sites all recommended mammography screening, at least implicitly, whereas the consumer sites questioned the value of screening ($P=0.0007$).

Funding

All 13 advocacy groups accepted sponsoring from industry, apparently without restrictions. The Canadian Cancer Society noted that “Partnership with the Canadian Cancer Society can assist your company in reaching your commercial objectives.” In contrast, the three consumer organisations explicitly acknowledged the risk of bias related to industry funding: two said that they did not accept grants from industry, while the third noted that only 15% of its budget can come from corporations, only 5% from any single source, and that this funding is restricted to general operating support.

Information items

The sites had a median of three information items out of the 17 possible. The median number of items was nine for the three consumer sites, which were sceptical about screening, and three for the other sites ($P=0.03$).

The four most common information items were the same as in the 1998 study of pamphlets (see table), but more websites described the relative and absolute risk reduction of death from breast cancer ($P=0.006$ and $P=0.005$, respectively), the proportion of women recalled ($P=0.006$), and the predictive value of a positive mammogram ($P=0.02$). The relative risk reduction was usually given as 30%, but estimates varied from none to 50% reduction. Three times as many sites provided the relative risk reduction as provided the absolute risk reduction (table).

For the seven new items we added to those used in the survey of pamphlets, information was rarely provided on relative risk reduction of total mortality (only two sites did so) and risks related to radiotherapy (four sites). The three consumer sites mentioned overdiagnosis and overtreatment, but only four of the other 24 sites did so ($P=0.02$).

Bias in selection and presentation of information

The essence of the messages varied widely (see box). Most websites omitted information on important harms (see table) and emphasised possible benefits in a way that would be expected to increase uptake of screening. For example, 12 sites mentioned lifetime risk of developing breast cancer, usually followed by the annual number of diagnoses. In contrast, only three sites mentioned the relatively reassuring message that women have a more than 50% chance of surviving breast cancer once it is diagnosed, and only four stated that the lifetime risk of dying from breast cancer is about 3-4%.

Presence of information items about screening for breast cancer on 27 websites (from professional advocacy groups, governmental institutions, and consumer organisations) and in a 1998 survey of 58 pamphlets¹

Information items	No of sites mentioning information item				Occurrence (%)	
	Advocacy sites (n=13)	Governmental sites (n=11)	Consumer sites (n=3)	Total (n=27)	On websites	In 58 pamphlets ¹
Included in 1998 review of 58 pamphlets¹						
Lifetime risk of developing breast cancer	5	6	1	12	44	60
Lifetime risk of dying from breast cancer	1	2	1	4	15	2
Survival from breast cancer	1	1	1	3	11	5
Relative risk reduction of death from breast cancer	5	7	3	15	56	22
Absolute risk reduction of death from breast cancer	1	2	2	5	19	0
Number needed to screen to avoid one death from breast cancer	0	0	2	2	7	0
Proportion of screened women who would be recalled	6	4	2	12	44	14
Proportion of breast cancers detected by mammography (sensitivity)	2	3	2	7	26	26
Proportion of women without breast cancer who would have a negative mammogram (specificity)	0	0	0	0	0	0
Proportion of women with a positive mammogram who would have breast cancer (positive predictive value)	2	1	1	4	15	0
Added in this study						
Relative risk reduction of total mortality	0	1	1	2	7	
Carcinoma in situ	4	3	3	10	37	
Overdiagnosis and overtreatment	2	2	3	7	26	
Effect of screening on number of mastectomies or lumpectomies	1	4	2	7	26	
Risks related to radiotherapy	1	2	1	4	15	
Psychological distress related to false positive results	4	3	3	10	37	
Pain at mammography	8	5	1	14	52	

Comments on possible harms from breast cancer screening by websites

Overdiagnosis and overtreatment

"Regular mammography screening may actually increase a woman's chances of losing a breast ... Mammograms find some early cancers that might never have been diagnosed and some of these early cancers are treated by mastectomy"—Center for Medical Consumers

"We cannot determine at the time of diagnosis the type of tumor a woman has. The result is that we mistreat or over-treat many women diagnosed with breast cancer in our effort to help the others"—Breast Cancer Action

"Over-diagnosis and over-treatment are estimated to account for between 0-10% of cancers detected by breast screening"—BreastScreen Aotearoa (Our comment: it amounts to 30%)

"Screening detects primarily those early changes which will later develop into cancer [our translation]"—Kræftens Bekæmpelse (Our comment: this is not true for carcinoma in situ)

Risks related to radiotherapy

"Women may undergo unnecessary and/or inappropriate treatments ... chemotherapy and radiotherapy are toxic and should not be given to women who do not need them"—National Breast Cancer Coalition

"Because the current technique of radiotherapy defines both doses and target volume precisely, the doses to healthy near-by tissues are minimal. A Danish study with 12 years of follow-up did not find an increase in heart disease after radiotherapy (Hojris et al, *Lancet* 1999). The claims that current radiotherapy of breast-cancer patients causes heart disease are therefore not correct [our translation]"—Krefregistret (Our comment: this study had too little power and too short a follow up to exclude this possibility (11 v 11 vascular deaths), and a systematic review of radiotherapy indicated that in low risk women, such as those with cancers found by screening, it would be expected to increase mortality from all causes¹⁰)

"There are other more severe, but much rarer long-term side effects. Many of these don't happen now. This is because the treatment planning is much more exact"—Cancer Research UK (Our comment: there was no indication that the subject discussed was radiotherapy and no mention of the finding that radiotherapy can cause fatal cardiovascular disease)

Pain at mammography

"They are so satisfied that they recommend fellow sisters to get x-rayed in this way. They do this although two out of three experience the examination as slightly uncomfortable (52.3%), hurting (11.4%) or painful (2.5%) [our translation]"—Den Norske Kreftforening

"You should not feel pain"—American Cancer Society

"Fast and almost painless examination [our translation]"—Cancerfonden

"Shouldn't be painful"—Cancer Research UK

Issues related to carcinoma in situ, overdiagnosis and overtreatment, and number and type of operations were mentioned by a quarter to a third of the sites (see table), but often in a misleading or erroneous fashion (see box). Four governmental websites and one advocacy site indicated that screening leads to fewer mastectomies. One governmental and three advocacy sites noted that it is beneficial to detect and remove carcinoma in situ since it would then not recur. Only two such sites mentioned that screening can detect cancers that may never progress, compared with all three consumer sites ($P=0.007$). Only four sites noted that there could be risks associated with radiotherapy, but the risks were downgraded on three of the sites (see box).

The three consumer sites described psychological distress related to false positive findings, compared with seven of the governmental or advocacy sites ($P=0.08$); seven sites described it vaguely as "anxiety," and no sites gave an estimate of the incidence. The potential pain inflicted by the mammographic procedure was mentioned by 14 sites, three of which claimed that the procedure shouldn't be painful.

Discussion

The material about screening for breast cancer that was provided by professional advocacy groups and governmental organisations was information poor and severely biased in favour of screening. The material provided by the consumer organisations was much more comprehensive and balanced. It is worrying that so few websites live up to accepted standards for informed consent¹¹ since it is possible to persuade people to accept or decline cancer screening by withholding or including particular information items.^{12 13}

Overdiagnosis and overtreatment

The most important harms of screening—overdiagnosis and overtreatment—seem to be the best kept secret about screening. The overdiagnosis is about 30%, both in the screening trials^{8 14} and based on epidemiological data spanning 20 years after screening was introduced in the United States.¹⁴

These results indicate that the five websites that noted that screening leads to fewer mastectomies are seriously misleading. The opposite seems to occur. In the screening trials 20% more mastectomies were performed in the screened groups than in the control groups,⁸ and in the United Kingdom mastectomies increased by 36% for invasive cancer and by 422% for carcinoma in situ from 1990 to 2001, when screening was introduced.¹⁵ Because of overdiagnosis, screening also increases the use of radiotherapy,⁸ but only four sites gave the important information that radiotherapy was associated with risks,¹⁰ and three of the four sites downgraded this information.

Downgrading of other harms

The websites' statements that about 5% of screened women would be recalled at each screening round is far less disturbing than the information that the cumulative risk is 49% after 10 mammograms.¹⁶ The information that false positive findings can sometimes create "anxiety" is also much more soothing than the information that more than 10% of women screened will at some point experience important psychological distress for many months.^{6 8}

The websites generally downgraded the potential pain inflicted by the mammographic procedure. A survey of five studies found that 31% of women felt pain during their first mammogram and that a further 23% felt it was very uncomfortable.¹⁷ Furthermore, half of 81 women who declined an invitation to the second round of screening said that their major reason for doing so was because their first mammogram was painful.¹⁸

Tension between informed consent and high uptake

In accordance with policies of national screening programmes,¹⁹ most sites stated that women's decision whether to participate should be based on informed consent. Requirements for informed consent should be stricter when the healthy population is approached than when a sick patient consults a doctor, since healthy people have not asked for help and are considering participation in tests on a different basis. For breast screening, however, our healthcare systems have done the opposite and have sacrificed the obligation of a fully informed consent for a paternalistic role, as shown in the NHS leaflet that asks "Why do I need

breast screening?" rather than "Do I need breast screening?"²⁰ If the concern is, as screening advocates have suggested, that too few women would participate if they were presented with the relevant issues,^{4, 21} screening may be too controversial to be justifiable.

The bottom line of mammography screening

The effect of screening is uncertain since most trials are of poor quality.⁶⁻⁸ The most optimistic and most quoted result is a 30% reduction in breast cancer mortality.²² If it were true, it would mean that one woman would be saved from dying from breast cancer for every 1000 women invited to screening for 10 years.²² After 10 years of screening, 90.3% of the women would be alive, whereas if they were not screened 90.2% would be alive.^{22, 23} However, it is also possible that no one will be saved, since the women may die from something else, such as from complications from the breast cancer treatment,^{8, 10} and since an effect of screening on mortality from all causes has not been demonstrated.^{6-8, 24, 25}

Optimistically, for every woman who has her life prolonged, five healthy women, who would not have received a breast cancer diagnosis if there had not been screening, will be converted into cancer patients.⁸ Whether this is a too high price to pay is open to debate, but if women and policy makers are not informed of this balance between major benefits and major harms—which they have not been so far—then there cannot be any discussion or rational decision making. The present situation is that a woman customer who visits a "screening shop" doesn't know what she is buying into, and most often the shopkeeper either doesn't know or doesn't tell. This is untenable.

Suggested improvements in the information women are offered

Possible benefits and harms should get similar attention and should be presented in a similar fashion. The symmetry of information should also be respected for cumulated risks. If the lifetime risk of getting breast cancer is noted, then the lifetime risk of getting a false positive diagnosis should also be noted rather than the risk at each screening round.

Since people should be informed about the uncertainties of screening,¹¹ they need to know that the effect of screening is uncertain.

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What is already known on this topic

A 1998 survey showed that the information material in pamphlets presented to Australian women invited for breast cancer screening was biased and insufficient, and did not allow fully informed consent

What this study adds

In 2001 the quality of the randomised trials of mammographic screening was criticised in a comprehensive systematic review, which questioned the benefit of screening and documented important harms

Despite these findings, the information presented to women on websites by professional advocacy groups and governmental organisations was selective and biased and failed to mention major harms

Websites of consumer groups were more balanced and comprehensive than sites of professional advocacy groups and governmental organisations

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