What are the psychological factors influencing attendance, non-attendance and re-attendance at a breast screening centre?

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Summary

We describe some preliminary findings from a pilot study using three recently developed questionnaires which assessed items such as the health beliefs, knowledge about cancer and attitudes to breast cancer screening in 242 women invited to attend for mammographic screening in South East London. We suggest that these questionnaires should be used in all regional centres both to monitor psychological variables and to identify local problems within the service which may be influencing the up-take of invitations to come for screening.

Introduction

The complex psychosocial factors affecting compliance and regular attendance at screening centres are fundamental issues which must be thoroughly investigated if the National Breast Screening Programme is to be successful[1]. The HIP screening programme in New York, for example, showed that participants tended to be younger, married, better educated, Jewish and had less distance to travel than non-participants[2]. In this country data from studies examining the sociodemographic and psychological characteristics of women invited for screening reveal significant differences between attenders and non-attenders. One study, for example, reported that non-participants tended to be of lower socio-economic status, were non-partakers of other health care services, saw screening as unnecessary and felt that they had too many work or family commitments[3]. Compliance is variable in different regions and early reports from socially deprived areas such as South East London are not very encouraging[4]. To date the psychosocial factors influencing re-attendance in Great Britain have not been systematically studied.

Aims

To examine some of the complex psychosocial factors influencing attendance, non-attendance and re-attendance at a breast screening centre, eg:

(1) Are women who attend for screening more knowledgeable about risks of developing breast cancer?
(2) Are women who are complacent and/or who lack knowledge about breast cancer less likely to attend?
(3) Do women made overly anxious by the invitation and information leaflet fail to attend?
(4) Are women more likely to attend if they (a) enjoy a good doctor/patient relationship with their GP, and (b) belong to practices that are positive about the screening programme?
(5) What are the most potent sources of information concerning screening: TV and radio, family, friends, magazines and newspapers, etc?
(6) Do more women reporting a 'good' experience when first screened re-attend 3 years later than those reporting a 'bad' experience?
(7) Do women made anxious or who find having a mammogram an unpleasant, painful or embarrassing experience discourage others from attending?
(8) Are difficulties with transport, getting time off work, or opening hours of the screening centre significant factors in the decision not to attend?

Method

Sample

The sample consisted of (a) 122 women attending a breast screening centre in South East London on different sessions during June, July and August 1989; and (b) 120 women invited during the same period who failed to attend.

Assessments

Three self-assessment questionnaires were administered to determine the following:

Questionnaire 1: Experiences on receiving invitation; experiences at the screening centre; practical factors influencing decision to/not to attend; relationship with GP.

Questionnaire 2: Knowledge of prevalence, risks and causal factors in breast cancer.

Questionnaire 3: Beliefs concerning personal susceptibility; beliefs concerning perceived costs/benefits of breast screening.

Questionnaires 2 and 3 were similar in structure to instruments used previously in a study examining the relationship between women's health beliefs and their practice of breast self-examination (BSE)[5].

Procedure

One hundred and twenty-two women attending the breast screening centre in Butterfly Walk Shopping Centre, Camberwell Green, were given a letter from the authors explaining the purpose of the study, that is the need for research to improve compliance and to create the most comfortable and convenient system. Questionnaires were taken home for completion and women were asked to return them in pre-paid envelopes within 2-3 days *before* receiving their

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1. How did you feel when you received the invitation to come for screening?
(Please tick the box which applies for each of these items)

	very	a little	not at all
worried	11%	44%	46%
irritated	5%	18%	75%
pleased	78%	15%	7%

2. Was the information clear and understandable?

very	fairly	not at all
92%	8%	0%

3. Had you heard about breast screening before receiving the invitation from any of the following?
(Please tick any that apply)

your doctor (GP)	20%
friends/family	34%
radio/TV	35%
magazines	22%
newspapers	24%

4. Before deciding to come, did you discuss the invitation with any of the following?
(Please tick any that apply)

your doctor (GP)	7%
friends/family	60%
other	6%

5. Have you ever had a mammogram (breast x-ray) before?

Yes	No
11%	89%

If yes: When?
Where?

6. How often do you examine your own breasts?
(Please tick whichever applies)

never	rarely	regularly (monthly)
24%	45%	31%

7. Has anyone close to you ever had breast cancer?

Yes	No
15%	85%

If yes: Who was this?
(Please tick any that apply)

mother	
friend	
sister	
daughter	
aunt	

8. When did you last see your GP?

last week	last month	last year
16%	48%	36%

Do you always see the same doctor?

always	sometimes	never
59%	40%	1%

Can you talk to him/her easily?

Yes	No
88%	12%

9. Did you have any difficulties getting to the screening centre, such as transportation problems or getting time off work during the day?

Yes	No
6%	94%

Please give details

10. At the screening centre, did you feel
(Please tick box for each item)

	very	fairly	not at all
relaxed	48%	45%	8%
anxious	16%	38%	46%

11. Were the staff at the screening centre
(Please tick box for each item)

	very	fairly	not at all
pleasant	89%	9%	2%
unhelpful	13%	0%	87%

12. How long were you required to wait?

less than 20 mins	20–60 mins	over an hour
69%	31%	0%

13. Was the mammogram
(Please tick box for each item)

	very	a little	not at all
embarrassing	9%	19%	73%
uncomfortable	27%	64%	10%
painful	21%	41%	38%

14. Do you intend to come again in 3 years time?

Yes	Unsure	No
88%	12%	0%

15. Would you encourage anyone who asked you about screening to come along?

Yes	Unsure	No
93%	7%	0%

Any other comments

Figure 1. Questionnaire I

KNOWLEDGE ABOUT PREVALENCE AND CAUSAL FACTORS

Please read the following statements and tick those you believe to be true about breast cancer

1. The chances of a woman getting breast cancer in this country are – (please tick one)

Less than 1 in 100	35%
About 1 in every 55	49%
About 1 in every 12	14%
Don't know	2%

2. Most breast lumps turn out to be (please tick one)

Cysts	72%
Cancer	5%
Don't know	24%

3. The chances of a breast lump being cancer increase in women aged – (please tick one)

1. 25–35	0%
2. 35–45	11%
3. 45–55	50%
4. 55–65	36%
5. over 65	1%
6. don't know	2%

4. A woman is more likely to develop breast cancer if she is – (tick any of these you think may apply)

single	4%
married without children	6%
married with children	13%
did not breast feed	12%
took the pill	40%
has relatives with breast cancer	49%
is past the menopause	25%
has been hit in the breast	35%

Figure 2. Questionnaire II

results. To eliminate possible sampling biases, women were approached on different sessions, that is either morning or afternoon, and on different days of the week during an 8-week period. Non-attenders booked for the same session were sent a letter respecting their rights not to attend but asking for help in determining factors which made them decline the invitation. They were also sent slightly modified questionnaires which omitted items concerned with experiences at the screening centre.

Results and discussion

Compliance

Two women approached did not take questionnaires due to illiteracy and one woman, accompanied by a residential care assistant, was too mentally disturbed to complete any forms. One hundred and thirteen of the 120 women (93%) who attended the screening centre returned their questionnaires. A frequency analysis of the response to items on each questionnaire is shown in Figures 1-3.

Non-attenders

In contrast to the excellent compliance (93%) by women who attended for breast screening and then returned their completed questionnaires, the response from those women who failed to attend was extremely poor. Of the 120 sets of questionnaires sent out eight were returned by the post-office, three were returned by women who had subsequently attended for screening and only nine of the remaining 109 (8%) were completed or partly completed and returned. It is impossible to determine whether all of the 'non-attenders' actually received their letters inviting them for screening in the first place and consequently we cannot be certain that all of our questionnaires were received by the women either. It is unfortunate that nationwide FPC registers are as yet both incomplete and inaccurate. This is a particular problem in an inner city area such as Camberwell and is a situation that demands urgent attention, as the process of compliance can only begin when the invitation for screening is received by a woman.

Perceived susceptibility to breast cancer (even numbers)
Perceived cost/benefits of screening (odd numbers)

All % values

	strongly agree	agree a little	disagree a little	strongly disagree
1. If more women went for breast screening there would be fewer deaths from breast cancer	93	5	2	0
2. My health is too good at present even to consider thinking that I might get breast cancer	12	20	15	53
3. If a lump is found in your breast it is usually too late to do anything about it	3	5	24	69
4. Whenever I hear of a friend/relative or public figure getting breast cancer I realise that I could get it too	57	29	6	9
5. If I examine my own breasts regularly I might find a lump sooner than if I go for screening	33	31	12	24
6. There are so many things that could happen to me that it is pointless to think about breast cancer	8	15	15	62
7. Even though it is a good idea, I find examination of my breasts an embarrassment	4	21	10	65
8. The older I get the more I think about the possibility of getting breast cancer	21	31	17	31
9. Coming for screening would/has made me worry (unnecessarily) about breast cancer	9	20	9	62
10. If I was found to have breast cancer following screening the chances of it being cured are high	65	25	5	6

Figure 3. Questionnaire III

An earlier study of attendance and non-attendance in SE London revealed that 35% of invitations sent were never received due to inaccuracies in the FPC database[4]. If that figure is still true then it is possible that 42 of our 120 questionnaires were never received. This still means that the response rate of questionnaire return from non-attenders at the screening clinic is a dismal 9 of 78 (11.5%). However, the nine questionnaires that were returned to us by this group of non-attenders provided some very interesting material and despite this small number their responses do provide insights into the possible reasons for non-attendance in certain women.

Of the nine sets of questionnaires returned, one woman failed to answer any of the questions. She wrote a letter explaining why not:

> '. . . my reasons are:
> (1) I really don't want to know if I have cancer, and
> (2) if I do have cancer, it cannot be cured.
> So I prefer to remain as I am, as daft as it may sound to you.'

Four of the non-attending group of women who completed the first questionnaire declined to fill in the other two, concerned with knowledge about breast cancer and perceived susceptibility to cancer and costs/benefits of screening. One of these women wrote on the questionnaires:

> 'I have no beliefs in any of the following. I have never seriously considered this problem.'

This may be a highly significant statement, as such an attitude may be typical of other non-attenders and explain some of their behaviour. Those women who prefer never to think about potentially distressing subjects may well be demonstrating their only means of coping with fears of breast cancer. Not only do they fail to respond to invitations to attend for screening, but also they avoid confronting their fears by refusing even to think about the subject.

Responses to questionnaires

Reactions on receiving the invitation: The majority of attenders (93%) were pleased when they received their invitations to come for screening, although 55% felt worried.

Experiences at the screening centre: Most women attending felt positive about the screening centre and its staff, although 21% found the mammogram very painful and 27% found it very uncomfortable.

Information and knowledge about breast cancer: All found the information sent with the invitation clear and understandable, but there were a disturbing number of misconceptions about breast cancer. Few women appreciated the fact that the risks of the disease increase with age, and 29% of women did not know that most breast lumps are not due to cancer. Furthermore, the women in our sample underestimated the prevalence of breast cancer. This is a surprising finding, as most studies show that lay populations tend to overestimate the incidence of cancer in general. As far as causal factors thought important in the development of cancer, several myths and misconceptions were apparent. It was reassuring that our sample realized the significance of heredity, with 49% indicating that having relatives with the disease placed one at increased risk. The next most frequently cited causal factor (40%) was the contraceptive pill. This was probably due to the media publicity surrounding publication of a paper in the *Lancet* earlier in the year[6]. The notion that trauma causes cancer was the third most frequently cited factor, with 35% of women indicating that being hit in the breast was important.

Radio and TV, together with family and friends, seem to be important sources of information about screening. This finding highlights the potential value of encouraging the media to provide accurate information.

Importance of the GP's role

Only 20% of women had heard about screening from their GP and even less (7%) had discussed the screening invitation (despite the fact that 63% had seen their GP within the previous month). It should be remembered that in this area the letters of invitation are all signed by the woman's GP. Although breast screening is a community-based service, it would appear from our study that as yet the woman's GP is underused as a means of influencing her decision to attend for screening. There is evidence that involvement of the GP is vital. One study of factors influencing attendance or non-attendance for breast screening conducted in Edinburgh showed that 33% of attenders felt that their decision to attend was influenced by their general practitioner's 'interest' in screening[7]. Under their new contract GPs will be expected to discuss breast screening with their patients and, where appropriate, encourage them to attend.

The majority of women (69%) never or rarely practise BSE, but 64% felt that regular BSE might reveal a lump earlier than going for screening. This result provides a classic demonstration of the fact that mere knowledge or beliefs about a disease do not always produce rational behaviour. One reason that some women do not engage in BSE, despite their belief that it is a valuable practice, is due to their lack of confidence about being able to do it properly. Motivated women who attend for mammographic screening might also benefit from instruction and training from a breast care specialist nurse while at the screening centre. Some women find BSE embarrassing and thus embarrassment at exposing the breast may also deter women from attending for screening. There is some evidence of cultural and religious differences. For example, Catholic women are more likely than Jewish women to find BSE embarrassing and furthermore those Catholic women who found BSE embarrassing were more likely to delay seeking treatment if they found a breast lump[8]. We have no data yet on the attitudes of other religious groups living within our multi-ethnic communities in various cities throughout Britain.

Typical comments made by women who did attend

Several women mentioned that their employers were reluctant to permit time off work for screening and others said that they were encouraged to put forward more 'socially acceptable' reasons for absence on their certificates, eg:

> 'The personnel manager (at work) said that I should write down "dental appointment", as breast cancer screening wasn't a very nice thing to put on the form.'

The opening times of a screening centre may well need to be much more flexible and responsive to local needs. In particular in those areas where families are dependent on the income from women who work, taking time off and losing money for the putative benefits of screening is most unlikely to prove popular.

Several women were unhappy about the fact that the screening centre displayed the word 'breast' so obviously, as can be seen in the following quotation:

> 'I'm sure that some women are put off by the word "breast" above the shop front.'

Others claimed that they had walked around outside for some time until they were certain that nobody who knew them was around. Perhaps some market research on acceptable titles for the shop-front screening centres should be done.

It was clear from the questionnaires that many women (60%) discussed with friends or family the decision about attending. Furthermore, as 27% found the mammogram 'very' uncomfortable and 21% found it 'very' painful, discussions about this might well be a contributing factor to some of the non-attendance. The bad experience of one woman may influence the decision to attend in many others.

> 'One woman told me that she wouldn't advise me to go as it hurts so much.'

> 'Do they really have to press so hard? I had no idea they needed so much pressure.'

Radiographers obviously have to ensure that the compression necessary for good quality mammograms is applied gently for as short a time as possible. Women might also experience less discomfort if they are taught to relax their muscles.

Although women received an information leaflet and found this clear and helpful, some expressed surprise at the procedure:

> 'I didn't know that you had to stand up for it. I expected to lie down.'

Forewarned is forearmed; thus a novel experience is less anxiety-provoking if an individual has had time to rehearse it mentally. This demands that women acquire accurate expectations of the procedure. Constant reappraisal of information literature provided may be needed to ensure that it conveys correct and helpful facts about mammography. Most people working in breast screening centres are motivated, compassionate individuals. Their interest and attitudes are important to monitor and encourage, as they play such a vital PR role in maintaining attendance and re-attendance.

> 'The staff couldn't have been nicer, I had been really worried about it ever since getting the letter, but they really put me at my ease.'

Conclusions

The social influence, behaviour and beliefs of family, friends and important others can act as major barriers or triggers to the acceptance of a wide variety of different preventative and health maintenance services. Also the various hypotheses women have concerning the causal factors in breast cancer may influence their own perceived susceptibility to the disease and may therefore affect their health behaviour. The Health Beliefs Model of Rosenstock[9], for example, would suggest that for a woman to go along for mammographic screening she should hold at least some of the beliefs shown in Table 1. One reviewer looking at the Health Belief Model as it

Table 1. Application of Rosenstock's Health Belief Model (1974) to breast cancer screening

(1) Belief in personal susceptibility to breast cancer
(2) Belief that breast cancer would have at least a moderately severe impact on some component of life
(3) Belief that attending for mammographic screening would have beneficial impact: ie early detection would reduce severity of disease
(4) Belief that disease can be present without experiencing symptoms
(5) Belief in the efficacy of treatments
(6) Belief that the potential benefits outweigh the costs

applies to participation in programmes for early detection argued that health belief variables were the best discriminators in the take-up of screening[10].

It is most unlikely that a standard message in the form of information leaflets or letters is going to prove suitable in all the different areas where screening will be started. Women in the predominantly middle-class area around Guildford, for example, have a system and network of behavioural responses adapted to the environmental, physical and social conditions in which they live. These may contrast dramatically with the cultural, perceptual and social norms, values and behavioural responses found in a deprived inner-city area such as Camberwell. The health education messages may not only have to be quite different but they may also have to be conveyed by different means. Illiteracy for example is underestimated. Thus the role of the GP is likely to be of crucial importance in encouraging more women to participate in screening programmes, by introducing the topic of mammographic screening whenever a woman in the target age group visits the surgery.

There is still a great deal of basic research work to be done to determine the best means of improving compliance and to ensure that women regularly attend every 3 years. Furthermore, we must ensure that this is done without provoking needless anxiety and distress in women. Until we have more reliable evidence that the treatment of the small screen detected lesions picked up by mammography is both necessary and effective, women should not be repeatedly cajoled into accepting screening. For an individual woman, given her own social circumstances and particular attitudes and beliefs, non-attendance at a screening centre could be seen as a rational decision. The research contributions of social scientists have played an important part in helping us understand women's health beliefs. Ignoring such research or withholding support for it could make the mammographic screening service an expensive failure.

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