Anxiety before, during, and after participation in a population-based screening mammography programme in Waikato Province, New Zealand

Margaret Brunton, Claire Jordan, Ian Campbell

Abstract

Aim This study investigated anxiety levels before, during and after mammography in the Waikato breast cancer screening pilot.

Method A sample of 1085 women on the Waikato database were sent survey questionnaires, which included questions about the anxiety experienced. Data from 584 completed questionnaires were obtained.

Results Two significant findings were identified. The first was that population-based screening can ultimately reduce anxiety for participants who receive a clear result from their mammogram. The second finding was that levels of worry throughout were related to ethnicity. Maori and Pacific Island women reported higher levels of worry than New Zealand European and Asian women about developing breast cancer (p<0.001), while awaiting their appointment (p=0.041) and results (p=0.046). Across all groups, levels of worry about developing breast cancer were also related to level of education (p=0.018), a family history of breast cancer (p=0.002), stress levels during screening mammography (p<0.001), and experience of pain during the procedure (p<0.001). At least some months following receipt of their results, 67% (95% CI 63-71) of all women experienced reassurance from receiving a clear result.

Conclusions The results show that the population-based screening programme demonstrates greater potential to ultimately relieve (rather then increase) anxiety for participants who receive a clear result from their mammogram.

This research investigated how participation in a free-of-charge, population-based, breast-cancer-screening pilot programme influenced levels of anxiety in a sample of New Zealand women in the Waikato region. Breast cancer is the most common cancer among women in New Zealand. Ten percent of women will experience breast cancer over their lifetime, and incidence increases with age. Eighty-four percent of cases will occur in those over 54 years old.

The Ministry of Health’s most recent report illustrates that 25% of all cancer registrations and 20% of all cancer deaths among New Zealand women result from breast cancer.\(^1\) Mortality rates are higher in the ethnic minority groups of Pacific Island women, who tend to present later with advanced disease.\(^2\) Furthermore, there is a similar trend for indigenous Maori.\(^3\) In the continuing absence of an effective means of primary prevention or a ‘statistical cure of symptomatic invasive breast cancer’,\(^4\) screening mammography currently offers the best means to reduce mortality in women aged fifty years and over.\(^5\)

However, one of the potentially adverse effects of population-based screening mammography programmes is that they can contribute to anxiety in the population,
and this may even extend to women who are not eligible (e.g. because of age).\textsuperscript{6} For eligible women, although anxiety tends to be associated with outcome risks of screening mammography such as false positives,\textsuperscript{7} anxiety has also been associated with the invitation process\textsuperscript{8} and with exposure to radiation during screening mammography.\textsuperscript{9,10} It has even been argued that screening mammography programmes are undesirable because they can induce anxiety.\textsuperscript{11}

Accordingly, as the success of the programme requires ongoing participation, and anxiety associated with the process or outcome can inhibit participation,\textsuperscript{12} it is important to understand how women experience or perceive anxiety when participating in a screening mammography programme.

\textbf{Method}

There were 14,392 women registered on the database of the Waikato screening mammography pilot programme, who had participated in the third round of screening between November 1995 and April 1998. Participants had consented to participate in evaluation surveys of the pilot programme. They had also been asked to nominate their ethnicity on the enrolment form.

A sample of 1,100 women (grouped by region, age, and ethnic group) were randomly selected from the database by programme staff. To ensure adequate numbers, Maori were oversampled. Specific ethnic samples were selected to represent 35\% of Maori and 4\% of the New Zealand European groups of women on the database. Because of the small numbers registered on the database, all women of ethnic groups other than New Zealand European and Maori were selected. Women who developed cancer were excluded from the screening database, and so were not included in the sample. However, women who had been recalled in the past (6\%), and whose mammograms had not indicated the presence of cancer, were included.

A questionnaire was developed to assess how worried participants had felt at various stages of the screening mammography process. The level of anxiety was measured using a 4-point Likert scale. Following approval from the Waikato Ethics Committee, a two-stage pre-test was conducted among seven groups of a total of 60 women.

In October 1999, a total of 1,085 survey questionnaires were distributed. Excluding the 34 returned as ‘not available’ (8 deceased, 4 living overseas, 1 male) or with ‘gone, no address’ the net number of questionnaires distributed was 1051. A reminder letter was sent to those who had not responded within 5 weeks. To enhance data recovery from the limited number of Pacific Island women on the database, most of their questionnaires were hand delivered and collected by health workers employed by the screening programme to promote participation among eligible women.

Of the 639 (61\%) questionnaires returned, 611 were completed satisfactorily. Of the 639 (61\%) questionnaires returned, 611 were completed satisfactorily. Of these 611 women, 584 were in the sample frame of four ethnic groups—i.e. aged between 50 and 64 years (the eligible age screening mammography at the time). (The group of 15 women categorised as ‘other’, and the group of 12 women over the age of 64 were not included in any ethnic or age-based analyses carried out, which provided a usable response rate of 56\%).

Demographic information about the respondents, including ethnic origin, is illustrated in Table 1 below. Statistical analysis was performed using SPSS (Release 8.0.0 22/12/97). Tests of significance were applied using chi-squared tests for independence in contingency tables.
Table 1. Demographic information obtained from the 584 survey respondents

<table>
<thead>
<tr>
<th>Age</th>
<th>Domicile</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>50-54</td>
<td>224</td>
<td>In a city</td>
</tr>
<tr>
<td>55-59</td>
<td>204</td>
<td>In a rural town</td>
</tr>
<tr>
<td>60-64</td>
<td>156</td>
<td>In the country</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnic origin</th>
<th>Occupation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Maori</td>
<td>153</td>
<td>Wages or salary</td>
</tr>
<tr>
<td>New Zealand</td>
<td>339</td>
<td>Unpaid work in home</td>
</tr>
<tr>
<td>European</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pacific Island</td>
<td>51</td>
<td>Self employed</td>
</tr>
<tr>
<td>Asian</td>
<td>41</td>
<td>Retired</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of education</th>
<th>Annual income (NZ dollars)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary School</td>
<td>28</td>
<td>Less than $15,000</td>
</tr>
<tr>
<td>Secondary School</td>
<td>366</td>
<td>$15,000 to $30,000</td>
</tr>
<tr>
<td>University</td>
<td>68</td>
<td>$30,001 to $50,000</td>
</tr>
<tr>
<td>Trade or Polytech</td>
<td>43</td>
<td>Greater than $50,000</td>
</tr>
<tr>
<td>Other sources</td>
<td>79</td>
<td>Don’t wish to answer</td>
</tr>
</tbody>
</table>

Table 2. Frequencies of levels of worry at various stages of mammogram

<table>
<thead>
<tr>
<th>Level of worry</th>
<th>General level of worry about breast cancer</th>
<th>Level of worry awaiting mammogram</th>
<th>Level of worry awaiting results of mammogram</th>
<th>Level of reassurance</th>
<th>After mammogram</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>135 (23%)</td>
<td>258 (44%)</td>
<td>186 (32%)</td>
<td>Felt reassured</td>
<td>393 (67%)</td>
</tr>
<tr>
<td>A little bit</td>
<td>288 (49%)</td>
<td>265 (45%)</td>
<td>294 (50%)</td>
<td>Felt the same</td>
<td>184 (32%)</td>
</tr>
<tr>
<td>Quite</td>
<td>80 (14%)</td>
<td>38 (7%)</td>
<td>75 (13%)</td>
<td>Felt more worried</td>
<td>7 (1%)</td>
</tr>
<tr>
<td>Very</td>
<td>81 (14%)</td>
<td>23 (4%)</td>
<td>29 (5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>584</td>
<td>584</td>
<td>584</td>
<td></td>
<td>584</td>
</tr>
</tbody>
</table>
Results

The respondents were experienced in mammography screening, with over 80% having had two or more screening rounds. Most respondents (71%) reported that their most recent mammogram had been within the previous 12 months. When asked about the worry or level of stress they experiences at various stages of the screening process, women volunteered 1248 additional comments, resulting in several pages of open and detailed feedback.

General level of anxiety about breast cancer

Respondents were asked about how worried they normally felt about getting breast cancer (Table 2). The number of respondents expressing either no or little worry was significantly greater than the number expressing that they were either quite or very worried (p<0.001). There were no significant differences in higher levels of worry about breast cancer between women participating in initial (prevalent) and subsequent (incident) rounds of screening (p=0.587). Demographic variables of age (p=0.649), domicile (p=0.210), occupation (p=0.460), and annual income (p=0.308) did not have a significant effect on the level of general anxiety about breast cancer.

However, ethnicity proved to be highly significant (p<0.001) with Maori and Pacific Island women showing much higher levels of worry than their New Zealand European or Asian counterparts. Level of education also proved significant (p=0.018), with those having a higher level of education indicating lower levels of worry about breast cancer. The 68 women who had a higher level of education (university educated) reported lower levels of worry about breast cancer (19% were ‘quite’ or ‘very’ worried). This compared to 26% of the 366 women educated to secondary school level and 39% of the 28 women who had been educated only to primary school level.

Fifty-eight women reported a family history of breast cancer, and levels of worry for this group were significantly greater (p=0.002) than those who reported no family history of breast cancer (Figure 1). Twenty-five percent of those with no family history of breast cancer reported feeling ‘quite’ or ‘very’ worried about the possibility of breast cancer, compared with 48% of those who did report a family history of breast cancer. However, this association between level of worry and family history was only significant for women aged 50-54 years (p<0.001) (55–59 years, p=0.068; 60–64 years, p=0.345).

Anxiety awaiting appointment for screening

Women were asked about the level of worry they experienced prior to the appointment (Table 2), once they had made a decision to participate in a screening mammogram. For most respondents, waiting for their appointment was not a time of high levels of worry (p<0.001) with 89% of respondents indicating that they were ‘not at all’ or ‘a little bit’ worried. This level of worry was not associated with the number of mammograms previously undertaken (p=0.595). Ethnicity was the only significant demographic variable, with Pacific Island women (10%) and Maori women (6%) expressing higher levels of feeling ‘very worried’ than Asian (2%) or New Zealand European women (2%; p=0.041). Several women commented that the difficulties they experienced in obtaining suitable appointments contributed to their level of anxiety at this stage of the process.
Anxiety during the process

To assess how many respondents found the physical process of screening mammography stressful, they were asked what level of relaxation or stress they experienced during their mammogram. Most women reported feeling relaxed or quite relaxed (87%), and the numbers of mammograms experienced was not significant (p=0.383). However, the experience of pain or discomfort during the mammography was directly related to the level of stress reported during screening (p<0.001).

The 161 women who reported they were either ‘quite’ or ‘very’ worried about the possibility of breast cancer did experience higher levels of stress during their mammogram (20%), compared to the 423 women who had only minor, or no level of worry about breast cancer (10%, p<0.001). Twelve percent of women who reported feeling stressed and 2% of women who reported feeling relaxed during screening mammography, said they would either reconsider or refuse further screening (p<0.001). The level of anxiety experienced during the process was not significantly related to any demographic variables, but was related to the level of worry experienced while awaiting the appointment and the level of worry about breast cancer in general, as shown in Table 3.
Table 3. P values for significance of relationship between experience of relaxation or stress during mammography and other variables

<table>
<thead>
<tr>
<th>Demographic information</th>
<th>Ethnic Origin</th>
<th>Domicile</th>
<th>Age</th>
<th>Occupation</th>
<th>Annual Income</th>
<th>Level of Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>P value</td>
<td>0.432</td>
<td>0.160</td>
<td>0.201</td>
<td>0.488</td>
<td>0.509</td>
<td>0.707</td>
</tr>
</tbody>
</table>

**Feelings during mammogram**

<table>
<thead>
<tr>
<th></th>
<th>Worry while awaiting appointment</th>
<th>General level of worry about breast cancer</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>None/Little</td>
<td>Quite/Very</td>
<td>None/Little</td>
</tr>
<tr>
<td>Relaxed</td>
<td>475 (93%)</td>
<td>34 (7%)</td>
<td>381 (75%)</td>
</tr>
<tr>
<td>Stressed</td>
<td>48 (64%)</td>
<td>27 (36%)</td>
<td>42 (56%)</td>
</tr>
<tr>
<td>Total</td>
<td>523</td>
<td>61</td>
<td>423</td>
</tr>
</tbody>
</table>

**Anxiety while awaiting results**

Eighty-two percent of women reported feeling ‘not at all’ or ‘a little bit’ worried while awaiting the results of the mammogram (Table 2). This was related to the way women felt during the mammogram (p<0.001), with 91% of those who felt relaxed during the mammogram feeling ‘not at all’ or ‘a little bit’ worried while awaiting the results. Demographic variables demonstrated no significant relationship with the number of mammograms undertaken (p=0.663), age (p=0.564), domicile (p=0.316), income (p=0.180), occupation (p=0.168), or level of education (p=0.140).

Once again, however, a significant relationship was observed with ethnicity (p=0.046). Twenty-three percent of Maori and Pacific Island women reported feeling ‘quite’ or ‘very’ worried, compared with 15% of New Zealand European or Asian women. The 58 respondents with a family history of breast cancer also experienced higher levels of worry while awaiting their results (28%), than those without a family history of breast cancer (17%, p=0.035). The level of anxiety at this stage was not significantly related to the length of time spent waiting for the results (p=0.450).

**Effect of experience on plans for future mammography**

Respondents were asked if they planned to have a mammogram when next called by the programme. A significant relationship was identified between the level of anxiety during the process and plans for future screening (p≤0.001), with 96% of those feeling relaxed during the process stating they would agree to take part in future screening, compared with 79% of those who reported feeling stressed during the process.

**Long-term anxiety following mammogram**

It was also important to assess what effect the outcomes of screening mammography may have on population levels of anxiety about breast cancer. Respondents were therefore asked whether having a screening mammogram had influenced their level of
worry about breast cancer (Table 2). Significantly more women (67%) reported they felt reassured, or less worried by the process; 32% felt the same and only 1% felt more worried (p<0.001). No demographic variables had a significant effect on level of worry at this stage of the process; however, those who felt ‘more’ worried all reported that some abnormality had been identified on their mammogram.

When responses were compared with the reported level of worry about breast cancer prior to screening, even 51% (95% CI: 43–60) of those who women were ‘not at all worried’ still obtained reassurance from their mammogram (Figure 2). There were no significant differences in level of reassurance obtained across experience of mammography, with 67% of women who had participated in one round of screening experiencing reassurance, compared with 69% of those women who had participated in two or more rounds of screening (p=0.875).

Figure 2. Percentage of respondents (with 95% confidence intervals) who obtained reassurance from screening mammography related to their initial level of worry about breast cancer

Discussion

It has been suggested that fear of cancer is ‘one of the most powerful sources of anxiety during screening mammography.’13 In this study, none of the women surveyed were currently scheduled or invited for a mammogram, however 77% of them reported that they normally felt some level of anxiety about the possibility of breast cancer. It is suggested that women with a family history of breast cancer may be so worried that they are less likely to participate in regular screening mammography.14

Women with a family history of breast cancer in this research were more likely to report higher levels of worry about breast cancer (including the procedure, and
awaiting results) than those women without a family history of breast cancer. Also, lesser-educated women, as well as Maori and Pacific Island women, reported higher levels of worry about the possibility of breast cancer than more highly educated Asian or New Zealand European women. Nonetheless, despite experiencing some level of anxiety at various stages of the process, most women felt reassured on completion of their mammogram. Overall, the majority of respondents (67%) felt reassured once their mammogram was completed and they received a clear result.

The low percentage of women experiencing any level of stress during the physical process of mammography confirms the findings from an earlier Waikato survey that fear of the procedure itself appears to be a minor factor for respondents. However, the significant relationship between higher levels of anxiety at this time and reconsideration of further participation in screening mammography demonstrates the importance of addressing anxiety during the process. Furthermore, although the level of recalled pain in this research is within the expected range of 5%–15% of women who report severe pain on mammography, the stress that was reported during the physical process of screening mammography was significantly related to pain (p<0.001), providing support for earlier findings.

The same women who reported higher levels of anxiety while waiting for appointments also reported higher levels of worry while awaiting results. This result is similar to that in other New Zealand studies, which reported that there were no significant differences between Waikato respondents’ level of worry while waiting for appointments and results, as was also the case with participants in the Southland-Otago Pilot Programme. This research revealed that Maori and Pacific Island women reported higher levels of anxiety than New Zealand European or Asian women both while awaiting appointments (p=0.041) and results (p=0.046).

Ultimately, however, the level of reassurance that women received from their mammograms, provided the result was clear, appeared to outweigh any anxiety they experienced beforehand. The women who participated in this study reported a high level of support for screening mammography. The majority viewed screening mammography as very important (88%) or important (11%). Even the 32% who said that their level of worry was unchanged still regarded the programme as an important part for their health management. Their ongoing participation and high level of commitment suggests that the benefits, including reassurance, far outweigh any risk of anxiety that women may experience during the process.

The process of screening mammography is associated with varying levels of worry for women. As every woman in this study had prior experience of mammography, the levels of anxiety in relation to screening may be underestimated in this survey. Because high levels of worry about breast cancer may already be prevalent in the ‘at risk’ population regardless of whether they are currently undergoing screening mammography, and this may deter some women from attending, further research is required to identify specific and appropriate interventions to deal with this anxiety. Similarly, the link between pain, anxiety and future intentions to attend warrants further investigation, as this research is limited to women who have chosen to participate in a pilot programme.

Although it is a potential source of bias in this study that it is based on 56% of those surveyed, to address the variable of non-responders in the research design, the 213
surveys returned after the reminder letter was sent in late November were coded as ‘late returns’ and compared with those of earlier returns. There were no significant differences among variables between respondents in the two categories, such as experience of anxiety, pain or reassurance obtained from mammography, which suggests that the sample was likely to be representative of the remaining population of non-responders in this study.

As the first New Zealand study of the screening mammography programme to identify ethnic subgroups, this research has indicated that Maori, Pacific Island, and lesser-educated women demonstrate significantly higher levels of worry both about breast cancer and some aspects of screening mammography. The propensity of the same ethnic groups to respond differently to invitation strategies from the programme may also be an outcome of their increased levels of anxiety. Accordingly, it is important to identify the specific needs of these women to address their current under-representation in the screening programme, so that they may obtain the benefits of reassurance and early detection.

Overall, however, contrary to suggestions from other researchers, this study does not demonstrate that screening mammography raises the ongoing level of anxiety in this population of women. The reverse had been shown. The majority of women felt reassured following their mammogram, and levels of anxiety about breast cancer were diminished.

**Author information:** Margaret A Brunton, Senior Lecturer, Department of Management and International Business, Massey University, Albany Campus, North Shore, Auckland; Claire Jordan, Lecturer, Institute of Information and Mathematical Sciences, Massey University (Albany Campus), North Shore, Auckland; Ian Campbell, Senior Lecturer, Auckland School of Medicine, Auckland (and Director, Waikato Breast Care Centre, Hamilton)

**Correspondence:** Margaret Brunton, Senior Lecturer, Department of Management and International Business, Massey University (Albany Campus), Private Bag 102 904. North Shore MSC, Auckland. Fax: (09) 441 8109; email: M.A.Brunton@massey.ac.nz

**References:**


