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The impact of a false-positive result from breast cancer mammography: a qualitative pilot study

Key Messages

1. Most women who underwent mammography were under 50 years of age and many felt that they should have had mammography biannually from 40 years of age onwards, increasing their risk of having invasive investigations such as a fine needle aspiration (FNA) and unnecessary short-term distress.
2. In contrast to western studies, despite having considerable short-term anxiety (fear of cancer following the disclosure of the abnormal film finding, procedural anxiety while undergoing the FNA, and further anxiety while awaiting the FNA result), most women did not have negative views of the experience with many saying it gave them peace of mind.
3. Some women felt that being asked to return in 2 years for monitoring after being told the test results were negative made them uncertain about how disease-free they really were. Many vowed to monitor their cysts to ensure they did not become malignant in the future.

Introduction

Population mammographic screening to detect asymptomatic breast cancer for women over 40 years of age is common in developed countries, but remains controversial.¹⁻³ Risks include anxiety and unnecessary investigations.⁴ Up to 1 000 000 false positives occur annually among 40- to 50-year-old American women.⁴ False positive test results increase anxiety, refusal to take future screening, and difficulty with accepting that the 'all clear' result really is correct. Most studies assessing the impact of false positive results in screening have been on Caucasian, African-American, Latina,⁵ and, rarely, Chinese women.⁶ We found no reports in the literature on the effects of false positive mammography results among Hong Kong Chinese women. Using qualitative methods, we studied the impact of false positive test results on these women.

Methods

This study was conducted from February 1999 to June 2003. We collected data from a Hong Kong breast unit linked to a walk-in mammography screening clinic. After an abnormal mammography, women generally undergo a fine needle aspiration (FNA) biopsy. We targeted around 20 women with a positive mammography (10 true positives and 10 who, following mammography and FNA, were redefined as false positives), thus isolating the false positive experience.

The site initially permitted recruitment of women identified from medical records who had FNA following referral from a radiologist. These women gave informed consent to a face-to-face qualitative interview exploring their experience and feelings regarding their provisional diagnosis and subsequent 'all clear' result after FNA or other investigations. All recruitment and interviews were performed by an experienced bilingual research nurse in a private and comfortable room on site after women had undergone FNA and received an 'all clear' result. Interviews were audiotaped and transcribed into Chinese. NViVO software (QSR International, Melbourne, Australia) helped code and categorise textual data.

Data analysis

We used a phenomenological analytic approach. Diagnostic meanings and impacts were refined, identifying significant statements (descriptions, phrases, and sentences directly pertaining to impact, interpretation, responses, thoughts, and feelings about the initial film report, FNA, followed by the 'all-clear' result) were extracted from each interview. Emerging semantic elements were thematically aggregated and clustered, to represent commonalities in the experience. Discrepant items underwent a reiteration. Categorical and semantic validity was ensured by having two investigators independently analysing, then discussing the transcripts to achieve agreement. This resulted in an exhaustive description of the significance of the false positive diagnosis experienced by these women.

Results

After interviewing nine women who had received false positive results, a fierce

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public debate erupted in Hong Kong over the risks and benefits of population mammographic screening for breast cancer. One of the investigators was perceived as opposing screening mammography as harmful to Hong Kong women. Supporters of mammographic screening perceived the study results would not therefore be objective. Shortly thereafter we were denied access to patients for this study. Despite several months' effort to re-establish the project, we remained excluded and project funding ran out. This report should be treated as a pilot study only and caution exercised when interpreting the results.

Subject characteristics

Nine women aged 40 to 62 years (four aged >50 years when screened) were recruited. Eight were married and one widowed. All had between one to five children. Five were blue-collar workers. None had a family history of breast cancer. All received mammography between October 1999 and March 2000.

Reasons for attending screening

Women's reasons for screening were classified into four groups: media, prompted by word-of-mouth, doctors' advice, and age older than 40 years. Sources for the last risk factor were unclear, other than that media reports had identified this as when women should begin screening: "once you reached 40 years old you'll be recommended to get a mammogram" (case 005). On being told of having an abnormal film, women expressed varying views: "when I got the call from the doctor I was scared and suspected that I may get cancer" (case 003). Others reported being unconcerned: "I wasn't worried; I'm old now and may die soon anyway. My...son is already 26 years old and...can take care of (himself)...so I don't have anything to worry about" (case 001). Some anxious women coped by avoidance: "I tried not to think about the problem; watched TV and listened to the radio" (case 002). Some remained worried until the FNA result was given: "even though the doctor said he would call me if there's something wrong, I think for those women who has a negative results they should be informed as well so that they won't be worried while waiting" (case 008).

The possibility of cancer

Cancer was recognised by all women as a possibility, and carried a variety of meanings, including breast removal, death, no cure, a tortuous process of treatment and its impact on daily life. Two main groups were identified: women who were not concerned about the possibility of having cancer and those who were concerned about this possibility. Women in the later group found the worry affected them in different ways: "I'm particularly afraid of cancer because my husband had cancer" (case 004). "I'm just worried that if I get cancer then I can't support my family" (case 004).

Some women were unable to concentrate on their work, suffered loss of appetite, had sleep difficulties, or felt "down" as a result of the abnormal film: "I always

worry about getting cancer so I didn't eat and sleep well" (case 007). "I tried not to think about it and I talked to my colleagues. Sometimes I would hide myself and cry and this is the only way to release my pressure" (case 004).

Experiences of false positive labelling

Women who had an abnormal mammography and then went on to have FNA or other investigations resulting in no confirmation of malignant disease describe several responses. Some discussed their experiences with other people who had developed cancer: "there was a long period of time that my husband had cancer.... (His) experience affected me a great deal and I think the treatment and the whole process is very scary.... So I don't know if I really get cancer how I'm going to face the disease. I'm so scared that I might consider not having any treatment" (case 004). The waiting between having FNA and getting the result was a difficult time for some: "we've waited too long for the results and we're worried and scared of getting cancer" (case 004). "I don't think it takes too long for follow-ups and mammogram. I understand that there're lots of people waiting" (case 001). Some coped by being confidently optimistic of a negative FNA result. Several continuously reassured themselves, some citing heuristics, such as the absence of discomfort, as evidence to support their belief that they did not have cancer. Such women tended to hold a positive outlook: "I have a false-positive experience before so I think this time the result should be negative" (case 003).

Results of the fine needle aspiration

A negative FNA made most women feel relieved and happy, and removed the need to worry, though some women seem to misunderstand the results: "it gives me 'peace of mind' that now I know I'm fine even though the result is negative" (case 009). "It's helpful that it tells me if there's anything wrong with my breast and doctor explains to me the results. It's not only for prevention; it can also tell you what happen to the breasts if the result turns out to be positive" (case 001).

For some women, however, the 'all clear' result was not the end of the saga and did not end their anxieties. Some were asked to return for repeat mammograms in future: "I'm not quite satisfied because he asked me to have mammogram every 2 years but I think it's not enough. What if there's something wrong again 1 year later?" (case 003). For some women, the uncertainty that they might develop cancer in the future was planted in their minds by the experience: "I asked him what's the difference between benign and malignant tumour but he didn't explain it to me" (case 004). "I feel confused about what he said to me and he didn't really answer my questions" (case 005). "I'm afraid it will turn into malignant and I think it's safer to remove the cysts and my brother will introduce a surgeon for me" (case 005).

However, some felt that they might be unlucky enough

to get a positive diagnosis of cancer, while others worried about how X-ray exposure influenced their future health: "I think I'm unlucky that I need to go through the painful biopsy procedure" (case 006). "I only worry about the swelling I got from the biopsy procedure. And I did 10 X-ray films so I worry that I've been exposed to too much X-ray and I may never know about the effect on my breasts or body" (case 008).

The experience of mammography and fine needle aspiration

Women found being unable to move for a long time difficult and commented on the discomfort of both procedures: "the procedure is awful and it's painful when the breast is pressed down by the machine. I think it's not useful because the first time I had the mammogram the result didn't confirm whether I'm fine or not and I need to do the exam again.... Although nurses are women but I still feel embarrassment because I was half-naked" (case 002). "I'm prepared for the exams but while taking the biopsy it took a long time and the machine pressed on my breast and I couldn't move for 45 minutes. Afterwards I got bruises on my breast" (case 004). This was overlaid by anxieties associated with the investigations themselves: "I feel scared and worried during the exam and when the doctor told me it may take 30 minutes then I feel worse. The nurses said I can't move a bit or else they need to repeat the procedure again and again. Once I saw blood came out from the wound I fainted. I wanted to escape but I couldn't" (case 008).

Women asked if they would have a mammogram in future gave mixed responses. Several said they would as a routine check-up to give them peace of mind: "I will have the exam 2 years later. If there's something wrong with my breasts again then mammogram can help to see what is wrong" (case 001). "I will stay in the programme and attend follow-ups regularly because I need to monitor the cyst and see if it will grow or turn into malignant" (case 006).

Would women recommend mammograms to their friends? Most women felt quite positive towards mammography as something that could help give peace of mind, that could be helpful to others, concluding that it was an accurate tool: "even though I think it's not useful for me still I will ask my sister and friends to join the programme; it may be useful to others and let them know their breasts are ok" (case 002). "I always ask my friends to have a mammography because it's about time for people of our age to have one. Cancer is quite prevalent these days because I've heard of many women have cancer. If one join such screening programme and turn out that she has cancer then she can start treatment earlier" (case 004).

Discussion

Overall, despite some anxiety about the abnormal film, women were quite positive about their mammographic experience. Overseas studies suggest that women who

receive a false positive mammographic screen are more likely to remain anxious for a considerable time afterwards, and may not be reassured by the 'all clear' from a negative FNA result.³

Other studies suggest that reducing the period between abnormal mammographic findings and FNA does not reduce anxiety or its persistence.⁷ British women who have had a false positive diagnosis are more anxious after 3 years, and have approximately twice the risk of adverse psychological consequences than women given an unambiguous 'all clear' after their mammography.⁸ Fifteen percent of such women did not attend for repeat screening 3 years later compared to eight percent who had received a clear result after mammography.

Some Hong Kong women were unconvinced by the clarification of their abnormality and stated that they would continue to attend for screening in future. Several women reported the test had given them peace of mind and that it had been useful. One woman stated that she would never have another mammography, because of the pain and discomfort of the mammographic procedure, and not the false positive result.

This study is limited by the small sample. The unfortunate blocking of recruitment was irreversible. The small sample means that data saturation is unlikely. Therefore there are probable experiences or dimensions of false-positive episodes we have not described. This project should be considered a pilot study. Therefore, we have not made any recommendations based on the limited data set described.

There are some points that we would like to emphasise as valuable data from this project: first, most of these women were under 50 years of age and were more likely to have false positives because such women have denser breast tissue, making film interpretation more difficult. Current recommendations for population mammographic screening are that it should not start before the age of 50 years,¹ although some oppose all walk-in and population screening for breast cancer, irrespective of age.³ Second, women seemed not to suffer residual adverse consequences from their false positive result. This in part may be due to limitations in their understanding of the meaning of a false positive, although all women knew they had an abnormal mammographic film. It is also likely that there was considerable awareness among the radiologists at the referring walk-in clinic of the possibility that ambiguous films might be false positives. Therefore the radiologists may have been particularly careful not to give the impression that the abnormal film indicated a serious problem, playing down the findings until the FNA could clarify the situation. Third, while women felt great relief at being told their FNA biopsy was clear, this was to some extent undone by then being asked to come back for further investigations in 2 years. This seemed to raise the spectre of doubt in

women's minds, preventing them from achieving closure on a worrying episode in their lives.

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