RESEARCH ARTICLE

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Reflections from Women with an Interval Breast Cancer Diagnosis: A Qualitative Analysis of Open Disclosure in the BreastScreen Western Australia Program

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Abstract

Background: 'Interval breast cancer' describes a malignancy that is diagnosed after a negative screening mammogram. Open disclosure is a process of addressing a negative health outcome that includes an apology and an opportunity for the client to discuss concerns. BreastScreen Western Australia has implemented a policy of open disclosure. The purpose of this study was to gain an understanding of clients' experience with interval cancer and their attitude towards the screening programme by conducting a thematic analysis of written responses from women participating in the open disclosure process. **Methods:** Women experiencing an interval cancer diagnosis between 2011 and 2020 were sent a questionnaire by mail. It included two broad questions with free-text responses. A qualitative analysis of the responses was conducted using an inductive approach. Responses were de-identified and data were thematically analysed and presented using verbatim quotations. **Results:** Five themes emerged in response to "what could we have done better?": 'nothing,' 'broaden scope,' 'service delivery,' 'breast density education' and 'more education' generally. Six themes emerged in response to "what did we do well?": 'staffing,' 'overall satisfaction,' 'reminders,' 'follow-up after interval cancer,' 'efficiency' and 'information and education provision.' An additional theme of 'storytelling' emerged from both questions: an opportunity for the woman to share her experience of cancer. **Conclusion:** Most women expressed positive attitudes towards the service and appreciated giving feedback in the open disclosure process. Several themes supporting the role of BreastScreen in education were identified, including providing information about breast density, breast health, and limitations of screening.

Keywords: Breast neoplasms- disclosure- mammography- mass screening

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Introduction

Breast cancers diagnosed following a negative breast screening mammogram and before the next scheduled screen are referred to as interval cancers. There is significant literature on the epidemiology and radiological classification of interval cancers, which occur in 8.4–21.1 per 10,000 women attending for regular breast screening (Houssami and Hunter, 2017). The large range represents the heterogeneity of reports of interval cancer rates, which include rates from different risk populations, different screening intervals and different screening rounds (initial vs repeat).

There is less research examining women's experience with an interval cancer, how it affects their attitude towards the screening programme and how they interact with the programme after the diagnosis. Interval cancers are often diagnosed later than other symptomatic cancers due to the reassurance from the recent negative mammogram (Bassett and Butler, 1991; van Dijck et al., 1993) and the cancer diagnosis may undermine confidence in the screening programme (Solbjor et al., 2012).

Open disclosure of harm is encouraged and often mandated in the health system (Australian Commission on Safety and Quality in Health Care, 2013). The practice of open disclosure has been shown to have many benefits including an opportunity to provide support to clients (Iedema et al., 2008) and retaining their confidence and trust in health services (Faculty of Radiologists, 2016). However there is little understanding about how this process could be implemented in the context of an interval cancer in a population screening programme. Concerns have been raised about open disclosure in breast radiology given the medicolegal sensitivity. Historically,

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false negatives from population breast cancer screening programmes have been cited as a common cause for litigation (Wilson, 2000). There is often an expectation that women will be angry or unwilling to engage with the disclosure process (Mullooly et al., 2021)

BreastScreen Western Australia (WA) implemented a policy of open disclosure in 2011, and to date this is the only BreastScreen service in Australia to practise open disclosure in response to interval cancers. Women are given the opportunity to provide written feedback and/or to meet with the medical director of the state program (described in more detail below). The aim of this study was to understand women's responses to their interval cancer diagnosis and their feelings about screening programme. The objective was to conduct a qualitative analysis of written feedback provided during the implemented open disclosure process by women experiencing an interval cancer diagnosis at BreastScreen WA between 2011 and 2020.

Materials and Methods

The study was reviewed by the Hospital Quality Improvement Committee of the Women and Newborn Health Service in WA and was determined to be a quality assurance project exempt from review by a Human Research Ethics Committee (Ref GEKO 39010). It was also approved by a subcommittee of the University of Notre Dame Australia HREC (Ref 2021-079S).

Study setting

Approximately 120,000 women attend BreastScreen per year in the state of WA, population 2.7 million. Asymptomatic women are eligible to attend biennially for a free mammogram if aged over 40 years. Recruitment is targeted to women aged 50–74. Most clients are at population risk. Those with a family history of breast cancer in a first-degree relative under the age of 50 are invited to attend for annual mammography. The interval cancer rate in the programme is 9.7 per 10,000 women-years (Noguchi et al., 2021). In the Australia screening programme, information about breast density is not routinely reported nor disclosed to clients. However, the state programme in Western Australia independently chooses to report and disclose this information. BreastScreen WA is currently the only programme in Australia to notify women of their breast density.

Disclosure process

Interval cancers can come to the attention of the screening programme in a various ways. A women who is diagnosed with cancer outside the screening program (for example through her general practitioner or private radiology service) may report her diagnosis to the screening programme. A clinician treating the cancer may report it. Interval cancer may also be identified through data matching between the cancer registry and the screening programme, which is routinely performed as part of the clinical quality assurance audit. Delays of more than a year may occur if the interval cancer is identified through data matching.

When the screening program becomes aware of an interval cancer diagnosis, the client is contacted in writing. Women were excluded from this process if they return for rescreening after the interval cancer diagnosis or are deceased. Each woman is provided with a letter acknowledging her cancer diagnosis and offering an apology for her situation. This is accompanied by a feedback questionnaire and an invitation to meet with the medical director to discuss the diagnosis and the results of radiological review of her mammograms. The questionnaire consists of three questions: 'what could we have done better?', 'what did we do well?', and 'do you have any other comments or suggestions?' The third question was only included in the initial three years of the study period and provided insufficient data. Therefore, data from this question were not included in analysis.

Data collection and analysis

Women returning feedback questionnaires following an interval cancer diagnosis between January 2011 (inception of the disclosure programme) and the end of 2020 were identified from the BreastScreen interval cancer database. Responses to the questionnaires were exported to a spreadsheet and de-identified. NVivo was used for data management and analysis.(QSR International Pty Ltd, 2020) Written comments from the questionnaires were thematically analysed using an inductive approach to identify common themes arising within responses across the ten years. Codes were identified within responses to questions, 'what could we have done better?' and 'what did we do well?' Codes were then categorised into broader themes to reflect key concepts communicated by women. Verbatim quotes were utilised to represent these themes accurately and in the words of the women. Coding was an iterative process and consensus on themes was reached by the study team.

Results

Women known to have been diagnosed with an interval cancer, without exclusion criteria for contact were offered the questionnaire and meeting with the medical director. It is estimated that 2,000 clients were contacted (approximately 200 per year during the study period). Two hundred and eighty written responses were received, including six letters from women providing feedback about their experience were not structured questionnaire responses. Four of the questionnaire responses were solely requesting to opt-out or opt-back into the programme and did not include any feedback, and therefore were omitted from the data to be analysed. A total of 276 responses were analysed. The mean number of women providing feedback was 28 per year (range 18–45). There was a similar number of responses to each question.

Five themes emerged in response to the question "what could be have done better?" In order of decreasing frequency, they were: 'nothing', 'broaden scope', 'service delivery', 'breast density education' and 'more education' generally. Six themes emerged in response to the question "what did we do well?" In order of decreasing frequency, they were: 'staffing', 'overall satisfaction', 'reminders', 'follow-up after interval cancer', 'efficiency' and 'information and education provision'. An additional theme that emerged from both questions, which did not fall under the themes above, was 'storytelling.'

What could we have done better?

Theme 1: Nothing (95 references in 10 years)

Most respondents, consistently across all years, believed that there was nothing that BreastScreen could have done better during their interval cancer experience.

"Nothing. The service provided has always been excellent"

"I'm not sure that anything could have been done better"

"Nothing - inflammatory breast cancer doesn't show well on mammograms"

"Nothing! As I discovered by self-examination in March 2014. I don't think BreastScreen could have detected"

"There's really nothing as the lump was closer to the underarm that the breast, even though it was still classed as the breast"

"Absolutely nothing. These things happen"

Theme 2: Broaden scope (51 references in 10 years)

The next most common response (arising every year) was the suggestion that BreastScreen should broaden its scope. This was often the suggestion that BreastScreen offer supplementary ultrasound and/or breast examination services. Many respondents also suggested that more frequent mammograms, or a broader age eligibility for mammograms would be beneficial.

"My breast cancer was found using ultrasound so including ultrasound exam as well as mammogram could get better results"

"It would be great if BreastScreen WA [Westen Australia] could provide ultrasound services as well"

"I should have an ultrasound alongside the mammogram. Even better. Having that option available to me at the time of booking the test or on arrival"

"It is still confusing that in 1.5 years I developed secondary breast cancer. Maybe yearly screening would have been beneficial"

"I know it comes down to funds, but it would be great to be screened annually"

"Recommend more people over 70 to be advised to get mammograms, cancer doesn't know your age"

"Perhaps younger women should be encouraged to have this screening"

"Strongly believe regular two-yearly reminders should continue after 70. I found a lump 18 months after my last mammogram at age 76"

Theme 3: Service delivery (39 references in 10 years)

Suggestions for improvements in service delivery arose as a theme across all years. Suggestions for improvement included an open-disclosure letter sooner following diagnosis and improved efficiency and quality of the mammography service. Improved data-matching or communication was also suggested, specifically relating to clients not wanting screening reminders after a breast cancer diagnosis.

"Been more prompt. It is nearly two years since I was diagnosed, and I informed BreastScreen nearly a year ago. To take a year to send a letter offering to discuss any questions is very poor and quite unacceptable, in fact TOO LATE. I'm not sure who would like to follow up with queries after this time"

"I must admit to being annoyed when this letter arrived as it has been 2 years since I was treated for breast cancer."

"Just wondering why it took 3 years to receive this letter? Happy to respond though."

"No apologies or sympathy - as I was a nurse I think a little empathy goes a long way sorry to be raving on."

"I did however receive 2 notifications that I was due for a mammogram after I had informed you I didn't have any breasts"

"Your record keeping is also questionable as I requested no further contact in 2013 and received a confirmation letter from [BreastScreen] at that time. I do not need to be reminded as that happens daily when I look in the mirror."

"Match data of my diagnosis sooner than now, almost two years later, to spare me trauma of repeated reminders for mammograms while undergoing treatment for breast cancer."

Theme 4: Breast density education (24 references in 9 years)

The subject of more education regarding breast density was a specific theme that came across strongly in all years. Women felt that BreastScreen has a role in making recommendations about management of dense breasts as well as notifying the woman of her density.

"If a mammogram shows a woman has dense breasts, in your results letter, I think you should recommend that she also has an ultrasound due to the limitations of mammography. The next person in a similar situation might not be lucky as I was that it was caught early enough."

"Stress the importance of following your instructions. You recommend that I see my GP [general practitioner] in 12 months due to breast tissue thickening - I waited 18 months - silly me!!!"

"After 2 'BreastScreen' mammograms no one mentioned that I had unusually dense breast tissue. If I had not actually detected the lump in my left breast it might have been late stage and not early as I was lucky to have been diagnosed. The other lump was only picked up by ultrasound. Could not feel it."

"I think for women with dense breast tissue a follow-up ultrasound should be arranged."

"On the bottom of the results letter it mentioned I had dense breasts. Unfortunately, I didn't realise this was a problem and my doctor (no longer my GP!) never mentioned it as a problem."

"Even though it was stated to me when I received the results about having dense breasts, I feel that there wasn't much emphasis on getting an ultrasound."

Theme 5: More education (20 references in 8 years)

Finally, a theme of wanting more education about breast care was found across most years. This included respondents wanting to have been informed that not all cancers can be detected on just a mammograms or an ultrasound alone, wanting BreastScreen to promote and teach breast self-examinations and encouraging general breast cancer awareness.

"You should tell women that there are breast cancers that don't show up on mammogram and there are cancers that don't show up on ultrasound. To be sure you need both.

"More verbal information about breast self-examination to allow for the 90% only identification of breast lumps."

"My breast cancer was picked up by me through self-examination between mammograms - could this (self-examination) be promoted and shown by BreastScreen WA?"

"What you could emphasise is for women to check their breasts every week in the shower - I would have found my lump earlier had I done a regular check myself."

"Bring awareness and attention to breast cancer."

What did we do well?

Theme 1: Staff (95 references in 10 years)

The strongest theme that emerged repeatedly (many times every year) was the professionalism and kindness of staff at BreastScreen.

"Everyone that attended to me was fantastic. I could not praise all staff enough. Doctors, nurses, support… fantastic"

"Everyone is always kind, explaining what is going to happen. Always putting people at ease."

"Sensitivity of staff in handling patients. Patient, kindly, gentle, understanding. All qualities above much appreciated"

"All staff to help with breast cancer are magic. Choosing great staff to make all feel like they are special at that awful time"

"I felt I was in good hands, people who knew what they were doing, and they made me feel as comfortable as is possible for this procedure"

"I have always been happy with the way your staff have conducted themselves. They are a dedicated, empathetic group of ladies"

Theme 2: Overall satisfaction (63 references in 10 years)

The next most frequent theme that arose in response to this question was of overall satisfaction with BreastScreen's services.

"I have always been very happy with the service that you provide. Thankyou"

"I think you offer an excellent service for women and to detect up to 90% of breast cancers is a great result"

"Whilst I was in your care, I received excellent, caring service and I have no concerns in this area"

"The moment I walked into your building, till the moment I walked out, my experience of your service was wonderful."

"The service you give is excellent and done with the utmost care and attention to detail."

Theme 3: Reminders (29 references in 9 years)

Appreciation of mammogram reminders arose as a theme across all 10 years.

"Reminders are always appreciated. The system works well."

"Sending out reminders"

"You regularly told me when my mammogram was due. Thanks!!"

"Your prompting about getting appointments and making it easy to place appointments."

"Reminding me to come in for check-ups. Persisting if I failed to turn up. Thank you."

Theme 4: Follow-up after interval cancer (22 references in 7 years)

A theme that arose in seven of the 10 years was appreciation of being followed up after diagnosis and providing an opportunity for feedback.

"Thank you for your letter - a lovely surprise and so reflective of the high standard of professionalism of the individuals who constitute BSWA [BreastScreen Western Australia]"

"Feedback form and doing something about it."

"I also appreciate 'exit' letter received with this form and the opportunity to comment"

"By sending me this letter asking me to come to discuss or if I have any questions regarding my diagnosis"

"Thank you for your letter. I often wonder if the journey would have been easier if the breast cancer was found earlier as I am still trying to pick up the pieces 2 years later. I hope this feedback helps with other women's experiences in the future."

Theme 5: Efficiency (20 references in 9 years)

Similarly, the efficiency of the service was a common response to what was done well.

"You are prompt and efficient. Thank you."

"Always very efficient with the procedure."

"You were very fast and efficient with service once I was diagnosed. It was an aggressive, large cancer. So, I really appreciated that."

"Always efficient and caring."

Theme 6: Information and education provision (16 references in 8 years)

The final theme that arose in most years was that information and education provision was done well by BreastScreen. Many respondents appreciated the provision of information regarding breast density.

"Make women aware of breast cancer and the need to take care of themselves."

"You gave good advice."

"I believe if I had not been kept aware of the importance of regular testing and self-examination my cancer would not have been detected at the early stage it was."

"I was grateful that you sent a letter informing me to contact my doctor, as I had dense breasts"

"My results on the follow-up letter did mention there

could be inaccuracies with my dense breasts. This did make me check my breasts so that's a good thing."

"Recommended follow up with my GP who sent me for ultrasound and biopsy"

"Pleased that an attached letter […] stated "particularly important for you to see your doctor for a breast exam". It was this letter that prompted me to make an appt with my GP. My GP felt hardness in my breast for my age and said this shouldn't be the case […] Cancer clearly seen"

Storytelling (80 references in 10 years)

The storytelling opportunity that the questionnaire provided emerged as an important theme in response to both questions. Many respondents used the questionnaire to share their story, without necessarily addressing strengths or areas of improvement in the program. Women recounted their experience of cancer diagnosis and treatment, which often related to their experience with general practitioners (GPs) and oncologists rather than BreastScreen. They also shared reflections on how cancer had impacted their lives. Many of these accounts contained potentially identifying information, so quotes are not presented.

Discussion

This study was a qualitative analysis of the first 10-years of a novel open disclosure process in a population-based breast screening programme. Feedback received from women involved in the process was largely positive, with themes of 'good staff', 'overall satisfaction' with service and 'no improvements needed' saturating the responses. As part of an evaluation of the Australian Open Disclosure pilot in other parts of the health system, Iedema et al., (2008) interviewed patients' and family members' about their experience of open disclosure following adverse events. Data from this study suggest that for consumers to be satisfied with an open disclosure process, the process should involve a formal open disclosure program, a full apology, the opportunity to meet staff and have the adverse event explained to them, and an offer of tangible support (Iedema et al., 2008). BreastScreen WA's open disclosure process is a formal program that addresses each of these elements.

Results from this study found conflicting data on information and education provision. This matter appeared as a theme under both questions 'what could we have done better?' and 'what did we do well?' Participants suggested more education be given regarding limitations of mammography and ultrasound, as well as the perceived 'importance' of breast self-examination. It is well established that false negatives are inherent in all population-based screening programmes, as no screening test can have a 100% sensitivity and specificity. However, communicating these predictable limitations of breast screening to clients in a form that they understand and retain remains a challenge for most population screening programmes (Bassett and Butler, 1991; Hersch et al., 2017). Conversely, a similar number of responses mentioned information and education provision as part of what they felt was done well by BreastScreen WA. Mention of raising awareness of breast cancer, the importance of screening and self-examination, and information regarding breast density was reported as a strength of the program.

A prominent theme that emerged from the data was the issue of breast density and screening practices. Again, both positive and negative aspects of this theme arose. Some women felt more emphasis on the recommendation of follow-up with a GP following the finding of increased breast density was required. Conversely, other women offered positive feedback and thanked BreastScreen WA for the accompanying letter educating them about breast density and the associated risks and implications. Some credited this letter for the early detection of their breast cancer. It is estimated that 40–50% of women of screening age in the USA have dense breasts (Sprague et al., 2014) but that proportion is likely lower for the BreastScreen population. Increased breast density is a risk factor for breast cancer overall (McCormack and dos Santos Silva, 2006; Pettersson et al., 2014) and for interval breast cancers in particular due to its masking effect (Houssami and Hunter, 2017). How to best manage dense tissue is a contentious issue as supplemental screening with ultrasound or MRI increase cancer detection but do not necessarily reduce the interval cancer rate (Zeng et al., 2022). They are also associated with other harms such as an increase in false positive examinations, (Melnikow et al., 2016; Siu and Force, 2016) unnecessary biopsies (Scheel et al., 2015; Burkett and Hanemann, 2016) and cost to women and the health system (Sprague et al., 2015). In addition, there has been no randomised controlled trial that demonstrates supplementary testing benefits outcomes for asymptomatic women with an increased breast density (BreastScreen Australia, 2016). The role of BreastScreen in management of breast density remains unresolved but in this study it has been identified as a major concern for women with an interval cancer diagnosis.

BreastScreen Australia's position statement on density does not recommend routine density notification or advice about options for management (BreastScreen Australia, 2016) BreastScreen WA's protocol of notification is unique in Australia and this may explain the apparent familiarity that women in this study demonstrated in their comments. It possible that women were diagnosed with their interval cancer when undergoing supplementary screening because of their breast density and this led to women making comments about breast density and supplemental screening in their feedback. It is also possible that women with dense breasts who had an interval cancer and had not had supplemental screening may feel that the supplemental imaging would have diagnosed their interval cancer, making them more likely to recommend it in their feedback.

Feedback regarding the open disclosure process was largely positive. Many women expressed their appreciation of receiving the letter and opportunity to provide feedback via the questionnaire. The few negative comments received were concerning a delay in receiving this letter after their interval cancer diagnosis. There were no negative comments about the open disclosure process as a concept. An Australian qualitative study on the process of open disclosure found an important aspect consumers desired was the need for timely contact, (Iedema et al., 2008) which aligns with findings from this study. This demonstrates that despite fears of medicolegal consequences, women in this study appeared to be happy to participate in an open disclosure process. However, it is also possible that women who felt less positive about BreastScreen did not participate in the process.

Many participants suggested BreastScreen WA broaden their scope of practice. Recommendations included offering supplementary ultrasound or breast examination services, in addition to more frequent mammograms and a broader age eligibility for mammograms. Currently, mammography is the only breast cancer screening method that is evidence-based for women at average risk (World Health Organization, 2014). However, For the general population, the potential harms of including a routine ultrasound outweigh the benefits, (Scheel et al., 2015) as it will only slightly increase cancer detection and will significantly increase the number of false-positives (Berg et al., 2008). A review of randomised controlled trials suggested there was no different in breast cancer mortality for screening intervals less than 24 months compared to those of 24 months and longer, (World Health Organization, 2014) and notably more frequent (annual) screening disproportionately increases harms especially false-positive results (Siu and Force, 2016). Likewise, screening women aged 40–49 was recommended only in well-resources settings (World Health Organization, 2014). This could be communicated to women to reassure them that the recommendations for screening age and modality are evidence-based.

This study has strengths and limitations. Strengths include robust qualitative methodology, a unique dataset and a novel programme spanning 10 years. No previous studies evaluating clients' perspectives of open disclosure in a breast screening programme have been identified. Limitations of this study include potential for significant bias in respondents, a potential lack of generalisability, and limited depth in qualitative data due to the small number and broad nature of the questions used as part of the open disclosure process. Bias may have been a limitation, as women who may have been unhappy with the open-disclosure process or their experience may have been less likely to respond to the questionnaire or engage with the service. This is particularly important when considering breast density, as only women with both interval cancer and dense breasts commented. Similarly, the setting of this study was only one state within Australia (as only BreastScreen WA has implemented open disclosure), so findings may not be representative of Australia overall or of international programs.

This research provides information describing the experience of Australia's only BreastScreen service to offer an integrated open disclosure process related to interval cancer. This study provides some reassurance that the experience of many clients and their ongoing attitudes towards the screening programme are generally positive despite the devastating experience of an interval cancer. This may give other programmes confidence to introduce similar disclosure programs, and to report evaluation of this process. The issues of how the screening program should explain the limitations of screening, the management of breast density and education around breast health have been identified as relevant and are topics for future research and policy review.

Author Contribution Statement

LC, MB: study design, data analysis, writing first draft, revision, final approval of manuscript. EW: study design, data collection, revision, final approval of manuscript. NH, HL, SE: data collection, revision, final approval of manuscript.

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Ethics approval

The study was reviewed by the Hospital Quality Improvement Committee of the Women and Newborn Health Service in WA and was determined to be a quality assurance project exempt from review by a Human Research Ethics Committee (Ref GEKO 39010). It was also approved by a subcommittee of the University of Notre Dame Australia HREC (Ref 2021-079S). LC is conducting this research as part of her studies for the degree of MD at The University of Notre Dame Australia.

Data availability

Not applicable for this study.

Conflict of Interest statement

The authors have no conflicts to declare.

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