"*It's about our bodies… we have the right to know this stuff*": a qualitative focus group study on Australian women's perspectives on breast density

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ABSTRACT

Objective

This study aimed to explore Australian women's current knowledge, perspectives and attitudes about breast density (BD); and information needs to inform effective evidence-based communication strategies.

Methods

Fourteen online focus group sessions with a total of 78 women in New South Wales and Queensland, Australia aged 40-74 years without a personal diagnosis of breast cancer were conducted. Audio-recorded data was transcribed and analysed thematically.

Results

Women had a very limited knowledge of BD. Overall, women expressed a preference for more frequent mammograms and/or supplemental screening should they be told they had dense breasts, despite being presented with information on potential downsides of additional testing. The majority of women were supportive of the notion of BD notification, often suggesting they had a 'right to know' and they would prefer to be educated and informed about it.

Conclusion

The potential of being informed and notified of BD is found to be of interest and importance to Australian women of breast screening age despite lacking current knowledge.

Practice Implications

This study highlights that policy makers and screening services need to consider how to weigh up these views and preferences of women with current evidence surrounding BD in deciding about implementing population-based BD notification.

1. Introduction

High breast density (BD), most commonly classified as having predominantly heterogeneously or extremely dense breast tissue on mammography [1], is one of a number of independent risk factors for breast cancer [2, 3]. It is estimated that approximately 43% of women in the United States (US) breast screening population are classified as having dense breast tissue [4]. BD is therefore said to be one of the most common risk factors for breast cancer. Furthermore, dense breast tissue reduces the sensitivity of mammography [5], increasing the risk of having a false negative result and/or interval cancer diagnosis [6].

In response to a largely grass-roots effort from women over the past decade in the US, the majority of states have now enacted laws mandating BD notification in mammography reports [7, 8]. In 2019, the US Congress passed national BD legislation advising that mammography facilities must include BD information in reports sent to women and their physicians [9]. In other countries however this information is not routinely provided in breast screening programs. For example, BD is not reported in the Australian population-based screening program, and the BreastScreen Australia Standing Committee on Screening recommended that 'until more evidence is available on how breast density is best assessed and managed (including evidence to support clinical pathways), BreastScreen Australia should not routinely record breast density or provide supplemental testing for women with dense breasts'[10].

Although the overall aim of BD notification is to alert women with high BD of their increased risk of breast cancer and the possibility that mammography may perform less well for them, the evidence to support BD notification to women in population-based screening is not clear [11]. Criticisms include that BD notification does not take into consideration other important risk factors for breast cancer, and that notification may increase women's anxiety about their risk without assisting/providing any means for them to reduce their risk and anxiety. BD notification may prompt supplemental screening for women with high BD (e.g., ultrasound or magnetic resonance imaging (MRI)), but it is not clear whether this provides any long-term health benefit [12-14]. While these imaging modalities when used in addition to mammography have been shown to increase breast cancer detection, they may also

cause harms, including false-positive results and increased overdiagnosis and overtreatment [15, 16].

To date, both quantitative and qualitative studies seeking to understand the implications of BD notification and legislation for women have been conducted [17], but there is currently no published evidence regarding the beliefs of women outside the US. Thus, there is an important gap in understanding how women, who are not currently being notified about BD through population-based breast screening, think or feel about the topic of BD. This understanding has implications for countries – such as Australia and some European countries – where there are advocacy groups and petitions promoting national BD notification, and where policy makers are currently considering implementing BD notification. This study therefore aimed to explore Australian women's current knowledge, understanding and experience of BD reporting; perspectives and attitudes about BD; and information needs to inform effective evidence-based communication strategies. Our focus is potential notification within screening programs like that in Australia, which provides publicly-funded population-based breast screening for women aged 40-74, with biennial invitations from age 50-74.

2. Methods

2.1 Study design

We conducted a qualitative study using online focus groups to collect data. Unlike a typical focus group, we first provided structured information about BD, with opportunities for questions, and then discussed participants' understandings, thoughts and feelings about the implications.

The study was approved by the University of Sydney Human Research Ethics Committee (2020/160). Participants read the participant information statement which was sent via email and gave consent which was signed electronically using a secure platform (DocuSign) prior to participating in the focus group.

2.2 Participant recruitment

We recruited a community sample of women in New South Wales and Queensland, Australia (two states in the northeast of Australia) aged 40-74 years without a personal diagnosis of breast cancer, as our focus was on population-based screening of asymptomatic women. An independent research recruitment organisation (Taverner research) used random digit dialling and social media advertising (e.g., Facebook) to approach potential participants. Potential participants completed a pre-recruitment eligibility check online before being contacted by telephone by trained Taverner interviewers to confirm key details. Participants who qualified through both screenings then underwent internet speed and technical testing.

To gain a diverse range of perspectives, we used quota sampling to ensure inclusion of participants across various screening-eligible age groups (40-49, 50-59, 60-69 and 70-74). Each participant was given $100 gift voucher as compensation for any costs of attendance.

We aimed to conduct two focus group sessions with each age group in each state, except for 70-74, only one focus group session in each state. We recruited approximately six participants per group in order to optimise group dynamics (i.e., ensure everyone is able to participate and there are enough people to keep the flow of the conversation going). This number of participants enabled us to reach thematic data saturation, as indicated by data redundancy (i.e. when participants no longer raised original themes) [18, 19].

2.3 Focus group presentation and discussion

We conducted focus groups online (via Zoom) in September 2020. Each session comprised: introduction and consent, demographic questionnaire, warm-up discussion, a detailed presentation with periods of discussion (approximately half of the session being presentation time and half discussion time), and a final questionnaire. Sessions lasted approximately two hours and were facilitated by one female moderator (BN). Another female moderator (HD) was present during the online sessions to take notes and attend to participant technical and other queries. Both moderators had experience and/or were trained in conducting qualitative focus groups and interviews.

BN gave the audio-visual presentation (see online supplementary Appendix A for slides), which had been developed and reviewed by a multidisciplinary team including public health researchers, health psychologists, breast physicians (clinicians with expertise in breast cancer/screening), and two consumer representatives. The presentation included a combination of pictures, plain language, and infographics appropriate for a range of numeracy levels [20]. We presented a range of published evidence describing BD measurement and implications, and explained the potential for false-positives, overdiagnosis and overtreatment [21] associated with supplemental screening in dense breasts using simple pictograms and annotated graphs. We conducted a face-to-face pilot focus group with three women aged 40-49, and an online (Zoom) pilot focus group with six women aged 50-59.

Box 1 summarises the presentation content and gives an example of the types of questions asked to guide discussions. At the beginning of each group, we made it clear that some information presented may be unfamiliar and/or cause disagreements amongst the group. We highlighted that we wanted to hear their honest thoughts and opinions and emphasised our neutrality throughout by repeating statements of this kind, and by not interpreting views expressed by participants as positive or negative. A proposed strategy for BD notification was able to be discussed for and against in detail, and these contrasting opinions led participants to articulate their own points of view in greater depth [22]. Throughout the presentation, we strongly encouraged participants to request clarification as often as required.

Box 1. Breast Density (BD) focus group presentation topics and key discussion questions

PowerPoint presentation content	**Corresponding questions for discussion**
1. Breast cancer screening What breast screening is and how it is done	1a. Have you had a mammogram before?
2. **Breast Density (BD):** What it is (independent risk factor for breast cancer, different categories, implications for breast screening, how it is measured, uncertainty)	2a. Have you heard or read about the term 'breast density' before? 2b. Do you feel you understand this information? 2c. What are your initial thoughts about this information? 2d. How does this information make you feel?

3. **Current evidence on the benefits/harms of breast density information/notification and what women should do about their breast density:** • Recommendations for women with high breast density • Benefits and harms of supplemental screening (including false positives, overdiagnosis and overtreatment) • Uncertain evidence about best approach	4a. What are your thoughts on this information? 4b. How does this make you feel? 4c. Do you feel you understand what it's saying? If not, what is unclear or confusing about it? 4d. Do you think the benefits of BD notification currently outweigh the harms, or visa-versa? Why? 4e. Is there anything that worries you about the current evidence or suggestions about what women should do?
4. **Vignettes about breast density:** Presentation of two hypothetical scenarios about women receiving BD information/notification and possible outcomes • Maria, 62-year-old, no symptoms or family history, found to have heterogeneously dense breasts during routine screening mammogram • Susan, 44-year-old, no symptoms, elderly mother recently diagnosed with breast cancer, found to have heterogeneously dense breasts during mammogram	5a. What are your thoughts and feelings about Maria's/Susan's scenarios? 5b. What do you think Maria/Susan should do? 5b. If you had just been told you have high BD, how do you think you would feel? How would you react? 5c. What would be your approach to deciding about what to do with this information? Who would you talk to? 5d. What do you think you would want to do in terms of further screening or lifestyle changes if you were told you had high BD?
5. **Current landscape of breast density notification/legislation:** • International landscape • National landscape in Australia	3a. Have you heard about BD notification laws in the US? 3b. What are your thoughts on what is happening in the US? 3c. What are your thoughts on the current landscape of BD notification in Australia?
6. **Communication:** • Information needs • Potential future communication strategies	6a. Do you have any thoughts and suggestions about further information to support BD notification? 6b. Do you have any thoughts or suggestions about communication strategies?

2.4 Data collection and analysis

Focus group discussions were audio-recorded on a recording device external to Zoom, transcribed verbatim and analysed to identify recurring themes and data patterns using thematic analysis method [23]. The data was managed using NVivo 11 software [24]. Two researchers independently reviewed all transcripts. The analysis initially took an inductive approach to ensure that the findings were grounded in participant responses and the data was analysed at semantic level. Using constant comparison [18, 25], the two researchers continually looked for similarities and differences in the data and in coding within and

across transcripts. Final coding was performed by the two researchers, with HD coding all of the data and BN double-coding half. The final coding was then examined to identify overarching themes and concepts.

We also administered brief online questionnaires at the start and end of each focus group, which included questions about demographics, cancer worry [26], breast screening history, wellbeing (WHO-5) [27], understanding and opinions regarding BD and its notification, and potential emotional response and screening intentions if notified of BD. The majority of these data have been incorporated into Table 1, with the remaining free-text questions on understanding and opinions incorporated into the thematic analysis presented in text below.

3. Results

Seventy-eight women of various ages from diverse socioeconomic backgrounds took part in 14 focus groups (Table 1). 24 participants (30.8%) were born overseas, which was similar to the percentage of overseas-born population nationwide (30%)[28]. 37 participants (47%) had a university degree or above, which is slightly higher than among the general Australian population (36%) [29]. The sample reported general wellbeing and low levels of cancer worry. Most women (n=37, 85%) had experience in breast cancer screening. Among them, screening through the publicly-funded screening program was most common (n=53, 68%). Few mentioned proactively initiating screening or receiving mammography in their 40s, with reporting not yet having breast screening as they had not reached the eligibility age (50-74) to receive an invitation for screening.

Table 1. Participant characteristics and responses

Characteristic or response	No. of participants (Percentage) n=78 (%)
Age	
40-49	23 (29.5)
50-59	23 (29.5)
60-69	21 (27)
70-75	11 (14)
Marital status	

Married/living with a partner	41(52.6)
Divorced/separated/widowed	18 (23)
Single	19 (24.4)
Aboriginal or Torres Strait Islander	2 (2.6)
Birth Place	
Australia	54 (69.2)
New Zealand, UK, USA	16 (20.5)
Other (India, Indonesia, Malaysia, Netherlands, Pakistan, South Africa, Bosnia & Herzegovina, Hong Kong)	8 (10.3)
Years since moving to Australia (if born overseas)	
<10	3 (3.8)
10-29	2 (2.6)
>30	17 (21.8)
State	
New South Wales	41 (52.6)
Queensland	37 (47.4)
Rurality*	
Urban	47 (60.2)
Regional	30 (38.5)
Remote	1 (1.3)
Highest educational qualification	
University degree	37 (47.4)
Diploma or certificate	27 (34.6)
HSC or leaving certificate (or equivalent)	8 (10.3)
School certificate or intermediate certificate (or equivalent)	6 (7.7)
Employment status§	
Full time	5 (6.4)
Part time	36 (46.2)
Retired	16 (20.5)
Studying or other	20 (25.6)
General self-rated health	
Excellent, very good or good	68 (87.2)
Fair or poor	10 (12.8)
Family history of breast cancer	
Yes	15 (19.2)
No	63 (80.8)
Been previously told or notified of BD	
Yes	9 (11.5)
No	69 (88.5)
Worry about developing breast cancer	
Not worried at all	21 (26.9)
A bit worried	50 (64.1)
Quite or very worried	7 (9.0)
Number of breast screening rounds attended	
None	12 (15.4)
One	16 (20.5)
Two	6 (7.7)
Three	6 (7.7)
Four or more	38 (48.7)

Time since last screening (if screened)	
<3 years	54 (69.2)
>3 years	12 (15.4)
Screening service used (if screened)	
BreastScreen (publicly funded screening program)	53 (67.9)
Private screening service	13 (16.7)
WHO-5 Well-Being Index score† (Mean (SD))	66.6 (17)
How anxious do you think you would be if you were told you had dense breasts?‡ §	
Not at all anxious	23 (29.5)
A little bit anxious	39 (50.0)
Moderately anxious	10 (12.8)
Very anxious	4 (5.1)
Do you think you would be interested in supplemental (additional) imaging (e.g. ultrasound, MRI) if you had dense breasts?‡	
Yes	51 (65.4)
No	8 (10.2)
Unsure	19 (24.4)
Do you think women with dense breasts should be informed of their breast density?‡	
Yes	74 (94.9)
No	1 (1.3)
Unsure	3 (3.8)
Do you think all women should be informed of their breast density?‡	
Yes	71 (91.0)
No	5 (6.4)
Unsure	2 (2.6)

*Calculated using ARIA lookup tool.[30]

†A score of 0 represents the worst possible well-being and 100 represents the best possible well-being.[27]

‡Asked at the end of the focus group in Questionnaire 2.

§ Includes missing data

The thematic analysis identified six main themes, some of which with sub-themes. Participant quotations have been selected and presented in Table 2 to illustrate both common and diverse responses.

Table 2. Main themes and sub-themes with additional supporting quotes

Themes/ sub-themes	Support quotes
Prior knowledge, and responses to information about what BD is	

	I've heard the term…I think if you're sometimes more well-endowed I think breast density can be an issue as to how well they can read the mammogram. QLD_60-69
	When I was told that I had, many years ago, that my, I had a breast, a density, it was never explained what it was. And I just thought, oh, it's because I'm maybe overweight, and I was at the time overweight. And I thought, oh well, if I lose some weight that density will go. NSW_70-74
	I'm surprised …, you come out of the mammograms and really you, you know nothing. All you hear, all you get is a letter saying you've got no, no, no breast cancer issues. After all these mammograms I'd really like to know. QLD_60-69
	I just think that when I heard it, it just sounded like there's a higher degree of, um, uncertainty and that even having the tests are not going to guarantee that those that actually have the denser breast are going to, um, that any potential cancers that they might have or the breast cancer will, is unlikely to be picked up. QLD_50-59
Reactions to information about supplemental screening, false positives, overdiagnosis and overtreatment information in relation to BD	
	As much as I would like to say that I'd sit on the fence, in reality I'm kind of like, well ok, what's next? Like… sort of thing, and just live with, you know… I'd much prefer to be alive and have known that I've done everything to be in that point, whether it was a false positive or not, than be dead. NSW_40-49
	I'd rather be overdiagnosed and cop the consequences, whatever they, whatever the negatives are. NSW_70-74
	In the beginning when you first started talking I thought, well obviously if you are in that breast density category then you should definitely go ahead and, and follow up on either the MRI or the ultrasound. However,… as you kept talking I realised about the overdiagnosis, I think that it is… probably very worrying to, to go through all that and have all the treatment and if it's something that people don't have to have then probably why put them through it? NSW_60-69
	By the time we get to our age, in the 70's, you often have a variety of other things, conditions and if you've got good mental health and you get a diagnosis of you've got a lump and it could be cancerous, in some way you're better off, you're better able to handle it than if you were a younger category. QLD_70-74
Views on what to do if told of having dense breasts	
Views on Maria (62-year-old, no symptoms or family history, found to have heterogeneously dense breasts during routine screening mammogram)	*I'd go for the yearly certainly if it was a free option. But the rest it would depend on totally whether I could afford it or not. QLD_60-69* *The money thing has come into it straight away and she might not be in a position of (anything?) and, um… it's quite sad when you read it and you think that that's happening to people and that the rich can go tomorrow and get all those extra help but Maria might not be able to at all. So I think at her age I'd probably leave it and… just do the one-year mammograms or five years and then just think. QLD_70-74*

	Nobody in my family's had it and no one has died of it. Might be very unusual, but I just don't. Density is the only risk factor. I wouldn't do it." QLD_50-59
Views on Susan (44-year-old, no symptoms, elderly mother recently diagnosed with breast cancer, found to have heterogeneously dense breasts during mammogram)	*That's a very young age. You could still have quite young children… I think as anxious as it could make you, you know, false positives and all of that, I think you really do need to know that you've done everything possible, at that point in time without going overboard into MRIs if your ultrasound is fine." QLD_70-74* *If she's healthy and she's feeling fine and she's taken the tests necessary, maybe it's just something in the back of her mind that says, ok, I'm aware I'm in this category of, of higher dense, um, higher breast density, so it's just something to keep and eye out for, and yeah, maybe just make sure that she has her regular testing but doesn't overthink it. NSW_40-49*
Views on their own BD	
Being alert not alarmed	*If I did have that category C density that I would be, it's kind of alert, not alarmed. I'd rather know my density and that I need to be really vigilant. NSW_40-49* *I think if I knew nothing about breast density I would get my GP to explain it to me and having, er, been informed that, as you say, you can't see or feel it or anything, you can only, only see it on a mammogram, um, I would say, ok, I've got dense breasts. But, and that puts me into a higher category. However, at this stage I've done everything I can do, so I'll just be mindful of check, doing my regular checks and having my regular mammograms. QLD_70-74*
Have supplemental screening for peace of mind	*I'd be more open to, without any symptoms, be more open to have the other tests… or perhaps even, introduce the possibility with my doctor, you know, to look at ultrasounds or other things. Because I mean the thing that's really sticking in my head is the idea that you don't see the masses with the breast density. You may not see them. NSW_50-59*
Change nothing	*I'm a little bit fatalistic. I would just take it in my stride and say, well that's what my body is. Um, I've had skin cancers since I was in my early 20's, I've had a melanoma and stuff like that. So for me… my head really is, … I try very hard to keep my head in a place where this is my body, this is my life, this is my lot, and if I have dense breasts then it gives me a little bit of a higher risk factor for breast cancer, well that's just then part of the whole deal anyway. QLD_60-69*
Views on BD notification	
	I do think, again, education is so important because obviously having an increased risk… doesn't necessarily mean that you're going to have an aggressive breast cancer. You know, I think there needs to be a balanced approach to the education. So empower rather than create unnecessary undue concern. QLD_40-49 *I would want to know. Um, it gives you some knowledge to be prepared and take responsibility for your own health and decide what you want to do, um, about… your own breast health. QLD_50-59*
Views on current landscape of BD notification locally and internationally	*I think that's evidence of a two-tier health system, which shouldn't exist. And I think that people would be very stressed about the fact they couldn't access something that they thought might help them and give them a better quality of life going forward. So I see that as being inherently unfair that people are put in that situation. NSW_60-69*

	I know as we discussed earlier it's subjective according to the radiologist but, you know, does it, does it take much more to put it in the letter that you get anyway, that whether you do or not? I, I think that's disappointing. QLD_60-69
Suggestions on BD communication	
	"I'd want some information and you'd want people that are giving information to understand the information. so not just saying the words, 'oh, you've got dense breasts'… it would have to come with an explanation." QLD_60-69 *I think that my GP being notified would be sufficient for me, because the information would be passed on to me and we would discuss it. So therefore, that stops a big, I guess, nationwide alarmist program with maybe some women going, Oh my God, Oh my God, what does this mean? If your GP's notified then your GP explains it to you and you'd feel a lot clearer in your head. NSW_70-74*

3.1 Prior knowledge, and responses to information about what BD is

The majority of women either had not heard of BD before or had heard the term but did not know what it meant. Some women speculated that women with large breasts may have dense breasts, or that BD may be like bone density. The few women who had some knowledge of BD generally knew that BD makes it harder to detect cancer on mammography: they either had been told of their BD after screening, usually at a private screening facility, or had or drew on some healthcare-related employment experience.

When presented with information on BD, many women said they found the information interesting and intriguing, especially the link between BD and breast cancer risk. This led to some women wanting to know their own BD level and wondering why they had not been told about BD before. Some also mentioned '*having some knowledge to ask questions*' and '*what to look out for and listen for'* when having screening.

Women with some prior knowledge of BD often reported that the information given during the group differed from what they previously understood/interpreted. Women who had been told of their BD level often expressed frustration that they were not given information in such detail, such that they had misunderstood what BD meant.

The information on BD seemed to create a sense of scepticism among some women towards the sensitivity of mammography in finding cancer, and concern that mammograms can be falsely reassuring or have a higher level of uncertainty in women with dense breasts.

When uncertainties in BD measurement were explained, there was general acceptance and understanding of potential variations in BD classification by radiologists, some citing it as '*human factors'*. Some women further queried whether modern technology or a standardised system or '*second opinion*' could be helpful in reducing the variability.

3.2 Reactions to information about supplemental screening, false-positives, overdiagnosis and overtreatment information in relation to BD

When presented with information on false-positives, overdiagnosis and overtreatment associated with supplemental screening, women's reactions indicated that the context of BD was irrelevant. Most women expressed they would rather '*go all in*' and focus on true-positives rather than false-positives or would rather be overdiagnosed than underdiagnosed with breast cancer.

A smaller group of women were '*fence sitters*' on the issue of false-positives, overdiagnosis and overtreatment linked to supplemental testing. This minority were more likely to consider other risk factors or symptoms of cancer, express a desire for more information before making screening/testing decisions, recognise the uncertainties, or deliberate on potential benefits and psychological or quality-of-life implications of overdiagnosis and overtreatment.

It was common for both groups of women to cite their family or friends' experiences with cancer diagnosis and treatment while discussing their own views. Older women, especially those 70-74, expressed a more relaxed attitude towards potential cancer diagnosis. Age was also a consideration for some women in their views of additional testing and treatment.

3.3 Views on what to do if told of having dense breasts

3.3.1 Views on Maria (62-year-old, no symptoms or family history, found to have heterogeneously dense breasts during routine screening mammogram)

The most common reaction to Maria's situation was that the decision and action to be taken would depend on Maria's financial ability to undergo supplemental screening, with some

labelling it as a '*financial decision*'. This view was shared across all age groups. Some expressed their frustration that people having the option to undergo further testing but not having the financial means to do so '*causes a divide between the haves and the have nots*'. Due to the out-of-pocket cost being less expensive and '*less-invasive*', ultrasound was more favourable than MRI when it came to the choice of further testing. Some favoured the free option of going for yearly mammograms instead of biennial when the other options were considered unaffordable. Others expressed willingness to pay for further testing such as MRI regardless of cost for '*peace of mind'* or '*mental satisfaction'*. They emphasized that they would be better off both financially and mentally '*having the question settled*' and '*stopping that anxiety by getting it looked at straight away'* by having breasts investigated more thoroughly than '*suddenly finding out you have terminal cancer*' and '*going down that path*'.

For a few others, they favoured going for a yearly mammogram and were more likely to take on board the consideration of potential harms of supplemental screening and the non-modifiable nature of BD. Other factors such as family history, personal breast cancer history, age, symptoms and comorbidity were also discussed.

Women expressed their desire to be guided by their doctors if they were in Maria's situation, especially if the doctor explains the issue and the options well or if they already had an existing trusting relationship with their GP.

3.3.2 Views on Susan (44-year-old, no symptoms, elderly mother recently diagnosed with breast cancer, found to have heterogeneously dense breasts during mammogram)

One noticeable difference in women's reaction to Susan's situation as opposed to Maria's is that the financial cost of supplemental testing was not as much of a concern. There was an overwhelming inclination towards getting supplemental screening, citing Susan's relatively young age and the family history. Family history seemed to be more of a concern to some women than the BD itself. Some women also expressed that given Susan's age, if she is to have cancer it is likely to be aggressive one and therefore, she should investigate early on.

For a few women, Susan's mother being elderly when diagnosed with breast cancer (rather than being young) and BD being the only other risk factor known for Susan, led to a preference for continuing regular screening and just being vigilant.

3.4 Views on their own BD

When asked about what they would do if they were told of having dense breasts, there were three types of views among women: be alert not alarmed, have supplemental screening for peace of mind, and change nothing. '*Being alert not alarmed'* was the most common view.

3.4.1 Being alert not alarmed

Many women expressed that knowing they have higher BD would make them more alert and vigilant towards their breast health and would prompt them to have their biennial screening. There was also an emphasis on seeking advice from healthcare professionals who are '*trustworthy*', asking questions and gathering further information about false positives, overdiagnosis and other risk factors in assessing the steps to be taken. Women expressed that '*to be forewarned is to be forearmed*', *'education is everything'* and healthcare professionals could have a role in reducing any anxiety by providing information on what to do and when to be concerned about BD.

3.4.2 Have supplemental screening for peace of mind

For the few women who expressed a preference for going for supplemental testing, their reasoning was more around being concerned about mammograms not being very sensitive in finding cancers in denser breasts and for '*peace of mind*'. Similar to the discussion about Maria's scenario, the choice of modality was most often ultrasound rather than MRI.

3.4.3 Change nothing

A few women suggested they would not act on the BD information in their current situation. Those women commented it is mainly their outlook on life, such as being '*fatalistic*' or not being a '*worrywart*', and '*would just add it to sort of… inventory of own health, something to know about'.*

3.5 Views on BD notification

The majority of women across all age groups were supportive of the notion of BD notification, saying that they would prefer to be educated and informed about it and given the choice to make decisions about their own health. We observed a very strong view that women should have the *'right to know'* about their own body and healthcare and that BD information could be empowering for women in deciding how to manage their breast health. Some also expressed that they would prefer open communication about BD and the uncertainties associated with it rather than being told '*you will be fine'* after a mammogram without being advised of high BD. A few also stressed that being told of their BD would not necessarily make them panic or become anxious and emphasised the importance of appropriate communication based on knowledge but not fear.

Some women voiced their concerns about widespread notification of BD, commenting that it might cause undue anxiety. These women mentioned the data that it was common for women, especially young women, to have dense breasts and worried that telling them about BD and its implications might '*create unnecessary chaos in the mind*'. Again, there was also a concern about the unaffordability of supplemental screening.

3.5.1 Views on current landscape of BD notification locally and internationally

In response to explanations about the current landscape of BD notification in Australia and in other countries including US, Canada and UK, the majority of women expressed their disappointment and surprise at the decision of BreastScreen Australia to not notify about BD. Although the presentation highlighted that the decision was based on the latest evidence, some women understood it as BreastScreen withholding this information or '*keeping this in their back pocket'.* Even when explained that BreastScreen is not measuring

BD in the first place, women felt that BreastScreen is '*only doing half the job'*. There was a sentiment that if BD is a risk factor for breast cancer and impacts the sensitivity of mammography, women should be told as part of the screening process.

Some women also expressed their disappointment at learning that private screening services may provide BD information in their reports because this creates inequity within the healthcare system in Australia. Some also queried whether BreastScreen's decision was about saving money. Participants said that women '*should have access to that [BD information] no matter who does the test [mammogram]'*.

A minority of women expressed their understanding of BreastScreen's decision, attributing this to a desire to prevent unnecessary confusion among women, or a reflection of the need for more research, or concern that '*giving people snippets of information that they're not counselled about can be really dangerous*'. Some, especially women who were born overseas, also expressed their satisfaction and trust with the healthcare system and preventative and education programs in Australia, implying that they trust the government's decision.

3.6 Suggestions on BD communication

When asked for thoughts or suggestions about future communication about BD, many women suggested including BD information in mammography reports which should come directly to themselves as well their GPs. They stressed that the letter should not just tell women whether or not they have dense breasts but also include explanations as to its implications.

Some also suggested women could opt-in to receive BD information before going through breast screening, while some women emphasized that it is important for BD information to be communicated by GPs or other healthcare providers with tailored information so as not to cause unnecessary anxiety and fear in women.

Across all age groups, women suggested including BD information in general breast cancer related educational materials or programs or to have public awareness or media campaigns using channels such as social media, TV, websites, or communication materials in GP clinics to increase awareness among women on a wider scale.

4. Discussion and Conclusion

4.1 Discussion

This focus group study in a sample of women in Australia, where population-based BD notification does not currently exist, demonstrated that there is very limited awareness and knowledge regarding BD in the community. Of those women who had heard of BD or had previous exposure to BD information, there was still very limited understanding, and frequent misinterpretations. Similar qualitative findings have been reported from US studies where BD notification was mandated: in these studies, despite moderate awareness of BD, women still had inadequate knowledge[31-34]. Once presented with further information about BD, Australian women in this study expressed a high level of interest in developing a deeper understanding. They also expressed the importance of women of breast screening age having access to personal BD information.

Overall, women expressed a preference for more frequent mammograms and/or supplemental screening should they be told they had dense breasts. This is despite being presented with information about potential harms of these modalities including false-positives, overdiagnosis and overtreatment of breast cancer [15, 16], as well as the uncertainty in evidence around long-term outcomes of breast cancer diagnosed through supplemental screening [12-14]. For most women, BD's association with increased breast cancer risk appeared to outweigh any downsides of additional testing. This is not surprising given public messaging that 'cancer screening saves lives' resulting in highly positive attitudes and public enthusiasm towards cancer screening [35, 36]. Studies also demonstrate that women do not fully understand, or tend to overestimate, the benefit of screening [37] and the fear of cancer or the 'cancer effect' increases interest in screening, despite indications that a detected cancer may be indolent in nature [38].

In the focus groups, women often suggested they had a 'right to know' any information about their bodies and BD should be measured and reported as part of the screening programs. They generally felt that this information would make them alert and not alarmed and queried why they hadn't been told before. Our finding is also consistent with a common theme in similar research: there is a tendency for participants to see the provision of health information as intrinsically valuable, whether or not there is any evidence, or any apparent mechanism, for that information to improve their health outcomes. While this premise has been the driving force behind the BD notification movement in the US [7], the question around the usefulness of BD notification remains in relation to what women with dense breasts can do to manage their risk of breast cancer [16, 39]. While BD notification may be justified for some women given their overall breast cancer risk, at a population level it is unknown what benefit this information would provide to women and what potential harms it may cause. With such uncertainty at this time, screening services[10] and policy makers face a challenge: balancing conflicting values of minimising harm, stewarding resources, and respecting women's expressed desire for information.

This study has strengths and limitations. It is the first study outside of the US to look in-depth at the views of women who have little previous awareness or knowledge of BD (in a population where no formal BD notification system exists). It makes a timely contribution to the debate about the possible consequences and value of providing BD information to women through population-based screening programs [11, 17]. Women were of screening age, recruited by independent social research company, stratified by age and included a mix of those with/without a family history of breast cancer. The focus group presentation was developed based on evidence-based data and by a multidisciplinary team and consumer representatives and was both informally and formally pilot tested. Women were encouraged to ask questions throughout which provided insights into points of confusion. Where some of the evidence was variable or inconclusive this was made clear to participants. However, the amount and complexity of some of the information presented during the 2-hour focus group may have been challenging for women to comprehensively process as they were hearing it for the first time. Further, the majority of women were not told or aware of their breast density at the time of the research, therefore their reactions to information presented may not necessarily reflect how they would react in reality if notified

of their BD level. We did not measure participant health literacy and therefore, were not elaborate on how women's health literacy level might have impacted their responses. Women who voluntarily took part in this study may be more interested in breast health and future research comprising of a national representative sample of women is warranted. Furthermore, the online nature of the study (via Zoom rather than face-to-face) may have made some of the information more difficult to convey. However, this enabled women to participate from urban, regional and remote locations across two states in Australia.

4.2 Conclusion

The topic of BD and the potential consideration of countries outside of the US to implement population-based BD notification are of interest to women of breast screening age. As this study shows, women feel they have the right to know this (and any relevant information about their bodies), and most expressed strong preferences for supplemental screening should they be told they have dense breasts.

4.3 Practice Implications

Policy makers and screening services now need to consider how to weigh up these views and preferences with current evidence surrounding BD. Healthcare providers may need training, guidance and education on BD, its implications and how to best communicate current evidence and uncertainties. This may be especially so for general practitioners, who are likely to become the first point of contact if women are to be informed of their BD through publicly funded population screening programs. Women may need community-level education with health-literacy sensitive and evidence-based information to enhance awareness and understanding and alleviate misinformation and concerns. The health system must also consider the potential flow-on costs of density notification, such as an increase in the use of supplemental screening and how this would be organised and funded. Further research however is needed to better understand both the psychological and health services impact of more widespread BD notification, and to determine how best to communicate the potential benefits and harms of density information to women.

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