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Australian Indigenous and CALD women overcoming barriers to health screens: better together!

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Introduction

It is well-documented that significant disparities exist in the health status and behaviours of women in Australia, influenced by a range of factors including income, ethnicity or Aboriginality, sexual orientation, disability, education, geographic setting, and age.¹⁻⁶ This research focuses on two of these factors – Aboriginality and ethnicity. Research consistently reports that Aboriginal and Torres Strait Islander women (hereafter respectfully referred to as Indigenous women) and Culturally and Linguistically Diverse women (hereafter respectfully referred to as CALD women) frequently do not access breast and/or cervical screening services because of practical, psychological and cultural barriers.^{1,7,8} Reviewed literature identifies barriers which prevent or hinder Indigenous and CALD women from participating in health screens, both in Australia and overseas. Despite the cultural diversity of the women studied, many barriers appear to be similar.

Aims/objectives

The aim of this study was to identify barriers and enablers which impact on Indigenous and CALD women participating in breast and/or cervical screens in rural and regional Australia. The study was part of a larger project undertaken by BreastScreen NSW Greater Southern (BreastScreen NSW) and funded by the Cancer Institute NSW, to establish pop-up, amalgamated breast and cervical screening clinics to be trialled at BreastScreen NSW fixed sites in Wagga Wagga, Albury and Queanbeyan with an aim to increase screening participation rates among Indigenous and CALD women. The University of Notre Dame Australia (Notre Dame) worked with BreastScreen NSW to support the research process and evaluate the implementation of the model. While this research was being undertaken, changes were made to guidelines about the frequency with which cervical screens should be undertaken, from two yearly to five yearly. Although this change impacts on the sustainability of the trialled amalgamated model, it is anticipated that the findings from this study and, in particular, the identification of barriers and enablers, will contribute to an increase in screening participation rates among these women. This paper reports on the barriers – those impacting the women and, to a lesser degree, those impacting the research.

Literature review

Disparities in health outcomes between Indigenous patients when compared to non-Indigenous patients are well-documented. The incidence of cervical cancer in Indigenous women, for example,

is more than twice that of non-Indigenous women, and mortality is four times the non-Indigenous rate.^{9,10} Indigenous people are more likely than non-Indigenous people to die from cancer, with one of the reasons being that their cancer may be more advanced by the time it is found, partly because Indigenous people may visit their doctor later and/or may not participate in screening programs.¹¹ Statistics such as these have led to a need for “a concerted health-service response ... to address geographic, socio-economic and cultural barriers to cancer prevention, screening and treatment in the Indigenous population”.¹²

Existing literature regarding breast and cervical cancer screening practices of CALD women in Australia, however, is more limited. As at 2017, only 2.2% of published health research in Australia had focused on multicultural health despite the increase of CALD populations.¹³ Additionally, sourcing data on screening participation rates, particularly for ‘at risk’ groups including CALD and Indigenous women, continues to be a challenge. Despite the Australian National Cervical Screening Program (NCSP) being introduced more than 25 years ago, a paucity of Indigenous-identified data in Pap Smear Registers remains because pathology report forms do not include Indigenous status.¹⁴ Nor do they include CALD status. While there has been considerable feedback regarding the setting up of the new National Cervical Screening Register which replaced the Pap test in Australia in December 2017, there is no guarantee that these data will be collected in future. Nevertheless, existing literature consistently reports that CALD and Indigenous women frequently do not access breast and/or cervical screening services because of practical, psychological and cultural barriers.^{1,7,8}

Research has identified several barriers to CALD women accessing healthcare screening, including a lack of knowledge and unfamiliarity and uncertainty with health systems; feeling incapable; language barriers; access; experiences of being a refugee and asylum seeker; a lack of primary healthcare services; a lack of health literacy; mismatch of expectations; and age-related factors.¹⁵ In addition to well-recognised issues such as language and culture, issues particular to rural and regional areas, including employment and community support, have also been highlighted.¹⁶ Other researchers who have focused on Indigenous women, identify similar barriers including: low priority of cancer screening and follow up; lack of awareness of existing services; cost; geographical isolation and transport; GP and staff shortages; high staff turnover; cultural barriers such as shame and fear; and discomfort with or distrust of mainstream services.^{6,7} Specific barriers such as a lack of “awareness of indigenous cancer data” and “poor identification of Aboriginality” were also identified.⁶

Methods

The methodology was developed by Notre Dame in collaboration with BreastScreen NSW and included:

- literature review to inform research
- information sessions for Indigenous and CALD women to raise awareness about breast and cervical screens
- yarning and discussion (focus) groups to identify barriers and enablers which impact on participation
- post-screen interviews to gauge success of pop-up, amalgamated breast and cervical screening model
- key informant interviews as a means of triangulation.

BreastScreen NSW and Notre Dame worked in collaboration with local Aboriginal Community Controlled Health Services (ACCHS), Indigenous groups and multicultural organisations to hold initial information sessions for separate groups of Indigenous and CALD women. The information, including PowerPoint slides, videos and visual displays about breast and cervical screening, was developed in consultation with local CALD and Indigenous members to ensure it was culturally appropriate, and presented by BreastScreen NSW staff and a Women's Health Nurse. Each Indigenous information session was attended by at least one Aboriginal Health Worker. Each CALD session was attended by an interpreter who assisted with communication and understanding of the CALD participants. Time was allowed for questions, answers and discussion. The project was explained and women were invited to participate in yarning or discussion (focus) groups, followed by free screens if eligible, and one-on-one, post-screen interviews. Group bookings were arranged at fixed BreastScreen NSW sites where lunch was offered and transport provided to and from the clinics which were closed to the public. This ensured privacy for the separate groups of women. Interviews were also conducted with two key informants, including a general practitioner and an Aboriginal Health Worker. Focus groups, post-screen interviews and key informant interviews were recorded with the participants' permission, transcribed and analysed for common themes using NVivo 12 Plus (QST International Pty Ltd, 2018). Ethics approval for the project was obtained from The University of Notre Dame Human Research Ethics Committee, The Greater Western Human Research Ethics Committee and The Aboriginal Health and Medical Research Council.

Results

Information sessions

One hundred and two women attended 11 information sessions between November 2017 and October 2018 (Table 1). These included 64 CALD women, 28 Indigenous women and 10 non-Indigenous women, nine of whom were employed by local Aboriginal health services and one of whom was a Health and Rehabilitation Science university student who attended as an observer. Five information sessions were held in venues which were well-known to participants, including a TAFE NSW campus where participants attended English language classes, local multicultural council rooms, an Indigenous Neighbourhood Centre and local health service centres. Six information sessions were held at BreastScreen NSW clinics.

Focus groups

Fifty-seven women participated in 10 focus groups (FG) which were held between February and November 2018 (Table 2). These included 29 CALD women, 18 Indigenous women and 10 non-indigenous women who attended two of the focus groups – seven Aboriginal health services employees and one university student attended FG7; and two Aboriginal health services employees attended FG8. Six Indigenous women who participated in FG5 and FG6 were recruited separately by an Aboriginal Health Worker when the women presented at a local health clinic. Four focus groups were held at multicultural council rooms and a local health service centre. Six focus groups were held at BreastScreen NSW clinics.

Barriers

Analysis of the data revealed that many barriers facing these women are similar, regardless of cultural background. As a means of demonstrating the similarities of the barriers without potential bias, cultural backgrounds have not been identified. Tables 1 and 2 show participant ethnicity. The main barriers are:

- lack of awareness and information about breast and cervical screening

- lack of health literacy
- communication problems
- embarrassment and shame
- competing health/life priorities
- difficulty navigating the health system
- fear of screening procedure and/or results.

Lack of awareness and information

Lack of awareness about BreastScreen NSW was a common barrier, especially for CALD women. While cervical screening is a regular procedure for new arrivals to Australia, breast screens are not. Unless these women were alerted by their doctors or some other means, they were generally unaware of the breast screening service – “They don’t know about it. If you don’t know about it, you can’t do it”. Most women said they would have a breast screen if their doctor reminded them but, conversely, if their doctor did not tell them, they would not – “... if the doctor doesn’t tell them to have a screen, they don’t” and “Our doctors know best”.

There was also misinformation about BreastScreen NSW regarding the cost, with some women believing they had to pay – “We didn’t know [it was free]. The doctor said we had to pay” and “... sometimes we are working ... I can go and I can book myself, but it is very expensive”. There was also misinformation about the procedure – “... there is another lady who is from my country ... she told me it’s really painful and that made me afraid” and “It didn’t hurt as much as I thought ... I have been told that it’s pretty painful”. Misinformation of this sort was common among CALD and Indigenous women.

Lack of health literacy

Besides a lack of awareness and understanding about breast and cervical screening, there was also a lack of health literacy about women’s health procedures in general, among both Indigenous and CALD women – “If we don’t feel sick, there is no need to go [and screen]”. CALD women were sometimes unsure of what procedures they had had performed, either overseas or in Australia, or the purpose of those procedures, as indicated in the following comment by a newly arrived refugee via an interpreter – “... she not sure but she thinks they did it [when she came to Australia]”.

Communication problems

This confusion was exacerbated by low English language levels and communication barriers, which were also problematic for Indigenous women. As one Aboriginal Health Worker commented, “That’s why I go to a lot of appointments with clients, e.g. oncologists, because specialists use these big words. I actually said to one of them once, ‘Can you slow up and dumb it down please’ because he was even going over *my* head”. Other simple communication break-downs, such as out-of-date contact details – “And see, I’d moved, you know. We’ve moved twice”, also meant that some women did not receive reminders and, consequently, did not attend regular breast screens.

Table 1 Information Sessions and ethnicities of information session participants

Information session	Date	Group	Number of participants			Ethnicity
			CALD	Indigenous	Non-Indigenous	
IS1	29/11/17	CALD	28	-	-	Afghani, Yazidi, Pakistani, Chinese
IS2	19/12/17	CALD	12	-	-	Afghani, Yazidi
IS3	13/02/18	CALD	14	-	-	Burmese, Sudanese, Burundian
IS4	01/03/18	Indigenous	-	10	-	Aboriginal
IS5	27/06/18	CALD	2 ^a	-	-	Nepalese
IS6	06/08/18	Indigenous	-	3	-	Aboriginal
IS7	06/08/18	Indigenous	-	3	-	Aboriginal
IS8	21/08/18	Indigenous	-	6	8 ^b	Aboriginal
IS9	04/09/18	Indigenous	-	6	2 ^c	Aboriginal
IS10	31/10/18	CALD	8	-	-	Serbian, Bosnian, Macedonian, Croatian, Italian
IS11	01/11/18	Indigenous	-	0 ^d	-	Aboriginal
Total		102	64	28	10	

- a. Two Nepalese women and five Swahili women were to attend this information sessions. Only the Nepalese women attended.
- b. This information session was also attended by seven non-Indigenous Aboriginal health services staff and one non-Indigenous CSU Health and Rehabilitation Science student as an observer.
- c. This information session was also attended by two non-Indigenous Aboriginal health services staff.
- d. Five Indigenous women, including one Aboriginal Health Worker, were to attend this information session. None attended.

Table 2 Focus groups and ethnicities of focus group participants

Focus group	Date	Group	Number of participants			Ethnicity
			CALD	Indigenous	Non-Indigenous	
FG1	20/02/18	CALD	3	-	-	Afghani
FG2	20/02/18	CALD	9	-	-	Yazidi
FG3	05/04/18	CALD	7	-	-	Sudanese x 6; Burundian x 1
FG4	27/06/18	CALD	2 ^a	-	-	Nepalese
FG5	06/08/18	Indigenous	-	3	-	Aboriginal
FG6	06/08/18	Indigenous	-	3	-	Aboriginal
FG7	21/08/18	Indigenous	-	6	8 ^b	Aboriginal
FG8	04/09/18	Indigenous	-	6	2 ^c	Aboriginal
FG9	31/10/18	CALD	8	-	-	Bosnian x 1; Croatian x 1; Italian x 1; Macedonian x 2; Serbian x 3
FG10	01/11/18	Indigenous	-	0 ^d	-	Aboriginal
Total		57	29	18	10	

- a. Two Nepalese women and five Swahili women were to attend this focus group. Only the Nepalese women attended.
- b. This focus group was also attended by seven non-Indigenous Aboriginal health services staff and one non-Indigenous CSU Health and Rehabilitation Science student as an observer.
- c. This focus group was also attended by two non-Indigenous Aboriginal health services staff.
- d. Five Indigenous women, including one Aboriginal Health Worker, were to attend this focus group. None attended.

Embarrassment and shame

There was no evidence that any ethnic group had a specific belief which was a barrier to having breast or cervical screens, even though some generalisations could be made – “I think because of some cultures, maybe they may be shy” and “Some of them are embarrassed ... you’re exposing yourself”. Rather, each woman had her own beliefs which either hindered or enabled her to participate in health screens – “It’s just like embarrassing – it’s your body. And they’re looking at your parts” or “For me, I don’t mind [having to be undressed] ... I need to be safe. I don’t mind”. Another women whose husband had died from cancer said, “I don’t care how embarrassing it is, get it done!”.

While most women said they would prefer a female doctor or health nurse to perform a cervical screen – “I’m glad it was a woman doctor” and “... it just makes it that little bit easier, you know, havin’ a woman because we know that ‘you’ve gotta have one too’ you know”, at least two women preferred males – “I actually prefer a male to do it. It feels more natural a male doing it” and “I agree with you 100%!”. Some women preferred their own doctor – “If it’s your own doctor you feel more comfortable” while others preferred a “one-off” person in a clinic where they were unlikely to see that person again. When asked if their husbands or ‘men’ were supportive, the women’s responses were again dependent on individual rather than cultural beliefs – “For me, I didn’t think about my husband. I didn’t tell him I would do this. I can’t wait to go and check my breast!” while another responded – “My husband said, ‘Well, it’s better to be sure than sorry’ so he said, ‘You’d better start doing it!’”.

Competing health/life priorities

The majority of women said that competing health and life priorities were barriers to having breast and cervical screens which were seen to be less important. For new arrivals to Australia, settlement issues, or more pressing health issues, took precedence – “She was suffering with a problem with her eyes ... that’s why she wasn’t thinking about screens” and “She had problems with her teeth, so she was thinking about other things”. Another woman said, “I was [having regular screens] for a while, then I got sick and was in hospital for a while so I had to miss out, like”. There also appeared to be some complacency, although this could have been the result of fear or competing priorities – “You just don’t want to do it” and “[I got a reminder letter] but I ignored that”.

Difficulty navigating the health system

For the majority of women, navigating the health system was a barrier. CALD women said, “... we don’t know the way”. They needed the support of staff from multicultural councils and BreastScreen NSW and the support of other women in their group, to make the screening process easier – “... a group is better ... if someone is scared it is better and if one forgets, it is better”. The majority of Indigenous women also needed support saying that, if it had not been for the program and the group support, they would not have been able to come – “... having this session and meeting the ladies, made it more comfortable. But in retrospect, would I have done it on my own? Probably not” and “They won’t do it on their own”. Practical barriers to navigating the health system also included not having transport or public transport being inadequate – “... transport is a major issue”.

Fear of screening procedure and/or results

Most women indicated that they had some fear of the screening procedure or of what the screen might reveal. The women discussed their fears openly – “My mum had her left breast taken off 40 odd years ago, yeah ...”; “... two cousins passed away with breast cancer. They had both of them removed, but they still passed away” and “I was with Aunt going through that with her and not knowing all that time, and she didn’t either at one stage, and next minute she’s going through this. You don’t know. You don’t know.” Another women explained her fear this way – “... And I go [to

screen] and no problem, nothing. And my friend go and this lady said, 'Oh, big problem for you!' Oh, what's wrong? 'You have cancer.' Oh, my problem!''.

Despite their fears, only one woman gave 'fear' as the main reason why she does not screen and refused to have a screen on the day – "Yes, fear. It's fear! ... It's better not to know [the results]". All other women agreed that it was better to have the screens and know the results – "I need my body to be safe – healthy and well" and "It's good [to screen] because if we have any health problems we will know early". Other women overcame their fear through a sense of responsibility to their families. A women who had not had a breast screen since 2012 said, "I thought, you know what, no, I need to do it. ... I have a daughter and a lot of nieces I encourage ... even the young ones. ... Society has changed. They are getting more promiscuous younger, so they need to be aware and safe. And that's what I say to them ...".

Discussion

Analysis of the data and a review of the literature identified barriers which prevent or hinder Indigenous and CALD women from many different cultural backgrounds from participating in breast and/or cervical screens, in Australia and overseas. Many of the studies emphasise the need for culturally appropriate and sensitive approaches to interventions and strategies used to reduce disparities in health outcomes. While culturally competent approaches are necessary, however, they may not be as critical to reducing disparities as many researchers consider.

Brach and Fraserirector¹⁷, for example, reviewed cultural competency and disparities literature to answer their question, *Can cultural competency reduce racial and health disparities?* They identified nine major cultural competency techniques – interpreter services; recruitment and retention policies; training; coordinating with traditional healers; use of community health workers; culturally competent health promotion; including family/community members; immersion into another culture; and administrative and organisational accommodations – which they suggest, if carefully and appropriately implemented, could theoretically improve outcomes and reduce disparities. They cite several studies showing that, when compared to no intervention, culturally competent interventions with minority women had raised breast cancer screening rates.¹⁸⁻²¹

However, they also point out that the efficacy of these interventions "due to the emphasis on cultural competency" had not been concluded¹⁷ and highlight other cases where immunisation rates for minority children had been increased through interventions that were not particularly culturally competent.^{22,23} This point is worth considering in relation to increasing breast and cervical screening rates among CALD and Indigenous women and may suggest that education through the dissemination of information relevant to *all* women's health is more critical than specific cultural competency.

Other researchers suggest that many of the studies "consider migrants as a homogenous population" and point out that "variations will occur within and between cultures, based on factors such as cultural beliefs and practices, religion, and level of acculturation".²⁴ Henderson and Kendall⁵ also highlight the importance of conducting qualitative research into specific cultural groups in order to provide insights into the subtle differences. Likewise, in a systematic review of literature regarding migrant women in western industrialised countries, the researchers suggest that the diverse definitions of migrants used in the studies they included, limit the conclusions that could be drawn and call for further research which uses "clear, specific migrant definitions".²⁵

Culture, however, is an evolving concept and variations will occur, not only between different ethnic groups, but also between individual women regardless of their cultural background. This is particularly the case for women who have moved to and are assimilating into a new country. To define any ethnic group according to a 'clear or specific definition' has the potential to stereotype in a way which may be unhelpful for the individuals within the defined group.

Limitations

Apart from barriers which the women faced, challenges also faced the researchers as the project was conducted. While this is not uncommon, the circumstances are reported here as barriers which impacted the research:

- Ten Indigenous women attended an information session in March 2018. There appeared to be some interest following the information session and a yarning (focus) group was planned for May 2018. When the Aboriginal Health Worker later asked the women to confirm numbers, no one was interested so the yarning session, screens and post-screen interviews were cancelled.
- It is believed that momentum was lost while waiting for Aboriginal Health and Medical Research Committee ethics approval which was necessary to run the Indigenous focus groups.
- Seven CALD women agreed to participate in an information session and focus group in June 2018, have breast and cervical screens if eligible, and participate in post-screen interviews. These included two Nepalese and five Swahili women. Only the Nepalese women attended on the day.
- Five Indigenous women, including one Aboriginal Health Worker, agreed to attend an information session and focus group in November 2018, have breast and cervical screens if eligible, and participate in post-screen interviews. On the day, however, no one attended.

Conclusion

The barriers which prevent CALD and Indigenous women from accessing breast and cervical screens are complex and reflect the different beliefs, values and attitudes of each woman. Despite the diversity of cultural backgrounds, similarities in the barriers have been identified. The literature suggests that more research is needed to provide further insights into the differences between cultural groups. It was evident in the current study, however, that the choice to screen or not to screen was a personal choice, based on each woman being informed and then supported as necessary, rather than her choice being related to any specific cultural heritage.

While population-based approaches to screening for cancer have the potential to unintentionally exclude minority groups²⁶, more progress may be made towards the reduction of disparities in health outcomes, if less focus is placed on the *differences* between cultural groups, and more focus is placed on the *similarities* of the barriers facing individual women. Arguably, this approach can offer greater guidance for the design of health screen practices that may increase participation rates for a greater number of women, regardless of their cultural backgrounds.

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Presenter

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