



Environmental, structural and process barriers in breast cancer screening for women with physical disability: A qualitative study



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ABSTRACT

Breast cancer is the most common cancer in women internationally and is responsible for the deaths of thousands of women annually. Early detection of breast cancer is integral to ensure early intervention which increases survival rates and health outcomes for women. Despite the availability of breast cancer screening (BCS), previous research has identified that women with physical disability are less likely to access BCS and when they do, they encounter substantial barriers to these services. This paper presents the environmental, systemic and process barriers that women with physical disability face in undertaking BCS in New South Wales, Australia. A qualitative design was used to collect data via in-depth interviews which were audio-recorded, transcribed verbatim and thematically analysed. Twelve women with physical disability participated in interviews to share their experiences of BCS. Findings revealed that participants had both negative and positive experiences during BCS and are presented in the following four themes: Needing better access, Feeling like the machines aren't made for people like me; Experiencing health workers as being clinical and detached and; Facilitating and improving the experience of breast screening. Participants encountered substantial difficulties with the inflexibility of the diagnostic equipment. Further some conveyed that negative experiences of the procedure and interactions with staff while accessing mammography would deter them from returning for BCS. Informed and individualised care is required to enhance the experience of women with physical disability and thus increase uptake rates of this service.

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Introduction

People with disabilities are living longer due to advances in medical intervention in the treatment of diseases.^{1,2} Additionally, the prevalence of disability rises with age and so, as the population ages, the population of people living with disability also rises.^{2–5} This presents challenges for the health system and healthcare workers to ensure that the healthcare needs of people with disability are met. Previous literature suggests that people with disabilities have poorer physical, psychological and mental health than those without disability.^{6,7} Furthermore, current data indicates that despite having greater risk factors for poor health, women with disability have less access to health services and are less likely to utilise breast cancer screening (BCS) services than women without disability.^{7–9} This in turn decreases the likelihood

of early detection and intervention resulting in poorer health outcomes.

Breast cancer is the most common cancer in women worldwide, and responsible for the deaths of over 5,08,000 women globally in 2011.¹⁰ Early detection of breast cancer is integral to increase survival rates and enhance health outcomes for survivors.¹⁰ Mammography is currently recognised as the most effective procedure in breast cancer detection and regular mammograms are recommended particularly for women aged over 50 years.¹¹ In Australia, preventative BCS is available via private or public clinics, with either general practitioners or women's health nurses providing the service. Additionally, women over 50 years of age are encouraged to access mammograms which are free of charge in most locations.

Despite the availability of BCS, previous research internationally has identified multiple barriers for women with physical disability accessing BCS services.^{4,12} A study that surveyed women in the United States of America (USA), found that 5% of women without disability cited a lack of physician referral as a reason for not

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returning for BCS compared to 16% of women with multiple functional limitations.¹³ These authors also reported that women with physical disability faced greater barriers in accessing screening than women without disabilities.¹³ These findings resonate with recent research in France by Bussiere, Sicsic and Pelletier-Fleury,¹⁴ who also identified that the more severe the disability, the less likely women were to access BCS. In the study by Yankaskas et al., 5.5% of women with multiple disabilities compared to 0.7% of women without disabilities cited they did not return for screening due to difficulties with physical access to facilities. Further, 5.6% of women with multiple disabilities, compared to 0.5% of women without disabilities, cited parking difficulties prevented them from returning for screening. Difficulties with transportation was also a factor that influenced whether women returned for screening, effecting 7.9% of women with multiple disabilities compared to 0.6% of women without disabilities.¹³

Women with disability have also reported that a lack of information about the procedure, health care professionals' knowledge and consideration of their disability related needs, and whether they are treated sensitively and with respect, all influence their BCS experience.^{15–18} Addressing issues surrounding health care needs of women with disability is paramount to their wellbeing as the international literature indicates that people with physical disability are less likely to receive preventative health services than people without disabilities,¹⁹ and are less satisfied with the primary care they receive due to poor communication with primary care providers.²⁰ Such issues may contribute to the increasing prevalence of secondary health conditions among this population.²¹

Most previous research focussed on mammography and women with physical disability originates in the USA or Canada. Studies that have been conducted in Australia have interviewed women with both intellectual and physical disabilities to uncover 'intangible barriers' to BCS¹⁸ or observed women with physical disability having a mammogram.²² This paper is derived from results of a broader mixed methods study that aimed to explore breast and cervical screening practices in women with physical disabilities in NSW and the barriers and facilitators to them accessing preventative screening. Elsewhere we have presented the experiences of women with physical disability while accessing BCS (Authors Own). This current paper conveys insights provided by women who participated in the qualitative aspect of the study and highlights environmental, structural and process barriers for women with physical disability accessing BCS in New South Wales, Australia, with the aim of contributing to improving screening practices.

Methods

Design

Using a qualitative descriptive design, semi-structured interviews were used to gather narratives from women with physical disability about their experiences of BCS. Participants' narratives were collected during face to face and telephone interviews, transcribed verbatim and thematically analysed.

Table 1
Guide for interview questions.

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- What is your experience of breast cancer screening?
 - What is your experience of arranging or organizing to have your breast cancer screening?
 - How well were your needs met in accessing your breast cancer screening?
 - How well were your needs met in undergoing your breast cancer screening?
 - What things made it difficult for you to access and undergo breast screening?
 - From your experience, what things would make it easier for you to access and undergo breast screening?
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Ethical considerations

The conduct of the study was approved by the Institutional Human Research Ethics Committee. All participants were provided with details related to the study and informed that they could withdraw their participation at any time. Confidentiality was assured in the research process and in the dissemination of research findings. All identifying information was removed from the transcripts and pseudonyms replaced participants' real names in the presentation of the findings. Participants were asked to sign a consent form after confirming their understanding of their rights and the requirements of their participation in the study.

Recruitment

Purposive sampling was used to recruit women with physical disability who had undertaken BCS in New South Wales, Australia. Women's health organisations posted information about both phases of the study on websites and in newsletters and distributed hard copies of surveys and links to the electronic form of the survey through their networks. The final page of the survey asked women who were interested in participating in an interview to contact the researchers for further information about the study. To be included in the study, women were required to be aged 18 years or over, able to communicate fluently in English, have undertaken BCS and self-identified as having a permanent physical disability. After initial contact, participants were sent an information sheet that explained in detail the requirements of participation. If after reading the information sheet they remained interested in participating in the study, times for interviews were organised.

Data collection

Data were collected via in-depth face to face and telephone interviews according to participant preference. Although 16 women agreed to participate, data saturation was reached after 12 women were interviewed. Eleven of the participants were interviewed via telephone and one chose to be interviewed face to face. The duration of interviews ranged from 18 to 66 min with an average of 40 min. Participants were initially asked "What is your experience of breast screening?" Further prompt questions were asked throughout the interview if necessary to uncover how well women's needs were met in terms of breast screening access and procedures, and barriers and enablers to breast screening (see [Table 1](#)).

Data analysis

Audio recordings of interviews were transcribed verbatim and data were analysed inductively and thematically. The process of analysis commenced as soon as the first interview was completed. As recommended by Braun and Clarke,²³ and Grbich,²⁴ the authors immersed themselves in the data, reading and re-reading the transcripts while listening to the audio recordings. As well as ensuring accuracy of individual transcriptions and providing

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