

ORIGINAL RESEARCH

Breast cancer knowledge among women with intellectual disabilities and their experiences of receiving breast mammography

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Abstract

Aim. This paper is a report of a descriptive study of understanding of breast cancer and experiences of breast mammography among women with an intellectual disability.

Background. Despite the efforts of government policies and documents to ensure equal access to improve health screening for people with intellectual disability, the uptake for breast mammography in this population still remains lower than that of the general population.

Method. A qualitative approach using four focus groups was undertaken with 19 women identified as having a borderline to moderate intellectual disability all of whom had received a breast mammography. Data collection took place in 2009. Analysis of the data was undertaken using thematic content analysis.

Results. The women's knowledge of breast cancer including associated risks, preventative factors and signs and symptoms were extremely limited with their sources of knowledge primarily coming from carers or nursing staff on receipt of an invitation for mammography. Although these women expressed a positive attitude towards their experiences of breast mammography, they also described negative feelings of fear and anxiety, attributed to a lack of understanding about the screening process. A lack of information and embarrassment were identified as the main barriers to screening for this group.

Conclusion. This study highlights the need for accessible multi-format information in order to facilitate health promotion and education in women with intellectual disability, their family carers and healthcare staff working with this target group in order to enhance the knowledge and awareness of breast cancer and screening.

Keywords: breast mammography, cancer, intellectual disability, knowledge, services, women

Introduction

As the life expectancy of people with intellectual disability increases, more women will live to experience the same age-

related illnesses as the general population inclusive of breast cancer (Walsh *et al.* 2000; Tuffrey-Wijne & Davies 2007, Tuffrey-Wijne *et al.* 2007). Recent evidence has reported that the average life span of women with intellectual disability to be

71 years of age (Bittles *et al.* 2002) indicating that in developed countries, they too will survive to the age group, which is at the greatest risk of breast cancer (50–69 years of age).

The World Health Organisation (2000) has expressed concern as evidence suggests that the prevalence rates for cancer are increasing not only for the general population but also for women with intellectual disability. Data on the prevalence or incidence of breast cancer in women with intellectual disability is limited although clear evidence for its occurrence is available from both institutional (Jancar 1990) and community studies (Davies & Duff 2001, Sullivan *et al.* 2004). In a large retrospective cohort study by Sullivan and Hussain (2004), the incidence of breast cancer in women with intellectual disability was only slightly lower than that of the general population. With an exception for women with Down's syndrome who apparently are at lower risk of breast cancer, women with intellectual disability share at least a similar risk of breast cancer with other women (Patja *et al.* 2001; Satgé & Sasco 2002). However, studies have reported on the associations between parity and breastfeeding (Maskarinec *et al.* 2006) where women with intellectual disabilities are less likely to have children and to breastfeed, which may therefore increase their risk of breast cancer.

Background

In the United Kingdom (UK), the government has produced a number of policy documents (Scottish Executive 2000, Department of Health 2001, 2006a, 2006b) and papers in parallel to policy, providing guidance on good practice to those involved in the care of people with intellectual disability (NHS Executive 1994, NHS Cancer Screening Programme 2006). These documents emphasize that people with an intellectual disability should have equal access to all general and preventative health services and also access to education and resources to inform decisions about health promoting behaviours. In spite of this emphasizing, however, it is frequently cited that people with intellectual disability are less likely to access health support and preventative screening (Whittaker & McIntosh 2000, Lennox *et al.* 2001, Powrie 2001).

Despite the fact that the Health of the Nation Strategy (Department of Health, 1992) not only set targets for reducing the number of deaths due to breast cancer, but also raised questions about access to screening programmes, the government paper entitled 'Valuing People' (Department of Health 2001, 2006a, 2006b) indicates that the uptake rates for breast screening for women with intellectual disability is still poor. This finding is evidenced by a number of studies in women with intellectual disability reported to be among the least frequent users of screening mammography (Cowie &

Fletcher 1998; Piachaud *et al.*, 1998; Sullivan *et al.* 2003; Lalor & Redmond, 2009). Furthermore, Davies and Duff (2001) highlighted that only 52% of eligible women were screened following their invitation for breast screening. These findings are statistically significant when considered alongside the specific risk factors for getting breast cancer in women with intellectual disability e.g. nulliparity. With few women with intellectual disability availing of breast mammography, accurate comparisons on the incidence of breast cancer among women with and without intellectual disability remains difficult as limited evidence exists for the intellectually disabled population (Willis *et al.* 2008).

In a recent review of breast cancer and intellectual disability, Willis *et al.* (2008) highlighted that few studies have consulted women with intellectual disability and their carers about what they knew or understood about breast screening. Although more is being published on cancer in people with intellectual disability, there is still a lack of literature on breast screening amongst women with intellectual disability. The voices of women with intellectual disability are not represented in current research with the only study consulting women about breast screening being conducted over a decade ago by Pehl (1999), cited in Pehl and Hunt (2004). As the study was unpublished, the authors were unable to comment on the work.

The study

The aim

The aim of the study was to describe understanding of breast cancer and experiences of breast mammography among women with an intellectual disability.

Design

Given the exploratory nature of this sensitive topic and the dearth of information from the service user's perspective, a qualitative approach using focus groups was chosen. It is now widely recognized that people with intellectual disability are the best and most valid source of information about their lives (McCarthy 1998). Furthermore, qualitative methods have been employed more recently to engage people with intellectual disability for the study; often, such methods have successfully used focus groups and semi-structured interviews (Gates & Waight 2007, Taggart *et al.* 2009). Importantly, as highlighted by Sullivan *et al.* (2004), focus groups have been used to identify barriers to mammography among sub-populations that are traditionally low users of mammography such as African American women and minority groups.

Participants

Purposeful sampling was employed to select potential women who met the inclusion criterion (Streubert & Carpenter 2007). In the present study four focus group interviews were held with 19 women. In three of the focus groups, there were five women and in the fourth focus group there were four women. All of the women had undergone breast mammography in the last 12 months and resided in some form of residential setting in three Health and Social Care Trusts in Northern Ireland. The data were collected throughout 2009.

Residential facility managers were contacted asking them to identify potential women with borderline to moderate intellectual disability, who had attended for breast screening in the previous 12 months, and to distribute the user friendly information sheets and consent forms to the women. Managers and/or key-workers were asked to read alongside the women, the information sheets explaining the nature and purpose of the study. If a woman was interested in participating in the study, they had to return the consent form to the research team. On receipt of the consent form, a member of the research team contacted the residential facility to arrange a time to visit the potential participant. Given the sensitive topic of this study and also the research team not knowing the potential women, a preparatory 'getting to know you' session was held with each of the women and the managers of their residential facility. These sessions aided in establishing a rapport with the women with intellectual disability, helped to inform them of the nature and purpose of the study, enabled the women to have any questions about the study answered and also to identify if the women were willing to participate in a focus group interview after obtaining written consent.

After this initial session, the women agreed to participate and a date, time and venue were chosen to hold the focus group. The focus groups on average lasted approximately 1-hour, took place in a venue convenient for the women such as a health centre or a residential facility and the focus groups were audio-taped. All the women were informed that if they wished, they could have their key-worker/advocate present; however, none availed themselves of this opportunity although residential staffs were always in the vicinity.

In order to avoid response bias namely the tendency amongst people with intellectual disability towards regency, suggestibility, confabulation and acquiescence (Dye *et al.* 2003), the research team gave careful consideration to the types of questions that were to be asked. Cognisance was also given to the apparent limitations identified with 'either/or', 'yes/no', multiple choice and open-ended questions and also avoidance of using leading or abstract questions (McCarthy 1998). Short, straightforward, everyday words and sentences

were used, which were less demanding linguistically. Questions were repeated and rephrased if necessary. This strategy helped to reduce anxiety and develop rapport between the research team and the women. A pilot study was conducted with one focus group and no difficulties were identified. These data formed part of the overall study.

Data collection

A semi-structured interview schedule was developed from the literature (Sullivan *et al.* 2003, 2004, O'Regan & Drummond 2008) and the research teams' personal experience. The interview format consisted of three sections with a number of probes in each section (See Figure 1). These probes aided the women to expand upon their answers thereby providing further clarity and explanation. However, initial ice-breaker questions were used at the start of the focus groups to put the women at ease and to introduce them to each other. The nature and purpose of the study was reiterated and the research team ensured that each woman had given her informed consent to be a part of the focus group and were in agreement to have the interviews audio-recorded.

The first section of the focus group asked a number of open-ended questions to examine the women's understanding and knowledge of cancer *per se* and more specifically breast cancer. This questionnaire included the risk and protective factors of breast cancer, the signs and symptoms of breast cancer and the source of their knowledge. The second section of the interview format sought questions pertaining to the women's experiences of breast mammography. These questions and probes allowed the research team to explore how the women were invited, how they consented to agree to attend for breast mammography and also their feelings leading up to and during their experience of the actual mammogram itself. Finally, the third section of the interview format sought questions around potential barriers for other women with intellectual disability refusing to attend breast screening and also possible solutions to address these barriers. It was noted that as no new information was emerging during focus group, four data saturation were achieved (Parahoo 2006).

Ethical considerations

The Office for Research Ethics Committee in Northern Ireland (ORECNI) granted Research Ethics Committee approval for this study and permission was obtained from the three Health & Social Care Trusts in Northern Ireland. The women's capacity to consent was assessed jointly by the research team and the residential manager, who knew the women well on the initial meeting: it was deemed by both parties that each

- 1) Do you know what cancer is?**
Prompts: Cancer is a very serious illness which could get worse if not treated, there are different types of cancer and some people who get cancer die
- 2) Do you know what breast cancer is?**
Prompts: Breast cancer is the most common cancer for women, some breast cancers can spread to other parts of the body, the best way of testing for breast cancer is by having a regular breast test, lots of people who get breast cancer can get better
- 3) Do you know what the signs/symptoms of breast cancer are?**
Prompts: What age should you go for breast screening, a lump or thickening which is different to the rest of the breast tissue, continuous pain in part of the breast or armpit, one breast becomes bigger or lower, A nipple becomes inverted or changes shape or position, skin changes including puckering or dimpling, swelling under the armpit or around the collarbone, a rash around the nipple, discharge from one or both nipples, under reporting of symptoms and therefore late diagnosis
- 4) Have you read/seen any written material on breast cancer for women with LD?**
Prompts: If yes, was this material easy to read (i.e. wording, use of pictures)? Where did you get this material? Have you watched any videos about breast cancer? Have you attended any educational/support groups on women's physical health issues? Did you find these things helpful? Have you visited a breast screening facility? Did you find these things helpful?
- 5) Has someone spoken with you about looking after your breasts/breast screening /breast cancer?**
Prompts: Who? What did they say to you? Did they use any aids? Were these helpful? Did they answer all your questions?
- 6) Do you know why some women are more likely to get breast cancer than other women (risk factors)?**
Prompts: Age, age at onset of menstruation, family history (mother, sister), dense breast tissue obesity, poor diet, low physical activity, not having children (nulliparity), long-term use of hormone based contraception
- 7) Do you know how to prevent yourself from getting breast cancer (protective factors)?**
Prompts: Eat healthy, do not smoke, do not drink too much, keeping the weight off, keeping active, wearing a bra that fits properly, knowing that you may have a history of breast cancer in your family, obtain regular health check-ups from your GP, regularly self-examine my breasts, get support regarding breast examination from family carer/ staff, know the signs/symptoms of breast cancer, use accessible information leaflets to help me, engage in education/support groups (incl. videos), take up the invitation letter from the GP to attend for a mammograph, attend well women clinics regularly

Figure 1 Example questions (with prompts) used in the focus groups.

woman had the full capacity to give consent. Informed consent was not simply contracted at the outset as outlined above but was a continuous process, which was re-assessed throughout the focus group. All women were reassured that the information that they provided in the focus group would remain confidential and the individuals would not be identified with the comments they made (Streubert & Carpenter 2007).

After a clear explanation was explained to each woman about the nature and purpose of the study and also the issues pertaining to consent using a user friendly participant information sheet, the woman signed the consent form and this event was witnessed by the woman's key-worker and/or researcher.

Data analysis

The data were subject to thematic content analysis using Newell and Burnard's (2006) framework. Interviews were transcribed and were checked and re-checked against the original recordings and were then brought back to some of

the women for verification. Key points made by the women were identified and assigned a colour code using the NVivo computer program (QSR International Pty, Doncaster, Vic., Australia). Similar codes were gathered together into categories. The research team referred back to original transcripts in order to ensure that the context of each woman's contribution was maintained. Peer debriefing enhanced that credibility of the data by allowing the second author to check the themes for accuracy; agreement was sought on any disparities before finalizing the labels of the themes and sub-themes.

Findings

There were 19 women identified as having a borderline to moderate intellectual disability and 16 of these women fell in the age range of 50–69 years of age; three women were below this age range (31–50 years of age). The themes identified in the focus groups are presented below and are supported with evidence in the form of narrative accounts expressed by the women (see Table 1).

Table 1 Themes

Themes	Sub-themes
1. Women's understanding of breast cancer	Knowledge Signs and Symptoms Risk and Protective Factors Sources of Awareness
2. Women's experiences of breast mammography	Lack of understanding Fear, pain and discomfort Positive experiences Support from carers and nurses
3. Perceived barriers to attendance	Lack of information Embarrassment
4. Perceived solutions to barriers	Accessible information Health promotion/education

Women's understanding about breast cancer

Knowledge

There was a consensus that the women had heard of the term 'cancer' and that there were many forms of cancer such as bowel, stomach, lung and skin cancer. However, when asked to describe what cancer was, there was limited knowledge with only two women describing it as 'an illness' or 'a disease'. One woman described what she understood to be cancer:

It's like a stump and that and it eats and eats and eats. Its like a germ in your blood.....you could be very sick with it too. (FG3)

In terms of breast cancer, when asked to describe what breast cancer was, there was an agreement amongst the women that it was 'a lump' in the breast.

Signs and symptoms

Limited knowledge around the signs and symptoms of breast cancer was also evident with only a small number of women able to name 'a lump', 'spots' and 'a red area.'

Risk and protective factors

The main causative risk factors reported by the women to be associated with breast cancer were related to lifestyle; such as 'smoking', 'diet', 'lack of exercise' and 'drinking'. In relation to the protective factors for breast cancer, again, much probing was required for the women to identify those same factors, which are aforementioned as risk factors namely an overall improvement in lifestyle.

Source of awareness

When asked where they had heard about breast awareness and screening it was evident that for most women, the topic was only brought up on receipt of an invitation for breast

mammography or for one woman from watching a hospital based drama on the television. And when asked about their awareness of organizations or networks that give support and information about breast cancer, only two organizations were named: 'Cancer Research' and 'Marie Curie' with the remaining responses associated with primary health care such as the 'doctor', 'nurse', 'hospital' and 'clinics'. It was generally said that the level of knowledge about breast awareness, breast cancer and prevention among the women was mainly limited. Further questioning revealed that for a small number of women, their knowledge on cancer in general was associated to knowing a family member or friend who had the disease and not to any health promotion or education that they had received on the topic; with the exception of a few women who had attended an education group and recalled someone bringing along a dummy and showing them how to examine their breasts.

Women's experiences of breast mammography

Whilst the majority of women generally expressed a positive attitude towards breast mammography, a lack of understanding about the breast screening procedure led to negative feelings of 'stress', 'fear' and 'anxiety' leading up to the screening.

Lack of understanding

A lack of understanding about the breast screening process was associated with increased stress and anxiety. Less stress and anxiety was found to be reported by those women who had the whole process of the examination explained to them accurately and in detail by either a family carer or a nursing staff. These women, on recall, were invited to participate in a health promotion activity by Action Cancer (this organization is a local cancer charity) aimed at increasing the uptake of breast mammography for this population, which had taken place 4 years prior in two Health and Social Care Trust areas. In collaboration with the Intellectual Disability Programme, the initiative involved receiving a letter for screening and an expanded package of care including a visit to a breast screening unit to have a look around and meet the staff and to receive information on breast awareness, screening and prevention and where light refreshments and aromatherapy were offered. One woman reported why she felt it was important to be fully informed:

If they explained it more to you for women with learning difficulties it wouldn't be so bad because you go in there and they say they are going to help you and not to be feared and you go in there and they

take your date of birth but they don't explain anything about it...I have a mild learning difficulty and I need encouragement to get to the doctor and nurses. (FG3)

Fear, pain and discomfort

It was evident for some women that their 'fear' was often attributed to the unfamiliar surroundings and in particular the mammography equipment:

Oh if you see the machine its very big oooh! It's a big brut of a thing oh my God. (FG4)

For one particular woman her fears and anxieties were exacerbated when the plates on the mammography machine were 'stuck', she stated:

It made me feel terrible she [radiographer] couldn't get them open you know she couldn't get them [plates] open and then she tried it again and eventually she got it open. (FG3)

For the most part, the women described having the screening performed as 'uncomfortable', 'painful' and 'sore'. Examples include:

It was like a sewing machine, it was sore when I got tested. (FG3)

I was frightened getting that thing [the plates on the mammography machine] down...when the top one [plate] went down it squeezed me...it was a bit sore here [pointing to her breast] it was tight painful. (FG4)

Positive experience

Despite the fact that the women had described their initial fears and anxieties prior to the mammogram and feelings of pain and discomfort during it, once the women had completed the screening process they said that the procedure was not as bad as they had thought:

I didn't mind at all. The quicker you got it done the better and that was it. The sore goes away again. (FG3)

When you got it done then there was nothing to it...nothing to worry about. (FG4)

Some of the women openly described themselves as 'brave' for undergoing breast screening and noted that they would do it again.

Support from nurses and carers

Whilst describing their experiences of breast mammography some of the women had often reported on the friendliness of the staff at the breast screening unit describing them as 'chirpy' and 'friendly' and 'kind', which helped to alleviate some of their initial fears and anxieties. During the

interviews, there was a sense that if a carer, staff member or someone the woman knew was present during the screening to offer support and reassurance, the process was easier. A strong feeling of relief was also apparent once the women had received the results of the mammogram as they openly made aware to the group that they were 'clear' demonstrating their heightened anxiety levels leading up to the results.

Perceived barriers to attendance

While breast cancer screening was perceived as important by the women, it was also recognized that some women with an intellectual disability might refuse to attend breast screening. Two main barriers were identified by women for non-attendance for breast screening; these were 'fear' and 'embarrassment'. These barriers were attributed to a lack of understanding resulting in feelings of 'fear' in terms of the procedure and the outcome:

Maybe they are afraid that they will have to go into hospital and get their breast removed or something. (FG4)

And 'embarrassment' of having to remove their clothing although this embarrassment was not the case for them as one woman expressed:

Sure it's just natural. Sure you take it [your bra] off at night before its bedtime. You just take it off there too. (FG3).

Perceived solutions to barriers

Although it was evident that breast mammography can arouse negative feelings and cause pain and discomfort, overall the women recognized the importance of undergoing screening for themselves and for others. The key solutions, identified by women with intellectual disability for this target population accessing breast screening services was centred around support both informational and emotional. When asked how or what could be done to encourage other women with an intellectual disability to uptake breast screening, examples of responses by the women included:

A wee story or pages to give...people like us would give people that weren't able or worried or scared to go. (FG2)

Talk to them, try to explain to the ones who can understand that its for their own health reasons and its not as scary or if some of their carers or whoever explained what it was going to be. And for someone to be with them and that the news maybe wouldn't be as bad as they think. (FG3)

Just say you have to go and get it done to keep yourself right...tell them there's nothing to be nervous about. (FG4)

There was also agreement among the women that user friendly leaflets or posters would be helpful in explaining breast awareness, breast screening and prevention albeit the information should be accessible with the writing 'big' and 'easy to understand'.

Discussion

The limitation of this study concerns the representativeness of the data reflected in the small sample size of this group thereby affecting the transferability of the findings. Hence, the findings may not be representative of the female intellectual disability population in the breast screening age. Nevertheless, a number of measures were undertaken to ensure the rigour of the data including transcribing the audio tapes verbatim, employing thematic content analysis and peer debriefing (Slevin & Sines, 2000). In addition, it would be valuable to conduct further research into the context, in which women with intellectual disability make healthcare decisions about breast screening and to have consulted with women with intellectual disability who had refused and withdrew their consent for breast mammography. This act would have afforded deeper insight into what could be done to encourage these women undergo screening.

The findings of this study revealed that overall this group of women with intellectual disability had limited knowledge about breast cancer despite having undergone breast mammography. This finding raises concerns as according to Denburg *et al.* (2005), informed decision-making about cancer screening requires that patients have a correct understanding of the test's purpose, benefits and risks. In addition, effective communication depends first on clinicians and patients sharing an accurate understanding of background concepts such as 'prevention', 'screening' and 'cancer.' In support of the good practice in screening for women with intellectual disability published by the NHS Cancer Screening Programme (2006), it is recommended that nurses and other health professionals adhere to the guidelines to establishing consent to breast screening for these women (McIlpatrick *et al.* 2011).

Although breast awareness initiatives targeted for women with intellectual disability have been demonstrated to be useful in providing education for women with intellectual disability and their carers about breast health and breast screening (Cowie & Fletcher 1998, Symonds & Howsam 2004), in this study, those women who had taken part in a breast awareness initiative still demonstrated limited knowledge about breast cancer. This limited knowledge highlights the need for ongoing health promotion and education using a variety of learning mediums including group discussions,

posters, leaflets and DVD's, which are accessible for this target group. The findings also clearly demonstrated the inability of the women to grasp the complexity of the signs and symptoms, potential risk and protective factors of breast cancer. Given the women's limitations in cognitive functioning, it is evident that it is essential for information to be broken down and the need for repetition of information to ensure that these women internalize and process the information provided.

However, it could be argued that the knowledge and understanding of breast cancer and screening among women with intellectual disability may not be inferior to the understanding among the general population. A survey conducted by Breakthrough Breast Cancer (2007) reported that many UK women lacked knowledge of breast cancer symptoms. This lack of knowledge is worrying given that women with intellectual disability rely on others as sources to inform them about breast awareness, breast screening and prevention. It is important that people with intellectual disability, their carers and staff working with this population are able to recognize signs and symptoms of breast cancer in order to detect the illness at an early stage to ensure effective treatment (Taggart *et al.* 2011).

In recollecting their experiences of breast mammography, the majority of women expressed a positive experience despite having revealed negative feelings of fear and apprehension linked to the women's lack of understanding and recalling feelings of pain and discomfort. Adequate information and support and reassurance from others including breast screening staff were seen to reduce the adverse affects of breast mammography. According to Sullivan *et al.* (2004), these factors are key elements in ensuring women's experiences of screening are positive and supportive. Involving these women's family members or nurses could reduce problems in relation to communication, consent and negative feelings including embarrassment (Lennox *et al.*, 1997). A lack of understanding leading to feelings of 'fear' and 'anxiety' was also identified by these women as a barrier to attendance for mammography in this population in addition to 'embarrassment'. It is evident that over the past decade, the perceived barriers for breast mammography for this group of women remain the same despite health promotion work and changes in policy. The barriers identified in this study both substantiate and echo those barriers identified in other studies (Davies & Duff 2001, Sullivan *et al.* 2003, 2004, Sullivan & Hussain 2004).

It is evident that there is a need for appropriate resources to help women with intellectual disability to understand the concept of screening as a preventative health measure. Recent research suggested that there are serious shortcomings in the information given to women in the UK who attend breast

What is already known about this topic

- The rate of breast cancer in women with intellectual disability is expected to rise with increasing longevity.
- Women with intellectual disability are less likely to access breast cancer screening.
- Government policies and documents have tried to ensure equal access and improve health screening for people with intellectual disability.

What this paper adds

- Intellectually disabled women's knowledge of breast cancer remains limited despite the recently published 'best practice guidelines' and participation in breast awareness activities and increase of mammography uptake.
- A lack of understanding leading to feelings of 'fear', 'anxiety' and 'embarrassment' were identified as the main barriers to attendance for mammography in this population.
- Providing information and emotional support were viewed by the women as a solution to improving access to breast cancer screening.

Implications for practice and/or policy

- Accessible multi-format information and structured education programmes are needed in order to facilitate breast cancer awareness in women with intellectual disability.
- Healthcare professionals need to examine literature, care pathways and practices to ensure that women with intellectual disability do not face barriers in accessing such services.

cancer screening (Gotzsche *et al.* 2009). A number of policy and research reports (Department of Health 2001, 2006a, 2006b; NHS Cancer Screening Programme, 2006) directed at the health needs of people with intellectual disability have highlighted a recurring theme of the need for accessible information and effective communication (McConkey *et al.* 2006, Gilbert *et al.* 2007). Broughton and Thompson (2000) suggested that it is the responsibility of the breast screening services to make information materials in an appropriate and understandable format to ensure equity of service provision for these women. The materials will enable those working directly with women with an intellectual disability to deliver accurate information and guide and support women and their carers through the screening process, thus enabling women to

make informed decisions about breast screening (McIlfatrick *et al.* 2011, Taggart *et al.* 2011).

Barr (1997) suggested a number of strategies designed to increase the quality and effectiveness of general healthcare services for people with intellectual disability. These included preadmission visits, assessment of needs, co-ordinated teamwork and improved communication. In the context of breast screening for women with intellectual disability, this procedure of screening can be facilitated by preappointment visits to the breast screening unit enabling the women to familiarize themselves with staff, equipment and surroundings and also providing accessible information leaflets in a range of formats and visual content before their screening appointment with the option of extended appointments. These will help prepare women throughout the breast screening process and alleviate negative feelings of fear, stress and anxiety. Mallinger *et al.* (2005) reported that while cancer information is crucial, it is not readily available and stress that patients rely on the information given to them by healthcare professionals. Therefore, it can be suggested that providing people with intellectual disability with adequate information will permit informed decision-making, increased patient autonomy and potentially enhanced psychological well-being (Taggart *et al.* 2011).

Given the limited research undertaken with women with intellectual disabilities about their understanding of breast cancer and their decisions to accept or decline the offer of breast screening, identifying or developing a new theoretical framework would offer conceptual clarification of this study's and similar studies' findings (Davies & Duff 2001, Sullivan *et al.* 2003, 2004, Sullivan & Hussain 2004). In other words, it would give greater insight and understanding into the beliefs, attitudes, social influences and volitional control underpinning these women and for many women with intellectual disability, their carers' decision-making processes about breast screening acceptance. The Theory of Reasoned Action (Ajzen & Fishbein, 1980) and the Theory of Planned Behaviour (Ajzen 1988, 1991) are two psychological theories that could be employed to underpin future studies to develop a conceptual model and explain the women's and their carer's decision-making processes. These two theories can be useful in designing structured breast screening education programmes for women with intellectual disability thereby supporting these women to adopt healthier behaviours and increase their uptake of breast screening.

Conclusion

Despite the efforts of government policies (Department of Health 2001, 2006a, 2006b), developments in guidelines

(NHS Cancer Screening Programme 2006) and the introduction of breast awareness initiatives (Cowie & Fletcher 1998, Symonds & Howsam 2004), the knowledge and understanding of breast awareness and cancer for the intellectual disability population still remains to be limited. Findings continue to highlight the lack of accessible information for this population group and emphasize the crucial role that intellectual disability staff, GP's, practice nurses, breast screening nurses and radiographers involved in the breast screening process have in ensuring that health promotion and education is delivered effectively to empower women with an intellectual disability to make informed decision about breast mammography. These findings can aid the breast cancer community to develop their literature, care pathways and practices to ensure that women with intellectual disabilities do not continue to face barriers in accessing breast screening services.

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Conflict of interest

No conflict of interest has been declared by the authors.

Author contributions

MT-K, LT and SM were responsible for the study conception and design. MT-K, LT and SM performed the data collection. MT-K, LT and SM performed the data analysis. MT-K, LT and SM were responsible for the drafting of the manuscript. MT-K, LT and SM made critical revisions to the paper for important intellectual content.

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