

**Key words:** Breast cancer, breast cancer screening, women with intellectual disabilities

**Accessible summary:**

- This paper looks at the experience of women with learning disabilities who go for breast screening (X-ray of the breast)
- Women with learning disabilities reported that there were many things that encouraged and discouraged them from going for breast screening.
- Carers were very important in supporting women with learning disabilities through breast screening

**Introduction**

Cancer-related illnesses account for approximately 12-16% of all deaths in people with intellectual disability (Emerson and Baines, 2010; Heslop *et al.*, 2014). Globally breast cancer is the most common cancer in women (World Health Organisation, 2015). Despite no definitive evidence about the incidence of breast cancer in women with intellectual disabilities, it is generally thought to be similar to women without intellectual disabilities (Patja *et al.*, 2001; Satgé *et al.*, 2014; Sullivan *et al.*, 2004). Although the National Health Service Breast Cancer Screening Programme (NHSBCSP) offers free mammograms to all women in the UK registered with a GP aged 47-73 every three years, (NHSBCSP, 2015) there is generally low up-take of breast screening by women with intellectual disabilities (Gillings-Taylor, 2004; Osborne *et al.*, 2012; Pehl and Hunt 2004; Poynor, 2003; Verger *et al.*, 2005, Willis *et al.*, 2008). However, some studies do report breast screening up-take comparable with those in the general population (Biswas *et al.*, 2005, Davies and Duff, 2001; Lalor and Redmond, 2009). These aside, lower participation means lower detection of malignancies, which may mask the actual incidence of breast cancer among this group of women (Sullivan *et al.*, 2003).

## **Review of the literature**

Numerous barriers have been identified that reduce the participation of women with intellectual disabilities in breast screening. They include physical disability; level of intellectual disability; ill health of the woman or carer; moving house; access issues such as transport; capacity to consent; fear of the procedure and embarrassment. These are consistent with those found in the general population (Cobigo *et al.*, 2013; Isaacs, 2006; Lalor and Redmond, 2009; Pehl and Hunt, 2004; Poynor, 2003; Parish *et al.*, 2012a; Sullivan *et al.*, 2003, Sullivan *et al.*, 2004; Svien, *et al.*, 2008). To address low-up take, there have been many reported education and training initiatives for health and social care staff to encourage women with intellectual disabilities to attend screening (for a comprehensive review see Willis *et al.*, 2010). Recent work by Parish *et al.*, (2012b) found that women with intellectual disabilities (n=91) who undertook an eight-week intervention focusing on breast and cervical cancer screening education, only had moderate increases in knowledge compared to another group (n= 84) who received their usual educational input from carers and health professionals. The authors concluded that for greater gains to be achieved longer interventions and increased investment was needed. Additionally, Willis has argued for regular up-dates about health issues to reinforce the knowledge and training for carers and ensure they can fully support women in their care (Willis 2015).

There is little published work on what influences women with intellectual disabilities to attend breast screening. Truesdale-Kennedy *et al.*, (2011) offer some insight from their work using focus groups with 19 women with intellectual disability who had received mammography within the previous year. Although poor knowledge about breast cancer/awareness and anxiety about the procedure were noted, positive experiences about having the mammogram were expressed in conjunction with emotional support, friendly staff

and being well informed. Analysing what influences women with intellectual disabilities to participate in breast screening is complicated because of their inherent difficulties in the area of decision making. This is compounded by the outcome of breast screening being abstract, in that it may or may not reveal a cancer, and such conceptualisation is often more difficult for women with intellectual disabilities (Dye *et al.*, 2007). Yet there is a clear need to fill this gap in existing research and understand more about the influences on participation in breast screening. The aims of the study reported here was to understand what influenced women with intellectual disabilities to participate in breast screening and explore their experience of having mammography.

## **Methods**

### **Design:**

The study drew on focused ethnography, which assumes that the researcher has intimate knowledge of the area (Knoblauch, 2005; Cruz and Higginbottom, 2013). Data collection tools reflected traditional ethnographic approaches, comprising interviews, observation and field-notes. Ethical approval for this study was granted by the local **south east Scotland** Central Office for Research Ethics Committees.

Purposive sampling was used and participants recruited with the help of gatekeepers who included managers within day centres, residential homes and Community Intellectual Disability Nurses (CIDN). Inclusion criteria required potential participants to have sufficient language ability to answer questions, be aged 45 years or over, <sup>1</sup> have capacity to consent and be within the mild-to-moderate range of intellectual disability. The latter three requirements were confirmed by each gatekeeper. Details of potential participants were passed on by the

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<sup>1</sup> Although breast screening is for women aged 47 and over in the UK, the age of eligibility in this study was reduced due to poor recruitment. The rationale for setting this age cohort was that these women would be the next cohort who would be screened.

gatekeepers to the researcher who then visited all potential participants prior to interview or observation to discuss the study and answer questions. It was made clear to the women that participation was not mandatory.

Gatekeepers took different approaches to recruitment: some asked that permission from paid- or family-carers was obtained prior to interview, others respected the woman's right to choose. During the recruitment process access was withdrawn in one day centre because one of the paid-carers objected to the information leaflets on the grounds that she thought it inappropriate to give out material containing the word 'breast' because there were male clients within the centre. Nevertheless, she championed the project although it was not approved at a staff meeting because the other staff decided that health was not relevant to their remit.

The gatekeepers did not disclose the total number of people with whom they discussed potential participation. Six women who were recruited were unable to participate for various reasons: support-workers' failure to schedule time, illness and bereavement. In three cases the gatekeepers over-ruled the woman's decision to participate, and these women were thanked and the reasons for not pursuing them as an informant explained. The final sample consisted of 14 women although two were used to pre-test the research tools leaving 12. All 12 were interviewed, with three agreeing to be observed.

Data collection:

All information and consent sheets were adapted to plain English and pictorial formats. The consent process was based on 'chunking' information into stages to reduce the cognitive demands, supported by easy-read materials (Goldsmith *et al.*, 2008; Nind, 2008). Before the interview or observation took place, the project was re-discussed to ensure the women understood what the research was about and had the opportunity to raise questions.

Participants were asked to re-confirm their willingness to participate. They were reminded that they could withdraw at any point during the interview/observation and assured that the information they provided would be treated confidentially. Consent was then formally taken, either verbally on audio tape or in writing.

Semi-structured, one-to-one interviews were utilised because they enabled the interviewer and women to clarify questions/answers and allowed the women to talk more freely. Where appropriate, questions were reinforced by pictorial prompts. All interviews commenced with the question 'Can you tell me a little about yourself?' The next questions explored how they kept themselves healthy before proceeding to specific aspects about keeping their breasts healthy. An in-depth discussion about breast screening was prompted by asking the woman if they had undergone the procedure. This led to ascertaining how they were supported through mammography. Of the 12 interviews, nine were conducted on a one-to-one basis, whilst the remaining participants asked their carer to sit in for support. Interviews lasted approximately 25 minutes but ranged from 20 to 45 minutes, the length being dictated by the woman's responses.

Observations reflected the ethnographic approach to the work and were used to see and hear discussions about breast screening/health or an actual mammogram being undertaken at first hand rather than relying on reports and justifications for actions. Thus it helped to understand the experience of the women and those supporting them during breast screening and contextualise discussions about breast/health. Observations were structured around 'what was the environment like?', 'what was said?' and 'what happened during the interaction?' (Simpson and Tuson, 2003). Four observations were undertaken, all in the woman's own

house, and the observations and post-observation discussions lasted approximately 45 minutes.

#### Analysis:

Transcription of the observation, interviews and field-notes were undertaken by the author contemporaneously. Analysis used a blended framework derived from Smith and Osborn (2003) and McCarthy (1999). Interviews and field-note transcripts and observation schedules were initially read until the researcher was familiar with the content. During each reading, material was compared and contrasted. This enabled key words and potential themes to be identified and then mapped back onto the transcripts/schedule. The potential themes were then condensed into a master list which formed the basis of two themes, '*Keeping myself healthy*' and '*Orange squeezer*'. Pseudonyms are used rather than participants' names in the extracts presented in the findings below. Trustworthiness of the themes was validated in a number of ways including peer examination and presentations of the themes to women with intellectual disabilities and paid-carers at three day centres who had requested feedback on the findings. In each case the themes were accepted without changes, despite there being opportunities to comment on them; rather informants who had not taken part in the study disclosed that they captured their own experience of breast screening.

## **Results**

### **Demographic information**

Three women lived alone but received support, one woman lived with her family and the rest lived in a group home with other people. One woman has a child although two women had been pregnant. Of the 12 women who participated in the study, 10 were eligible for a mammogram and eight had attended breast screening. Irene's case raised the total to nine.

Three women disclosed previous problems with their breasts. Marion had experienced bleeding nipples and was referred for a mammogram which indicated no malignancy. Tanya and Irene both had breast cancer resulting in mastectomies. Tanya had undergone treatment for cancer two years prior to being interviewed which she found difficult. She now attended yearly mammograms. Irene's story was different. Five years earlier her sister had been treated for breast cancer but she was not offered a prophylactic mammogram, as would be the case for other women who had a sibling with breast cancer. The paid-carer queried this but it had not been pursued. Irene was in her mid-forties when she had first found a lump and her doctor thought it was merely an abscess. Only when she became repeatedly unwell did her GP refer her to the breast unit where she was diagnosed with breast cancer. Despite this, Irene was very matter of fact about what happened:

*"..They found out I had cancer of the breast. So they got me in right away to the hospital and got it looked at... It would have been going on and I would be riddled."* (Irene, interview)

Irene had a mastectomy and then began chemotherapy before having radiotherapy and now has yearly mammograms. She was hoping to have reconstructive surgery.

### *'Keeping myself healthy'*

This theme explored how the women kept themselves and their breasts healthy. Only two participants smoked while six drank alcohol occasionally. Walking was commonly cited as the main exercise although two women reported carers supporting individualised exercise activities within the residential home. For most women, the idea of keeping healthy was interpreted primarily through their diet which was often used by the paid-carers to convey and reinforce the 'health message'. For example, after visits to the doctor or undergoing health procedures, many women were given a 'treat' (usually a coffee and a cake) and this occurred after breast screening. Six women were in regular contact with health professionals

because of ongoing health issues. Two had long-term health conditions and this was used to explain their lack of motivation in keeping healthy and for not attending breast screening.

*“Keeping healthy, it’s how you feel, I have arthritis in my arm and my health is poor so I can’t be bothered sometimes.”* (Morag, interview)

All the women disclosed that they had received information. This was mainly from a paid-carer, their GP or practice nurse, although one had received advice from friends whilst another learnt about breast awareness/screening from a course at her daycentre (and passed this knowledge on to her sister who also had an intellectual disability). Some of the women highlighted the problem of forgetting what they had been told. Despite this, over half were able to explain why they checked their breasts, with four mentioning cancer within these replies. Eight women said they examined their breasts; three checked every day and one when she remembered. Half the women reported they checked for ‘lumps’, whilst three gave very detailed responses, typified by Marion:

*“Dr George told me to check them for lumps. Dr George taught me to do this [actions checking the breast using the flat of hands to feel all over her breast]”* (Marion, Interview)

The detailed knowledge demonstrated by the three women may have stemmed having had previous problems with their breasts or recently attending a healthy women’s group.

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### ***‘Orange squeezer’***

The second theme, *‘orange squeezer’*, explored the women’s experience of participating in breast screening and identified the influences the women were exposed to when deciding whether to attend for breast screening. ~~Of the 12 women who participated in the study, 10 were eligible for a mammogram and eight had attended breast screening. Irene’s case raised the total to nine.~~

All the women were asked whether they personally had made the decision about participating in breast screening and all replied that they had. Decisions to attend were generally initiated on receipt of the invitation to participate but only three women remembered receiving this letter. It became clear how influential paid-carers could be in finalising the women’s decision:

*“I got a letter... and I think staff took it. At first I dinnae want to go and staff says ‘Jane you got to go’ and explained things to me.” (Jane, interview)*

Only two eligible women in this sample declined their invitation to attend breast screening and both insisted nothing could persuade them to go. Wendy had received a number of letters inviting her to attend for breast screening and she had chosen not to participate despite discussions with her CIDN, Clary.

*“...Clary asked about breast screening, Wendy replied that she ‘wasn’t wanting to go for screening’.”* (Wendy and Clary, Observation)

When interviewed, Wendy reported that her friends had found the experience of breast screening unpleasant. To compound matters, she had experienced a number of episodes of poor treatment when attending other hospital appointments. During the interview she described one example where she had put in a complaint:

*“... they couldn’t find the notes,...when they took me down...they started to do it [procedure] without anaesthetic... I was screaming the place down.... it has made me frightened of going in these places.”* (Wendy, interview)

Her friends and the experience above clearly influenced her decision not to undergo a mammogram. Although two other women disclosed receiving poor treatment when attending health appointments, both said this had not affected their decision to go for breast screening.

Paid-carers accompanied all the women to have their mammogram in this study, but their role varied depending upon the woman’s level of disability. The more independent women said their paid-carer gave them ‘moral support’, whilst those who were more dependant explained that they chaperoned and assisted them through the procedure. This was important as the experience of going for a mammogram was often negative, with a majority of the women speaking about the pain, difficulty in being manoeuvred (lifting and stretching of limbs), maintaining a certain position during the mammogram, the cold, embarrassment about being naked in front of strangers and being scared of the machinery.

*“It’s a bit sore having your breast put in [laughs] the machine. The worst thing is squeezing it.... It’s cold and painful.”* (Tanya, interview)

Irene used humour to lighten the experience of the pain when her breast was squeezed during the mammogram, naming the mammography x-ray machine the ‘orange squeezer’ and likened it to a ‘meat cleaver’. In contrast, the two women who had to have annual mammograms said they’d “*grown quite used to it*”. They recognised why they needed the procedure and hence could reconcile the pain with the necessity of screening. Three women remained undecided about returning for a mammogram, noting “[there’s] *no guarantee it won’t hurt so I don’t know*”, whilst five said they would not return because of the pain.

The culture of mammography also constituted a barrier in this study. Mammograms in the UK are allotted six minutes to complete per woman. This was sometimes hard for the women to adjust to and impacted on the experience.

*“I don’t like going there [mammography], I was shaky but the staff [paid-carers] said to me not to be scared. The nurse [mammographer] said I didn’t want it. But I did.”* (Mairi, interview)

Although Mairi received support and reassurance from her paid-carers, the mammographers were less empathic towards her.

## **Discussion**

All the women in this study said they had received information about breast screening but most had poor knowledge about how and what to look for **and reflects previous work** (Davies and Duff, 2001; Gillings-Taylor, 2004; Parish *et al.*, 2012, a/b; Pehl and Hunt, 2004; Poynor, 2003; Symonds and Howsam, 2004). The women reported forgetting the information which given the problems with memory within this population (Dye *et al.*, 2007) was perhaps

unsurprising. It reinforces the need for regular reminders alongside interventions and information about how to check breasts for all women with or without a disability given the increasing elderly populace. The quality of information given is important. Studies have shown that nurses and carers often lack confidence and knowledge to discuss cancer issues with people with intellectual disability (Kirby and Hegarty, 2010; Willis, 2015). Importantly, this study ~~suggests indicates~~ that health promotion is taking place in the day centres and home environment ~~suggesting that~~ it ~~and~~ is no longer the sole preserve of health professionals, in that some women relied on their carers to check their breasts and/or inform them about mammography. This has implications for where health funding and resources should be aimed. It also emphasises the role played by paid-carers in disseminating and reinforcing information about breast screening. What cannot be assured is whether these carers are able to give a balanced and factually correct message about breast screening to these women? Indeed, in this study health was not always regarded as an important part of the paid-carers' role, although the integration of health and social care which is occurring in the UK may reduce this perception (Scottish Government, 2014). Hopefully this will ensure that all paid-carers undergo regular training to raise awareness about the health needs of the population they support.

In this study one woman had a family history of breast cancer. Despite this, she was not offered prophylactic mammograms and despite her carer being aware of the need for them did not follow it up. There is little research regarding awareness of hereditary breast cancer in women with intellectual disabilities, with the exception of Schneider *et al.* (2000) and Satgé *et al.* (1998). Irrespective of this ~~This however suggests indicates that~~ greater awareness ~~and understanding~~ is required about the risk of hereditary breast cancer in women with intellectual disability. All the women in this study who had breast problems were all

under the age of eligibility for breast screening when their problems occurred and ~~supports~~ **adds to the literature** ~~work suggestion~~ **that** women with intellectual disabilities **may** present earlier with breast tumours (Satgé *et al.*, 2014).

The barriers to breast screening raised by women in this study (with the exception of coldness) **were** reflected in previous findings and applicable to all women undergoing mammography (Davies and Duff 2001; Isaacs, 2006; Parish *et al.*, 2012a/b; Poynor, 2003; Sullivan *et al.*, 2003; 2004; Satgé *et al.*, 2014). The culture of breast screening is focused on the procedure not the women and this ~~was~~ **may have been** alien for these women, ~~as they were used~~ **given that** ~~to a person-centred approach~~ **is the norm and** ~~where~~ care is taken at the pace of the client. This suggests that carers preparing women for breast screening need to be **more** explicit about what will happen, provide reassurance and consider reasonable adjustments, e.g. longer appointments, preliminary visits to meet staff and see equipment. **These issues have been raised previously in the literature** (Gillings-Taylor, 2004; Isaacs, 2006; Parish *et al.*, 2012 a/b; Sullivan *et al.*, 2003). Mammographers should also be more aware of the women's needs. However, implementing reasonable adjustments requires resources such as the time of the paid-carer and mammographer and these may not be forthcoming in the current economic climate.

The high uptake (75%) of breast screening in this study must be acknowledged. The reasons for this remain unclear. Selection bias by the gatekeepers is a possibility. However, a quarter of the women had experienced breast problems with two needing regular mammograms. These women, along with one other who had attended a course, were also more knowledgeable about their breast health and the necessity of mammography. This supports previous work suggesting good understanding of breast awareness/cancer, as well as

experience of mammograms, are factors that facilitated attendance at breast screening (Biswas *et al.*, 2005; Davies and Duff, 2001; Lalor and Redmond, 2009; Parish *et al.*, 2012a/b; Truesdale-Kennedy *et al.*, 2011).

In contrast to women in the general population, resistance to attending breast screening has rarely been documented in women with intellectual disabilities. In this study two women had not attended. Long term illness, peer discussion and poor treatment were potential reasons for non-attendance. These findings ~~demonstrate~~ suggest equality with all women insofar as they have the right not to attend. Despite this, the literature has seemed to be at odds with what was happening on the ground, in that little attention has been paid to the reasons for non-attendance. Greater emphasis has been placed on the need to attend breast screening within the literature on women with intellectual disability (Willis *et al.*, 2008). However the NHSBCSP is now producing more balanced advice which will be reflected in the information disseminated (NHSBCSP, 2015).

Unsurprisingly, a quarter of women in this sample experienced inequalities when accessing health care services. This reinforces concerns that people with intellectual disability are not guaranteed to receive appropriate treatment and that inequalities within health services remain (Lacono *et al.*, 2014; MENCAP, 2012). This is disappointing as public policy has been increasingly aimed at improving provision for people with intellectual disability (NHS Health Scotland, 2004; Scottish Executive, 2000; Scottish Government 2013). It raises the question as to whether the experiences of women in this study were exceptional or whether there are major deficiencies in meeting the needs of this population. Caution must be exercised in relation to the latter point. The qualitative nature of the study and the small purposive sample, which is not representative of the population of women with intellectual

disability, prevent generalisations being made. The findings can only represent a snapshot of experiences of participating in breast screening in one area in Scotland. Nevertheless, it sensitises the reader to the issues within practice that are presented by the findings and suggests that more research is needed into women's understanding of their experience of undergoing the procedure.

## **Conclusion**

The findings in this study supported previous work insofar as mammography was perceived negatively. The study illustrated the influential role which paid-carers play in disseminating health information and health promotion, and provided insights into why some women decide not to participate in breast screening. In terms of funding for health improvement, there is a need to target the home and day services rather than primary care providers, and this will require a fundamental change in direction for funders and policy makers. Alongside this is a need for investment to reform the culture within breast screening services and permit the adjustments necessary to meet the needs of this and other atypical populations. Cognisance also need to be given to the earlier presentation of breast tumours in these women.

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