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Exploring breast cancer and screening awareness among Irish women with intellectual disabilities

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Accessible summary

- We asked women with intellectual disabilities what they knew about breast cancer and screening programmes.
- We asked women what would put them off going to see a doctor if they found something wrong with their breast.
- Most of those we asked knew that a lump was a warning sign for breast cancer.
- Most of those we asked did not know about the risk factors for breast cancer.
- A lot of women did not know much about the breast screening programme.
- A lot of women said they would be worried about what the doctor might find.
- Improving breast cancer and screening awareness is important for women with intellectual disabilities.
- Women with intellectual disabilities need to be taught more about breast cancer and screening.

1 Introduction

Cancer incidence among people with intellectual disabilities is not significantly different to that of the general population (Patja, Eero, & Iivanainen, 2001; Satgé et al., 2014; Sullivan, Hussain, Threlfall, & Bittles, 2004). Although, gastrointestinal and oesophageal cancers are more common in people with intellectual disabilities (Cooke, 1997; Taggart & Proulx, 2014). Advancing age is a strong risk factor for breast cancer thus increased longevity in the intellectual disabilities population **is likely to** lead to increased cancer prevalence (Lacey et al., 2009; Newcomb & Wernli, 2010; Wilkinson & Cerreto, 2008). **Alcohol, obesity and physical inactivity account for over one fifth of breast cancer deaths (Danaei, Vander Hoorn, Lopez, Murray, & Ezzati, 2005). Lifestyle, genetic and reproductive risk factors are associated with increased breast cancer risk in the general and intellectual disabilities populations (Gierach, Yang, Figueroa, & Sherman, 2013; Kerr, Lawrence, Darbyshire, Middleton, & Fitzsimmons, 2013; Lacey et al., 2009; Newcomb & Wernli, 2010; Robertson, Emerson, Baines, & Hatton, 2014; Taggart, Truesdale-Kennedy, & McIlpatrick, 2011).**

Breast cancer warning signs include breast or armpit lumps or thickenings, changes in the breast or nipple size, skin dimpling, nipple discharges, nipple rash and breast pain (Cancer Research UK, 2014; Irish Cancer Society, 2012). **Delays in diagnosis among women with intellectual disabilities are associated with later presentation and poor prognosis. Such delays are attributable to communication difficulties, difficulties performing examinations and under-recognised pain (Satgé et al., 2014).**

BreastCheck, the National Breast Screening Programme, invites all women aged 50-65 years to have a free mammogram biennially. It is essential that all age eligible women be made

aware of the benefits and harms of breast cancer screening (Marmot et al., 2013; National Screening Service, 2017).

In Northern Ireland, Truesdale-Kennedy, Taggart, and McIlpatrick (2011) used focus groups to explore breast cancer understanding and mammography experiences of women with mild to moderate intellectual disabilities (n= 19). Findings indicated poor knowledge about breast cancer and non- lifestyle risk factors, and limited understanding about breast screening (Truesdale-Kennedy et al., 2011). In Scotland, Willis (2016) interviewed 12 women and observed 3 women **about** the screening process. Similarly the findings indicated poor breast cancer awareness. Although accessible information about mammography was given the women had difficulty retaining the knowledge (Willis, 2016). In a US study, 27 women with intellectual disabilities were interviewed to explore influences on mammography participation. Poor understanding about the relationship between mammography and cancer detection was found (Wilkinson, Deis, Bowen, & Bokhour, 2011). The findings of another US study which surveyed women with intellectual disabilities as part of a larger randomised controlled trial (n=202), also identified low breast cancer awareness and poor knowledge about mammography (Parish, Swaine, Luken, Rose, & Dababnah, 2012). Women's breast cancer knowledge improved following targeted cancer education interventions such as Women be Healthy and Women be Healthy 2 (Swaine, Parish, Luken, Son, & Dickens, 2014).

Many women with intellectual disabilities felt ill-prepared for the breast screening process. Challenges include unfamiliar surroundings, fear, professional attitudes and pain (D'Eath, Sixsmith, Connor, & Kelly, 2005; Truesdale-Kennedy et al., 2011; Wilkinson, Deis, et al.,

2011; Willis, 2016). Women with higher support needs, those requiring special positioning for exams, and women who were uncooperative were less likely to have had a mammogram (Horner-Johnson, Dobbertin, Andresen, & Iezzoni, 2014; Lalor & Redmond, 2009; Wilkinson, Lauer, Freund, & Rosen, 2011).

There is evidence of disparities in access to population based breast screening programmes. In an Australian context, 55.2% of age eligible women with intellectual disabilities (50-69 years) were reported to have had a mammogram compared to 75.9% of age eligible women (50-69 years) in the general population (Breast Screen Victoria, 2017; Department of Health, 2011). The NHS Breast Screening Programme invites all women aged between 50 and 70 for screening every 3 years (Cancer Research UK., 2011). Osborn et al. (2012) found that in the UK age eligible women with intellectual disabilities were 35% less likely to have a mammogram than women in the general population. Canadian women aged 50-74 years are routinely screened with mammography every 2 to 3 years (Tonelli et al., 2011). The proportion of Canadian age eligible women with intellectual disabilities who did not receive a mammogram was one and a half times that of age eligible women without intellectual disabilities (Cobigo et al., 2013).

Education to increase cancer warning signs awareness, medical help-seeking, and cancer screening leads to earlier diagnosis, treatment and improved prognosis (World Health Organisation, 2014). The aim of this paper was to explore the breast cancer and screening awareness of Irish women with intellectual disabilities using a cross-sectional descriptive survey design.

2 Methods

The study received full ethical approval from the relevant Research Ethics Committees.

2.1 Participants

Approximately 1300 women with mild to moderate intellectual disabilities reside in the South East Region of Ireland (Central Statistics Office, 2012; Kelly & O' Donoghue, 2012).

Eligibility criteria were that the women had to be over the age of 18 years with a diagnosis of mild to moderate intellectual disabilities in the service provider's records, be able to provide informed consent, and have the ability to communicate verbally.

Overall, 45 women with mild to moderate intellectual disabilities, aged between 20 and 59 years, attending seven intellectual disabilities services participated in the interviews. Almost two thirds of the women (62.2%) lived with family carers. Over one third of the women (37.8%) had either had a cancer diagnosis or had a family member/friend who had received a cancer diagnosis, see Table 1.

2.2 Procedure and data collection

To purposively recruit women with mild to moderate intellectual disabilities one member of the research team contacted all Service Managers at Intellectual Disability Services in the South East Region. An introductory meeting was organised with interested Service Managers. A follow up e-mail contained the study information and consent sheets, the inclusion criteria for the women, advertisement posters and invitation letters. As a requirement of the ethical approval a liaison person was appointed by each Service Manager to coordinate on-site meetings and recruitment.

Information meetings were arranged and advertised by accessible information posters at the day services to ensure women were aware the meetings were taking place. Women were not given invitation letters to reduce the risk of coercion into study participation. Family invitation letters were distributed by the liaison person to women to bring home to their families. Meetings explained the study rationale to potential participants and their carers using accessible information.

Interested women were re-assured that study participation would not involve any medical tests. They were given one week to consult with their families and keyworkers to ensure that they fully understood the nature of their participation in the study. The women were advised that it was their own choice to participate in the study. The liaison person at the service coordinated the recruitment of the women with intellectual disabilities and arranged the interviews with the researcher.

The Cancer Awareness Measure (CAM) Toolkits measure general and tumour specific cancer and screening awareness (Cancer Research UK, 2011). The toolkits contain the survey instruments, interview scripts, answer sheets, recruitment records and coding guidance, and are freely available for researcher use. CAM data is deposited in the UK Data Archive to build public knowledge about cancer and to develop improved communications and services that aim to improve cancer outcomes.

Questions were selected from the Generic and Breast CAM to assess the breast cancer and screening awareness of women with intellectual disabilities. **CAM can be administered as a**

face-to-face interview with the option to use prompts for people with literacy difficulties.

The CAM questions were adapted to pictorial prompts using images from the CHANGE Specialist Cancer Collection. For example, women were asked whether they thought a lump in the breast could be a warning sign for breast cancer, and the accompanying picture depicted a woman with a breast lump. These images were subject to a licencing agreement with CHANGE, a learning disability rights charity, which allowed their use only to create accessible information. The Breast Screening Programme questions were also adapted to an Irish context.

To assess knowledge of warning signs women were asked to indicate whether eleven symptoms could be breast cancer warning signs. Confidence, skills and behaviour to detect breast changes and act upon the findings were measured by asking the women about the frequency of breast self-examination, confidence to detect or report a breast change. Anticipated medical help-seeking delay was assessed by asking women how long they would wait before telling someone that they had found a breast change i.e. straight away, one week, two weeks or longer.

Knowledge of age related risk was assessed by asking women to indicate which woman in the picture i.e. young woman, middle- aged or older woman would be most likely to get breast cancer in the next year. Women's knowledge of risk factors was assessed by asking the women to recall breast cancer risk factors. Awareness of the breast screening programme was assessed by asking all women were they aware of the BreastCheck programme. Attendance at mammography was explored further with age eligible women and women who had attended the symptomatic breast clinic.

Women were asked to rate a series of questions about the barriers they could experience when seeking medical help for symptoms they thought would be serious. The sociodemographic information collected from women were age and residential status. Women were also asked about their personal knowledge about cancer i.e. did they ever have cancer themselves or did they know if anyone in their family or a close **friend had ever had a cancer diagnosis.**

Interviews took place during working hours at the intellectual disability service or at the woman's home in the evening and weekends. Prior to the interview the woman co-signed the accessible information consent form with the researcher, the carer (where present on the woman's request) and provided GP details. Notifying the GP on the women's involvement in the study was a requirement of the Research Ethics Committees.

Each woman was reminded that the interview was being recorded and that she could withdraw at any time. Interviews lasted between 15 and 20 minutes. **Thirty-two women wished the interview to be carried out in private due to the sensitive nature of the topic and to protect confidentiality, although access to a keyworker or parent was available at all times (National Disability Authority, 2009). Thirteen women decided to have keyworkers (n=12) or their mother (n=1) present throughout the interview.**

There was a risk of a woman disclosing a breast cancer symptom to the researcher during the interview. A protocol was developed whereby the researcher would notify the nurse educator of any such disclosure. The nurse educator would ensure that medical advice was

sought. All women were also advised that if they had any questions about cancer after the interview they could talk to the nurse educator at their service. Alternatively, the women and the nurse educator could arrange an appointment with the GP to further discuss these concerns.

2.3. Data Analysis

All participants were given a **study identifier** to maintain confidentiality. All survey data was inputted into SPSS Version 19.0 for analysis. Descriptive and chi-squared statistics were performed using SPSS. **Risk factor categories such as non-modifiable and lifestyle related risk factors were explored using descriptive statistics in the form of frequencies.**

Women were also compared by (i) **age (aged 40 years or older versus 39 years of age or younger)** (ii) residential status (residential/community versus family) and (iii) personal knowledge of cancer (Yes/ No). **Age was dichotomised based on the age categorisation used in the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (Mc Carron et al., 2011).** The Chi Square test was used to test for differences among groups for the variables age, residential status and personal experience of cancer in relation to breast cancer warning signs; the confidence and skills to detect breast changes; anticipated delay for seeking medical help; knowledge of screening programmes; and factors affecting medical help seeking on self-discovery of a symptom.

3 Results

Overall, a 'lump or thickening in the breast' was the most cited breast cancer warning sign among the women (77.8%). Women who resided in residential/ community settings

demonstrated higher recognition of each of the eleven breast cancer warning signs than women living with family caregivers, see Table 2. Similarly, women who had personal knowledge of cancer, such as self (n=2, historical diagnosis in childhood), close family member (n=7) or friend (n=8) had higher recognition of eight of the target warning signs than women without a personal knowledge of cancer, see Table 2. Older women were significantly more likely to recognise a 'lump or thickening in the breast' (94.2% v 67.9%, p=0.040), a 'pain in one breast or armpit' (76.5% v 42.9%, p=0.028) or a 'rash on or around the nipple' (70.6% v 39.3%, p=0.042) as breast cancer warning signs when compared to younger women, see Table 2.

Although there are no firm recommendations on the frequency of BSE it is important for all women to be aware about how their breasts should look and feel (Cancer Research UK, 2011). More women who lived in residential or community settings and younger women reported that they rarely checked their breasts when compared to women who lived with family carers and older women. Women without a personal knowledge of cancer were significantly more likely to rarely check their breasts than women with personal knowledge of cancer (57.1% v 47.1%, p=0.048). **Overall, 40% of the women felt unconfident that they would be able to detect a change in their own breast.**

Almost 80% of the women were unable to recall a single risk factor that might increase a woman's chance of developing breast cancer. Lifestyle factors and reproductive risk factor were recalled by a minority of the women, see Table 3. The maximum number of risk factors recalled was three by only one woman, who had experienced a close family member with a diagnosis of cancer. **Less than half the women were aware of the age related risk of breast**

cancer. There was no significant difference in awareness about the increasing risk of cancer with advancing age among groups.

Less than half the women (44%) were aware of BreastCheck, which was to be expected due to the age profile of the women. Four women over the age of 50 years were age eligible for the breast screening programme. Three of these women reported that they had both received an invitation to screening and had availed of the opportunity to have a mammogram. The fourth woman was unsure whether she had received an invitation to attend for a mammogram. A younger woman under the age of fifty years of age also reported that she had received a mammogram due to the discovery of a potential breast cancer symptom. There were no significant differences observed between women regarding awareness about BreastCheck when stratified by residential status, age and personal knowledge of cancer, see Table 4.

The majority of women (80%) reported that they would tell a carer within one week of the self- discovery of a symptom they thought might be serious. Emotional barriers such as worry about what the doctor might find and embarrassment talking about their breasts would put women off going to the doctor. Just 13.3% of the women mentioned that they would prefer an appointment with a female doctor to discuss the issue. **Service barriers** such as experiencing difficulty making a doctor's appointment were significantly more likely to impact younger women when compared to older women due to reliance on carers to make appointments for them (60.7% v 23.5%, $p=0.015$). A significantly lower proportion of women with a personal knowledge of cancer mentioned **the service barrier** 'the doctor would be difficult to talk to' compared to women without personal knowledge of cancer

(5.9% v 35.7%, $p=0.024$). **Practical barriers such as having competing demands or lack of transport did not have a significant impact on the women in this study, see Table 5.**

4 Discussion

The findings of the current study reflect the current body of evidence which highlights poor breast cancer awareness among women with intellectual disabilities based upon discussions with the women (Parish et al., 2012; Truesdale-Kennedy et al., 2011; Wilkinson, Deis, et al., 2011; Willis, 2016). Poor awareness of age related risk among the women was similar to that found in the general population e.g. Forbes et al. (2013). This is of interest in the context of a growing and ageing population in Ireland with anticipated growth in cancer incidence in the general and intellectual disabilities population (Doyle, Hourigan, & Fanagan, 2017; Mc Carron et al., 2011; National Cancer Registry, 2014).

Similar to Lalor and Redmond (2009) there was a high self- reported participation rate for age eligible women in the Irish breast screening programme, although the samples sizes in both studies are small and cannot be generalised. **Disparities of access to screening programmes are well documented internationally (Cobigo et al., 2013; Department of Health, 2011; Osborn et al., 2012). Reflecting the findings of Willis (2016) there needs to be more clarity in the screening invitation process. Women with intellectual disabilities may need adapted breast screening guidelines due to earlier breast cancer presentation (Satgé et al., 2014). It is crucial to ensure the women are made aware of the invitation and offered education about the mammography process to facilitate them to make informed choices about participating in the programme.**

Women with intellectual disabilities are often reliant on family members to provide preventative healthcare advice. It appears that family members are most likely not as well informed or lack personal understanding about preventative healthcare, and the appropriateness of such preventive healthcare for women with intellectual disabilities (Alborz, McNally, Swallow, & Glendinnin, 2003; Parish et al., 2012; Swaine, Dababnah, Parish, & Luken, 2013). In this study women with intellectual disabilities who lived at home with family caregivers demonstrated very low awareness about cancer prevention. This has implications given that that 70% of Irish women with mild to moderate intellectual disabilities live at home with family caregivers (Doyle et al., 2017).

Almost 40% of the women were unconfident that they would notice a change in their breast. Poor breast awareness coupled with inequalities in preparation, delivery of or access to screening may have implications on breast cancer early detection and treatment among women with intellectual disabilities across the lifespan (Reidy, Denieffe, & Foran, 2014; Willis, 2016). Almost one fifth of the women were undecided how long they would delay help-seeking for a symptom. These results support previous research about delays in cancer help-seeking in the general population (O'Mahony, McCarthy, Corcoran, & Hegarty, 2013). **Worry about what the doctor might find was reported as the key barrier that would delay early help-seeking. This echoes international findings in the general population regarding the impact of worry on help-seeking behaviours (Forbes et al., 2013; Saab et al., 2018).**

The use of validated and reliable CAM, leads to the development of a wider body of knowledge for marginalised groups (Robb et al., 2009). The current study adds to this

knowledge base. To the best of our knowledge this is the first time that that Adapted CAM has been used to explore the breast and screening awareness of women with mild to moderate intellectual disabilities. The data set was uploaded to the UK Data Archive for comparative purposes in future research exploring health inequalities for people with intellectual disabilities.

This cross-sectional study using recognition and recall questions could only estimate the cancer and screening awareness among the women. **The majority of women in this study had not previously received any education about breast awareness. Responses to recognition questions are most likely susceptible to social desirability; recall questions are dependent on recalling facts from memory which may be difficult for women with cognitive and memory limitations (Cameron & Murphy, 2007; Robb et al., 2009; Snowman, McCown, & Beihler, 2012).**

Similar to previous studies a non-probability purposive sampling frame was used to recruit women with intellectual disabilities attending intellectual disability services. This affects the generalisability of the results to the population of Irish women with intellectual disabilities. The risk of selection bias was minimised by inviting all eligible women in the service to the information meetings and giving them the information about the study. It is more than likely that the women with intellectual disabilities that were recruited were on the milder continuum of intellectual disability and thus more cognitively and verbally adept, **and able to provide consent.** This may have resulted in a bias in sampling. **Future studies could address these limitations by using a longitudinal study, widening the sampling frame to recruit women with a range of intellectual disabilities, and including those who are not**

attending intellectual disabilities services for example through women's or community groups.

Recent international reviews indicate a movement towards theoretically driven tailored health promotion interventions taking into account the perspectives of people with intellectual disabilities (Heller, Fisher, Marks, & Hsieh, 2014; Kerr et al., 2013; Naaldenberg, Kuijken, van Dooren, & van Schroyen Lantman de Valk, 2013). **This study adds to the body of knowledge that aims to raise cancer and screening awareness of among women with intellectual disabilities and their family caregivers, paid and non-professional carers, and the drive towards theoretically driven health education interventions to meet this goal (Greenwood, Wang, Bowen, & Wilkinson, 2014; Parish et al., 2012; Swaine et al., 2014).**

5 Conclusions

The results show poor breast and screening awareness among Irish women with intellectual disabilities which is reflective of international findings. **Internationally there is a call for more targeted breast cancer education for women with intellectual disabilities to facilitate them to become more active participants in their own healthcare. It is therefore timely to address this call and develop a theoretically driven health education intervention for Irish women with intellectual disabilities and their carers to raise breast cancer and screening awareness.**

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