


ORIGINAL ARTICLE

Determining the need for a breast cancer awareness educational intervention for women with mild/moderate levels of intellectual disability: A qualitative descriptive study

Susan Walsh¹  | Josephine Hegarty¹ | Elaine Lehane¹ | Dawn Farrell² | Laurence Taggart³ | Louise Kelly⁴ | Laura Sahm⁵ | Maria Corrigan⁶ | Maria Caples¹ | Anne Marie Martin¹ | Sabin Tabirca⁷ | Mark A. Corrigan⁴ | Mairin O'Mahony¹

¹Catherine McCauley School of Nursing and Midwifery, University College Cork, Cork

²Department of Nursing and Healthcare Sciences, Institute of Technology Tralee, Tralee, Ireland

³Institute of Nursing and Health, Ulster University, Jordanstown, UK

⁴Department of Academic Surgery, Cork Breast Research Centre-Cork University Hospital, Cork, Ireland

⁵School of Pharmacy, University College Cork, Cork, Ireland

⁶St. John of God Hospitaller Ministries, Dublin, Ireland

⁷Department of Computer Science, University College Cork, Cork, Ireland

Correspondence

Susan Walsh, Catherine McCauley School of Nursing and Midwifery, University College Cork, Cork, Ireland.
Email: susan.walsh4@hse.ie

Funding information

Health Research Board, Grant/Award Number: PDG/2015/2

Abstract

Objective: Following a review of the existing body of literature, this study aimed to explore the need for a breast cancer awareness intervention specifically targeted at women with mild/moderate levels of intellectual disability (ID) and provide perspectives on the preferred processes and content underpinning an intervention.

Methods: A qualitative, descriptive design using semi-structured, individual ($n = 5$) and focus group ($n = 5$) interviews were used to engage with a non-probability, purposive sample of key stakeholders ($n = 25$) including women with mild/moderate levels of ID, caregivers and healthcare professionals. Data were analysed using qualitative content analysis.

Results: Findings highlighted that an educational intervention should focus on breast awareness as opposed to breast cancer awareness. Additionally, findings identified that a combined breast awareness and healthy living intervention could be effective. However, the intervention needs to have a multimodal, hands-on, person-centred approach to learning which is underpinned by theory. Furthermore, integrating the caregivers and healthcare professionals into the intervention is recommended.

Conclusion: Findings from this study provide a foundation for developing and implementing a theoretically underpinned, multimodal, breast awareness and healthy living educational intervention for women with mild/moderate levels of ID.

KEYWORDS

breast awareness, breast cancer awareness, education, healthy living, intellectual disability, qualitative

This work was completed as part of a Master of Science by Research in Nursing, University College Cork.

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial](https://creativecommons.org/licenses/by-nc/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2022 The Authors. *European Journal of Cancer Care* published by John Wiley & Sons Ltd.

1 | INTRODUCTION

Breast cancer is the second most common cause of cancer death in women and is the world's most prevalent cancer (American Cancer Society, 2021; World Health Organisation, 2021). An intellectual disability (ID) is defined as limitations in intellectual functioning and adaptive behaviour expressed in practical, social and conceptual skills, which develops before the age of 22 years (American Association of Intellectual and Developmental Disabilities, 2022). The use of 'ID' in this article reflects word count limits. Although women with ID have a similar risk of developing breast cancer to those in the general population, they are often diagnosed with advanced breast cancer with a poor prognosis (Collins et al., 2014; Davies & Duff, 2001; McIlfratrick et al., 2011; Satge et al., 2014, 2020; Taggart et al., 2011; Walsh, O'Mahony, Hegarty, et al., 2021; Walsh, O'Mahony, Lehane, et al., 2021; Wilkinson & Cerreto, 2008).

Several barriers to breast cancer awareness for women with ID have been identified including a lack of understanding about breast cancer awareness, caregiver attitudes and knowledge, literacy skills and availability of health information (Arana-Chicasa et al., 2020; Davies & Duff, 2001; McIlfratrick et al., 2011; Satge et al., 2014; Taggart et al., 2011; Walsh, O'Mahony, Hegarty, et al., 2021). Furthermore, a review of literature has demonstrated a paucity of cancer awareness and breast cancer awareness interventions specifically aimed at women with ID (Walsh, O'Mahony, Lehane, et al., 2021). Findings from this review identified five interventions which aimed to increase cancer awareness or breast cancer awareness in people with ID, none of which focused solely on breast cancer awareness (Gilbert et al., 2007; Greenwood et al., 2014; Howieson & Clarke, 2013; Parish et al., 2012; Swaine et al., 2014). There is a similar shortage of quality interventions to increase breast cancer awareness amongst women in the general population (O'Mahony et al., 2017; Walsh, O'Mahony, Lehane, et al., 2021).

To address this notable gap, there is a need for an intervention to increase breast cancer awareness in women with ID. However, prior to developing or adapting an intervention, it is important to firstly engage with key stakeholders including women with ID to gain their perspectives. This ensures that the specific support needs of women with ID are at the core of the intervention, thus aiding its successful implementation.

1.1 | Aims of the study

Through engagement with stakeholders, the team sought to:

1. Explore the findings of the literature review; to determine the views of the participants as to whether there is a need for a breast cancer awareness educational intervention for women with mild/moderate levels of ID.
2. Provide perspectives on the preferred processes and content underpinning a breast cancer awareness educational intervention.

2 | METHOD

2.1 | Study design

A qualitative, descriptive design using individual semi-structured interviews ($n = 5$) and focus group interviews ($n = 5$) were used to engage with a non-probability, purposeful sample of key stakeholders ($n = 25$). This study was guided by the Intervention Mapping framework (Bartholomew et al., 2011) and Medical Research Council (MRC) (Skivington et al., 2021) framework for developing and evaluating complex interventions. The MRC enunciates the importance of engaging with stakeholders as part of the intervention design phase.

2.2 | Ethical considerations

Prior to the commencement of the study, ethical approval was granted. Informed consent was a continuous process. Proactive measures were taken to ensure all written materials were accessible for women with ID with respect to font style, font size and the use and placement of pictures (Mencap, 2002; NALA, 2016; National Disability Authority, 2009; National Federation of Voluntary Bodies, 2016). Women with mild/moderate levels of ID for whom there were no concerns regarding capacity to consent were identified by the key person in each organisation for potential participation in the study. A summary of the process of accessing and recruiting women with ID is seen in Figure 1.

2.3 | Participants and recruitment

Women with mild/moderate levels of ID ($n = 14$) were recruited from an organisation which provides a range of services for people with ID aged 18 years and over who are living in the community. Initial contacts were established by the researcher with a key person within these services who subsequently assisted with the recruitment process. Caregivers ($n = 2$) were recruited for one focus group. Healthcare professionals (HCPs) were recruited from a symptomatic breast clinic ($n = 4$) and through organisations providing services for people with ID ($n = 5$). A summary of the inclusion criteria for all participants is seen in Table 1.

2.4 | Data collection and data analysis

A combination of both individual interviews and focus groups was utilised in this study to support inclusion of all participants who expressed discomfort participating in a group situation. Both semi-structured individual interviews and focus groups involving women with ID have been used successfully in previous studies (Collins et al., 2014; Gilbert et al., 2007; Greenwood et al., 2014; McDonald et al., 2013; Ottmann & Crosbie, 2013; Parish et al., 2012; Swaine et al., 2014; Truesdale-Kennedy et al., 2011; Wilkinson

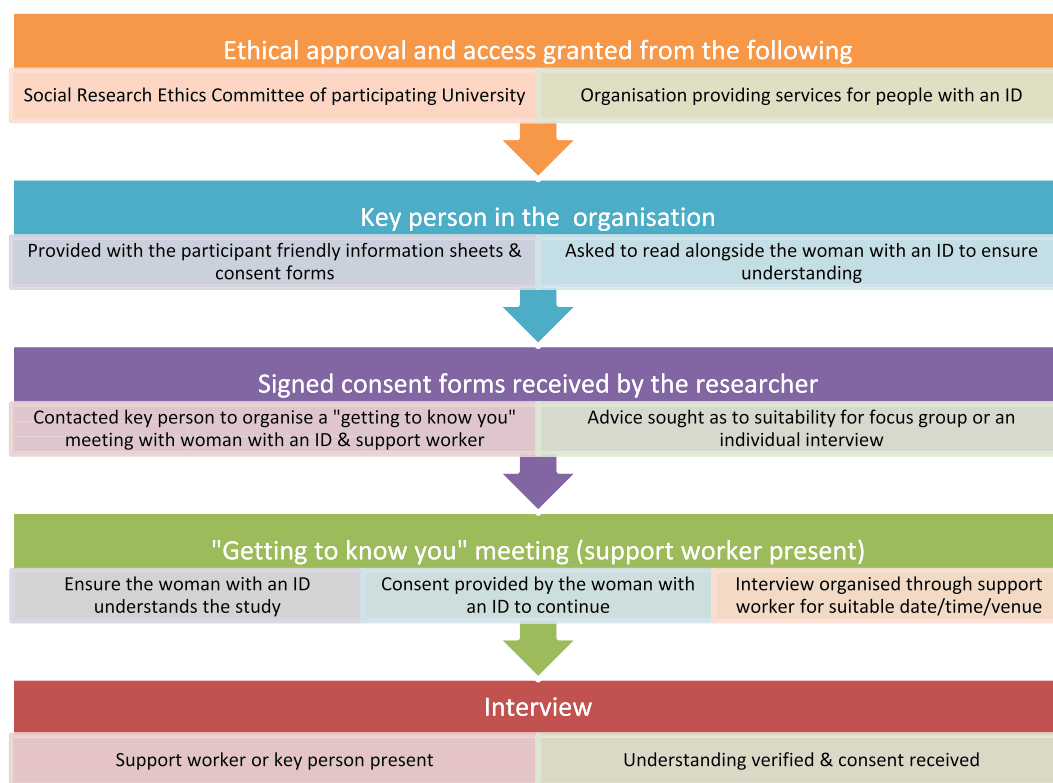


FIGURE 1 Summary of the process of accessing and recruiting women with mild/moderate levels of ID

TABLE 1 Inclusion criteria

Inclusion criteria for women with ID	Inclusion criteria for caregivers/ healthcare professionals
Over 18 years of age	Over 18 years of age
In receipt of service provision for mild/moderate levels of ID	Can read or speak the English language
Have the capacity to consent	Caregivers must provide support to a woman with ID
Able to participate and communicate in an interview or a focus group	Healthcare professionals must work in a breast cancer or ID setting and have contact with women with ID

et al., 2011). Whilst both individual interviews and focus group approaches were used, the data collection procedure and questions were similar.

The semi-structured interview schedule guided the interviews with prompts allowing for elaboration of any information. A socio-demographic questionnaire was also completed by the participants. Collectively, there were 25 participants interviewed, and the participant characteristics can be seen in Table 2. A pilot study involving two participants with mild/moderate levels of ID was conducted to assess the feasibility and validity of the data collection process.

All interviews were recorded via audiotape and notes were taken by the researchers (SW and DF) throughout the interviews with the

participants' permission. Data collection took place over a 1-month period. Consistent with other studies involving participants with and without ID, a token of a €20 gift voucher was received by all participants in appreciation of their time.

Data were analysed using qualitative content analysis, a strategy which is data-derived and allows for a straight description of the information provided by the study participants (Lambert & Lambert, 2012; Sandelowski, 2010, 2000; Vaismoradi et al., 2013). Data analysis commenced after completion of the first interview and continued throughout the data collection phase. Individual comments from participants were separated (meaning units) and transferred onto a table to allow for a more in-depth analysis (Elo & Kyngas, 2007; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). The meaning units were condensed, and codes developed to describe the data (Elo & Kyngas, 2007; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). The meaning unit and condensed meaning units were re-examined (SW, JH and MOM) to ensure the codes remained true to the data. Subcategories were developed and colour-coded based on similar content and context (Elo & Kyngas, 2007; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). Categories were developed from these codes and subcategories based on similarities. Subsequently, these categories were grouped according to their underlying theme. Analysed data were then clearly presented for peer reviewing (JH and MOM) and further analysis to ensure a complete understanding of the context of the data and to remove the risk of failing to identify categories (Hsieh & Shannon, 2005).

TABLE 2 Participant characteristics

Participant number	Age range (years)	Focus group or individual interview	Additional information
Women with mild/moderate levels of ID			Living arrangements
P1W	18–20	Focus group 1	Family home
P2W	18–20	Focus group 1	Family home
P3W	18–20	Individual interview	Family home
P4W	21–30	Individual interview	Family home
P5W	51–60	Individual interview	Residential care
P6W	21–30	Individual interview	Own apartment
P7W	41–50	Individual interview	Supported living
P8W	21–30	Focus group 2	Family home
P9W	21–30	Focus group 2	Family home
P10W	31–40	Focus group 2	Supported living
P11W	31–40	Focus group 2	Family home
P12W	31–40	Focus group 2	Supported living
P13W	31–40	Focus group 2	Supported living
P14W	31–40	Focus group 2	Supported living
Caregivers			Role
P1C	51–60	Focus group 3	Main caregiver
P2C	51–60	Focus group 3	Main caregiver
Healthcare professionals			Role
HCP1	31–40	Focus group 4	Community support worker
HCP2	31–40	Focus group 4	Community support worker
HCP3	41–50	Focus group 4	Community support worker
HCP4	31–40	Focus group 4	Basic instructor (ID)
HCP5	51–60	Focus group 4	Registered nurse intellectual disability
HCP6	41–50	Focus group 5	Consultant breast surgeon
HCP7	31–40	Focus group 5	Clinical nurse specialist breast care
HCP8	41–50	Focus group 5	Lecturer breast diseases
HCP9	41–50	Focus group 5	Clinical nurse specialist breast care

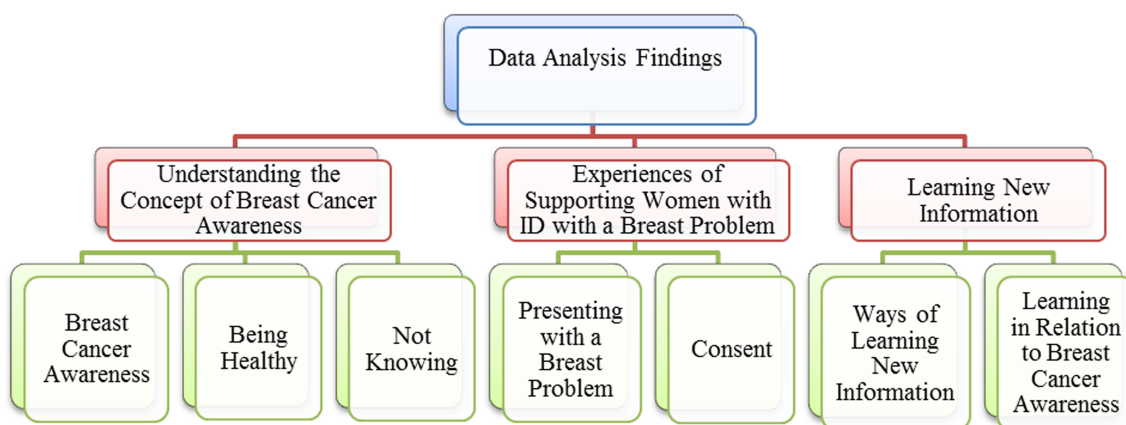


FIGURE 2 Summary of the findings: themes and categories

3 | RESULTS

Three themes emerged from the analysed data: (1) understanding the concept of breast cancer awareness, (2) experiences supporting women with ID with a breast problem and (3) learning new information. A summary of these themes and categories is presented in Figure 2.

4 | THEME 1: UNDERSTANDING THE CONCEPT OF BREAST CANCER AWARENESS

The concept of breast cancer awareness is complex; therefore, it was unsurprising that several categories were established to fully appreciate the participants' understanding of the concept.

4.1 | Breast cancer awareness

The caregivers portrayed more of an understanding of 'breast checking' than women with ID. However, awareness of the signs and symptoms of breast cancer appeared to be comparable with 'looking for lumps' being the main symptom voiced by most participants.

On many occasions during the interviews, women with ID expressed feelings of 'not wanting to get cancer' and 'wanting to be safe' from cancer. Furthermore, the word cancer evoked feelings of fear for women with ID and they portrayed a fatalistic association with the word 'cancer':

How to be safe in the family, if anyone else gets it [cancer], my mum and my sister and me, I want to, you know I want to be safe, you know, I do not want to get what my aunty got, I want to be safe about it you see.... (P1W)

What I'm afraid of is if I do get cancer is I'm afraid of dying. (P14W)

In contrast, the caregivers expressed mostly feelings of 'concern' for women with ID. Concerns about the emotional impact the word cancer has on women with ID in addition to concerns regarding their lack of breast cancer awareness.

4.2 | Being healthy

Although the concept of breast cancer awareness appeared challenging for women with ID to explain and understand, the idea of being healthy was a concept which established itself as being central to their lives. Consequently, it was a category which required further exploration during the interviews. Eating healthily, participating in exercise and being aware of unhealthy choices (e.g. smoking) were at the core of what participants constituted as being healthy. When asked to

define what eating healthy means, the women responded with 'eat the right amount of food in a day', 'plenty of vegetables', 'drink water' and watch 'portions'. On exploration of why it is important to eat healthy, responses included references to the 'grease and fats in the food' and being 'overweight'. Just over a third of the women with ID ($n = 5$) spoke about their attempts to lose weight including seeking assistance through weight loss programmes.

However, caregivers and HCPs working in an ID setting had mixed perceptions as to how healthy women with ID actually are;

They get jobs, they have money ... and they are eating what they are earning ... but diet and lifestyle, exercise would all be very low. (HCP3)

They're more health conscious than I was at their age. They're all about walking and jogging (P2C)

Besides a support need for education about breast cancer awareness, the findings have indicated that there is also a support need for continued education about being healthy.

4.3 | Not knowing

Not knowing whose responsibility, it is to facilitate breast exams for women with ID resulted in many discussions during the interviews with the HCPs as highlighted by the following:

I suppose we leave it [breast awareness/checks] up to the family. We would not check in. Actually, we possibly should, but we would not. (HCP3)

There appears to be no straightforward verdict in establishing who should be responsible for facilitating breast examinations for women with ID. Similarly, not knowing whose responsibility it was to provide breast cancer awareness information or what information should be provided caused considerable doubt for the caregivers and HCPs. One of the caregivers stated that she did not 'know how you'd actually go about' educating her daughter about breast cancer awareness with further comments such as 'we have to tell them really' and 'we have to advise them'. The use of the words 'have to' implies that they know it is their role but are possibly not doing it, especially given their acknowledgement of 'not knowing how to go about it'. This 'not knowing' acts as a barrier for breast cancer awareness education for women with ID.

5 | THEME 2: EXPERIENCES OF SUPPORTING WOMEN WITH ID WITH A BREAST PROBLEM

The second theme which emanated from the data analysis described the participants' experiences of supporting women with ID who have had a breast problem.

5.1 | Presenting with a breast problem

The findings revealed a dearth in the educational, training and support needs of the caregivers and the HCPs which would assist them in facilitating breast cancer awareness for women with ID. In addition, there was a consensus by the HCPs that caregivers had 'poor' levels of breast cancer awareness comparable to women in the general population and furthermore demonstrate no awareness of risk, outcomes, prognosis and treatment.

Additionally, the findings illustrated the support need for educational resources specific to breast cancer awareness for women with ID to be more readily available for caregivers and HCPs.

There's nothing out there. There's no easy-read format.
(P1C)

Whilst discussing their experiences, the topic of consent dominated much of the conversation with the HCPs working in a breast cancer setting.

5.2 | Consent

The HCPs surmised from their experiences that difficulties arise with consent due to the support needs of women with ID in understanding the information provided. Consequently, the caregiver has assumed the role as the decision maker and often they transferred this responsibility to the HCP. The burden then felt by the HCPs when surgery does not go to plan was highlighted:

So then, if something does happen to their person subsequently, then that is even more devastating than as somebody else has taken on the surgical planning.
(HCP6)

Correspondingly, throughout the discussions, HCPs working in a breast cancer setting recognised the importance of empowering women with ID to assume ownership of their healthcare decisions.

6 | THEME 3: LEARNING NEW INFORMATION

The final theme highlighted the ways women with ID learn new information.

6.1 | Ways of learning new information

The various formats and environments which assist the learning process for women with ID illustrate that one format does not suit all learning needs (Figure 3).

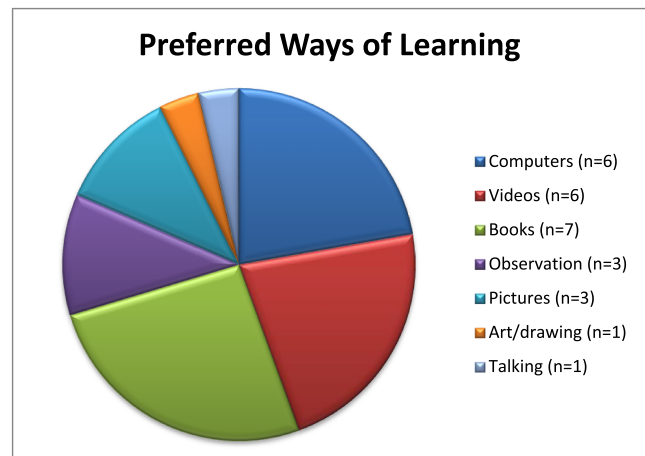


FIGURE 3 Preferred ways of learning of women with ID

Fewer words and more visual content emerged as key components in supporting the understanding of any educational resource:

I cannot write and I've trouble with me [sic] literacy ...
All I can write is my name, but could you make up an easy book? ... with pictures on it. (P10W)

Following on from this, the complexities of engaging women with ID in learning were highlighted during discussions with the HCPs primarily focusing on their support needs regarding attention maintenance and information retention. In addition, the HCPs in both the ID setting and the breast cancer setting highlighted the difficulties of developing education materials which would support all individuals across the continuum of ID.

Furthermore, the findings conveyed the importance of any education, particularly about breast examinations, not compromising the personal safety or boundaries of women with ID who may have personal safety support needs.

6.2 | Learning in relation to breast cancer awareness

On exploration of what the participants think is important for women with ID to learn in relation to breast cancer awareness, the main areas identified were breast cancer awareness, healthy living and women's health.

Women with ID expressed a desire to learn the signs of cancer and how to prevent cancer in order to look after themselves:

... what's the best signs for me to help me, to encourage me to check myself more often for preventing cancer in the future. (P13W)

Similarly, the caregivers and HCPs working in an ID setting believed learning how to examine their breasts is an important support need for women with ID. The caregivers also expressed support needs for continued education about healthy living and healthy eating. But the HCPs working in an ID setting believed that education about general women's health is a support need for women with ID.

The HCPs working in a breast cancer setting agreed that recognising symptoms was important, but so too is supporting women with ID in reporting any symptoms.

7 | DISCUSSION

Following a review of the existing body of literature, this study aimed to review the need for a breast cancer awareness intervention specifically targeted at women with mild/moderate levels of ID and provide perspectives on the preferred processes and content underpinning such an intervention.

This study has highlighted important issues regarding the educational support needs of women with ID about breast cancer awareness. Addressing these support needs would assist in reducing health inequalities for women with ID on an international level as the United Nations (UN) Convention of the Rights of Persons with Disabilities (CRPD) have emphasised the need for equality, accessibility to information, health and education for people with ID (Brehmer-Rinderer et al., 2013; Mittler, 2015).

From the analysis of the data, the key qualitative findings which emerged were breast cancer awareness, fear associated with the word cancer, being healthy, not knowing and learning new information.

7.1 | Breast cancer awareness

Overall, the caregivers and the women with ID appeared to have limited knowledge of the signs and symptoms of breast cancer with a lump being the most cited symptom. This limited knowledge demonstrated by both cohorts of participants was unsurprising as it has previously been documented in the literature by many authors (Hanna et al., 2011; McIlpatrick et al., 2011; Reidy et al., 2018; Satge et al., 2014; Taggart et al., 2011; Truesdale-Kennedy et al., 2011). Further validating this finding were experiences described by the HCPs working in a breast cancer setting which indicated that caregivers have little, if any, awareness regarding breast cancer risk, outcomes, prognosis or treatment.

Based on the findings from this study in the context of previous studies (Hanna et al., 2011; McIlpatrick et al., 2011; Reidy et al., 2018; Satge et al., 2014; Taggart et al., 2011; Truesdale-Kennedy et al., 2011), a need has been identified for education to improve breast cancer awareness levels for not only women with ID but also their caregivers and HCPs working in an ID setting.

7.2 | Fear associated with the word cancer

Past experiences of the women with ID have influenced their perception of cancer, particularly because their past experiences involved family members and friends who have died from cancer. As a result, there was an undeniable fatalistic association with cancer and a corresponding fear of getting cancer being voiced by the women with mild/moderate levels of ID. There is a dearth of literature exploring the experiences of people with ID with family or friends who have had cancer. However, two studies reported comparable findings describing how participants with ID voiced similar associations of cancer with death (Tuffrey-Wijne et al., 2010; Tuffrey-Wijne et al., 2012). Nowadays, the emphasis for cancer awareness health promotion campaigns is earlier detection, leading to an improved long-term prognosis (Allen et al., 2010; MacBride et al., 2012). Based on the above findings, it appears that this health promotion message has not reached women with mild/moderate levels of ID.

Previous studies have discussed fear but in the context of going for a mammogram specifically the unfamiliar surroundings, the procedure and the potential outcomes (Taggart et al., 2011; Truesdale-Kennedy et al., 2011). However, in the present study, fear took on a different meaning. The word 'cancer' evoked feelings of fear with the women expressing fears of getting cancer, fears of dying from cancer and some portrayed a fear of actually talking about cancer. Not only did the women with ID in this study express a strong desire to be safe from cancer but also for their families to be safe from cancer. This feeling of fear generated from the word 'cancer', and this desire to be safe from cancer do not appear to have been reported by previous researchers, therefore limiting comparisons. Similarly, the caregivers verbalised feelings of concern for women with ID and the need to protect them. Furthermore, the caregivers verified from their experiences that the word cancer tends to scare and frighten women with ID. Consequently, discussions about cancer awareness are often avoided to protect the woman with ID. The literature has provided little insight into this with respect to breast cancer awareness. However, the need to protect people with ID from a cancer diagnosis has been highlighted by many authors and often resulted in information being withheld (Flynn et al., 2016; Jones et al., 2006; O'Regan & Drummond, 2008; Tuffrey-Wijne et al., 2010; Tuffrey-Wijne et al., 2012). However, on some occasions, this decision to withhold information was based on the family or support staffs' personal preferences about receiving cancer information rather than those of the person with ID (Tuffrey-Wijne et al., 2010). The caregivers' personal beliefs and attitudes to cancer and cancer prevention have previously been acknowledged in the literature as potential barriers for supporting women with ID (Lunsky et al., 2003; McIlpatrick et al., 2011; Sisirak & Marks, 2015; Wyatt & Talbot, 2013).

Perhaps the focus should be on breast awareness as opposed to breast cancer awareness. Breast awareness may not evoke such feelings of fear as the word cancer is eliminated from the equation whilst breast awareness education would still equip women with ID with some of the tools in their ownership of this aspect of their own

health. Furthermore, focusing on breast awareness removes the barrier of the fatalistic association with cancer portrayed by the women with ID. In addition, it may alleviate the caregivers and HCPs' concerns of upsetting the woman with ID and in turn facilitate their supportive role by dispelling some of the pre-existing barriers such as personal attitudes to cancer.

7.3 | Being healthy

Early in the data collection, it was apparent that the term breast cancer awareness was challenging for the women with ID to comprehend. However, discussing what it means to be healthy was a topic which resonated with all the women whilst providing further insight into what they perceive as important.

Defining what it is to be healthy occurred without difficulty for the women with ID. The importance of exercise and eating healthy was at the core of their descriptions and appeared to have been learned by them from a young age. Similar definitions of what it means to be healthy were echoed in recent qualitative studies involving people with mild/moderate levels of ID (Caton et al., 2012; Kuijken et al., 2016). Akin to these previous studies, the women with ID in this study recognised that participating in behaviours such as smoking and drinking alcohol were unhealthy. Despite this desire to be healthy, low levels of exercise and increased incidence of obesity amongst women with ID have frequently been reported in the literature (Burke et al., 2014; De Winter et al., 2012; Doody & Doody, 2012; Hanna et al., 2011; Hilgenkamp et al., 2012; Hsieh et al., 2014; McCarron et al., 2011; McGuire et al., 2007; Sisirak & Marks, 2015). Correspondingly, many women with ID in this study were engaged in weight loss programmes which suggests that being aware of what it is to be healthy does not automatically lead to a healthier lifestyle.

Coincidentally, exercise and weight are considered modifiable risk factors which are an important component of breast cancer awareness. Although the women with ID may not recognise the link between the two, their awareness reassuringly demonstrates health-promoting behaviours. Although the education provided about exercise and diet was most likely for the purpose of general health as opposed to cancer prevention, it provides a basis for further health education such as breast awareness. Furthermore, the women's desire to be healthy should be capitalised on by incorporating breast awareness education into the ideal of being healthy.

7.4 | Not knowing

'Not knowing' whose responsibility it was to facilitate breast cancer awareness was evident throughout the interviews in this current study. The women with ID agreed that it is their responsibility to check their breasts, yet it remains unclear if they are frequently practising same. Although the caregivers believed that the responsibility for breast cancer awareness for women with ID lies with them, as

already reported, it appears they have not always accomplished this. The HCPs working in an ID setting believed the responsibility is not theirs but is the family and the caregivers' responsibility in addition to the family doctor or nurse. Consequently, breast cancer awareness practices appear suboptimal. Comparably, previous studies have reported that caregivers and HCPs are rarely engaging in breast cancer prevention and health promotion activities on behalf of women with ID due to a lack of knowledge, unclear guidelines and potential ethical issues (Arana-Chicasa et al., 2020; Collins et al., 2014; Hanna et al., 2011; Kirby & Hegarty, 2010; Wyatt & Talbot, 2013).

An area outside of the scope of this study which requires further research is who should facilitate breast examinations for women with ID if a woman may require physical support to do so.

7.5 | Learning new information

Many studies have determined that women with ID have significantly lower literacy levels than those without learning disabilities particularly in reading comprehension, functional reading skills, general intelligence, word recognition and spelling (MacArthur et al., 2010; Mellard & Patterson, 2008; Sisirak & Marks, 2015). Therefore, it was unsurprising to find in this present study that many of the women with ID favoured other methods of learning besides the written word. In recent years, the use of technology has been found to be a valuable tool in educating individuals with intellectual disabilities, highlighting the potential benefit of using a technology-assisted tool in educational interventions (Den Brok & Sterkenburg, 2014; Kagohara et al., 2012; Sisirak & Marks, 2015).

The findings from this study have indicated that there is a need for a multimodal, person-centred approach to suit the individual needs of the woman with ID. Ideally, what is required is simple information which is predominantly visual and is transferable from book format to computer format with a video component to meet individual learning needs/preferences. The need for such an approach is echoed in previous studies where an 'individualised supportive context' is seen as a facilitator in improving health literacy and health behaviours (Bergstrom et al., 2014; O'Regan & Drummond, 2008; Truesdale-Kennedy et al., 2011).

Similar to findings in the literature (Bergstrom et al., 2014), this study highlighted some of the complexities of engaging women with ID in learning which require consideration. For instance, the support needs of women with ID for information retention, sustained attention, level of intellectual functioning and finally the personal safety needs were seen as the primary concerns expressed by the caregivers and HCPs with respect to educating women with ID.

Generally speaking, health promotion interventions for people with ID are poorly developed and are rarely underpinned by theory (Kerr et al., 2013; Sisirak & Marks, 2015; Taggart et al., 2011; Willems et al., 2017). Corroborating with these findings, the five interventions identified in a previous literature review which aimed to increase cancer awareness or breast cancer awareness in people with ID did not appear to be based on specific theoretical frameworks (Gilbert

et al., 2007; Greenwood et al., 2014; Howieson & Clarke, 2013; Parish et al., 2012; Swaine et al., 2014; Walsh, O'Mahony, Lehane, et al., 2021). However, interventions designed to change behaviours should be theory based which would allow for an understanding of the personal and environmental factors which influence behaviours and behaviour change (Davis et al., 2015; Kerr et al., 2013; Willems et al., 2017).

8 | CONCLUSION

A combined healthy living and breast awareness educational intervention will provide women with mild/moderate levels of ID with the information, skills and support to empower them in making healthier lifestyle choices, becoming breast aware and assuming ownership of their own health. Engaging the caregivers and HCPs in education and training will provide them with the knowledge, skills and confidence in facilitating breast awareness education for women with ID. Consequently, this has the potential to lead to an earlier presentation of potential symptoms of breast cancer, earlier treatment, better prognosis and ultimately survival.

ACKNOWLEDGEMENTS

I owe many thanks to the late Ms Aine Byrne (Cope Foundation, Speech and Language Therapy Department, Cork, Ireland) for her contribution to this body of research. This research was funded by the Health Research Board (PDG/2015/2). Open access funding provided by IReL.

CONFLICT OF INTEREST

The authors of this article have no conflicts of interest to report.

AUTHOR CONTRIBUTIONS

Authors who conceived the original study idea and compiled grant application were S. Walsh, E. Lehane, D. Farrell, L. Taggart, L. Kelly, L. Sahn, M. Corrigan, M. Caples, A.M. Martin, S. Tabirca and M.A. Corrigan. The primary researcher who led the project was S. Walsh. Academic research supervisors who overlooked every aspect of the study from literature review, data collection, data analysis and editing of manuscript included J. Hegarty, E. Lehane and M. O'Mahony. Authors involved in the development of questionnaires were S. Walsh, J. Hegarty, M. O'Mahony, L. Taggart, A.M. Martin and M. Caples. The following authors were directly involved in the data collection (S. Walsh, D. Farrell) and data analysis (S. Walsh, J. Hegarty, E. Lehane, M. O'Mahony). The author who drafted the manuscript was S. Walsh. All authors provided critical feedback which helped shape the research and assisted in the editing of the manuscript: S. Walsh, J. Hegarty, E. Lehane, D. Farrell, L. Taggart, L. Kelly, L. Sahn, M. Corrigan, M. Caples, A.M. Martin, S. Tabirca, M.A. Corrigan and M. O'Mahony.

DATA AVAILABILITY STATEMENT

Research data are not shared.

ORCID

Susan Walsh  <https://orcid.org/0000-0001-7364-0410>

REFERENCES

- Allen, T. L., Van Groningen, B. J., Barksdale, D. J., & McCarthy, R. (2010). The breast self-examination controversy: What providers and patients should know. *The Journal for Nurse Practitioners*, 6(6), 444–451. <https://doi.org/10.1016/j.nurpra.2009.11.005>
- American Association of Intellectual and Developmental Disabilities. (2022). Definition of intellectual disability. <https://www.aaidd.org/intellectual-disability/definition> (Accessed 23rd January 2022)
- American Cancer Society. (2021). How common is breast cancer? [How Common Is Breast Cancer? | Breast Cancer Statistics](https://www.cancer.org/0-9/about-cancer/understanding/how-common-is-breast-cancer/) (Accessed 10th June 2021)
- Arana-Chicasa, E., Kioumarsib, A., Carroll-Scottb, A., Masseyb, P. M., Klassenb, A. C., & Yudellb, M. (2020). Barriers and facilitators to mammography among women with intellectual disabilities: A qualitative approach. *Disability & Society*, 35(8), 1290–1314. <https://doi.org/10.1080/09687599.2019.1680348>
- Bartholomew, L. K., Parcel, G. S., Kok, G., Gottlieb, N. H., & Fernandez, M. E. (2011). *Planning health promotion programs: An intervention mapping approach* (3rd ed.). Jossey-Bass.
- Bergstrom, H., Elinder, L. S., & Wihlman, U. (2014). Barriers and facilitators in health education for adults with intellectual disabilities – A qualitative study. *Health Education Research*, 29(2), 259–271. <https://doi.org/10.1093/her/cyt111>
- Brehmer-Rinderer, B., Zigrovic, L., Naue, U., & Weber, G. (2013). Promoting health of persons with intellectual disabilities using the UN convention on the rights of persons with disabilities: Early implementation assessment in Spain and Hungary. *Journal of Policy and Practice in Intellectual Disabilities*, 10(1), 25–36. <https://doi.org/10.1111/jppi.12018>
- Burke, E., McCallion, P., & McCarron, M. (2014). Advancing years, different challenges: Wave 2 IDS-TILDA. Dublin, Ireland: School of Nursing & Midwifery, Trinity College, Dublin.
- Caton, S., Chadwick, D., Chapman, M., Turnbull, S., Mitchell, D., & Stansfield, J. (2012). Healthy lifestyle for adults with intellectual disability: Knowledge, barriers and facilitators. *Journal of Intellectual & Developmental Disability*, 37(3), 248–259. <https://doi.org/10.3109/13668250.2012.703645>
- Collins, K., McClimens, A., MeKonnen, S., & Wyld, L. (2014). Breast cancer information and support needs for women with intellectual disabilities: A scoping study. *Psycho-Oncology*, 23(8), 892–897. <https://doi.org/10.1002/pon.3500>
- Davies, N., & Duff, M. (2001). Breast cancer screening for older women with intellectual disability living in community group homes. *Journal of Intellectual Disability Research*, 45(3), 253–257. <https://doi.org/10.1046/j.1365-2788.2001.00313.x>
- Davis, R., Campbell, R., Hildon, Z., Hobbs, L., & Michie, S. (2015). Theories of behaviour and behaviour change across the social and behavioural sciences: A scoping review. *Health Psychology Review*, 9(3), 323–344. <https://doi.org/10.1080/17437199.2014.941722>
- De Winter, C. F., Bastiaanse, L. P., Hilgenkamo, T. I. M., Evenhuis, H. M., & Ehteld, M. A. (2012). Overweight and obesity in older people with intellectual disability. *Research in Developmental Disabilities*, 33, 398–405. <https://doi.org/10.1016/j.ridd.2011.09.022>
- Den Brok, W. L., & Sterkenburg, P. S. (2014). Self-controlled technologies to support skill attainment in persons with an autism spectrum disorder and/or an intellectual disability: A systematic literature review. *Disability and Rehabilitation Assistive Technology*, 22, 1–10.
- Doody, C., & Doody, O. (2012). Health promotion for people with intellectual disability and obesity. *British Journal of Nursing*, 21(8), 460–465. <https://doi.org/10.12968/bjon.2012.21.8.460>
- Elo, S., & Kyngas, H. (2007). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107–115.

- Flynn, S., Hulbert-Williams, N. J., Hulbert-Williams, L., & Bramwell, R. (2016). "You don't know what's wrong with you": An exploration of cancer-related experiences in people with an intellectual disability. *Psycho-Oncology*, 25, 1198–1205. <https://doi.org/10.1002/pon.4211>
- Gilbert, T., Wilkinson, T., & Crudington, S. (2007). Supporting people with intellectual disability in the cancer journey: The living with cancer communication pack. *European Journal of Oncology Nursing*, 14(4), 357–361. <https://doi.org/10.1016/j.ejon.2006.12.005>
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24, 105–112. <https://doi.org/10.1016/j.nedt.2003.10.001>
- Greenwood, N. W., Tienwey Wang, C., Bowen, D., & Wilkinson, J. (2014). Testing the feasibility of a DVD-based intervention to promote preparedness for mammography in women with intellectual disabilities. *Journal of Cancer Education*, 29, 99–105. <https://doi.org/10.1007/s13187-013-0554-1>
- Hanna, L. M., Taggart, L., & Cousins, W. (2011). Cancer prevention and health promotion for people with intellectual disabilities: An exploratory study of staff knowledge. *Journal of Intellectual Disability Research*, 55(3), 281–291. <https://doi.org/10.1111/j.1365-2788.2010.01357.x>
- Hilgenkamp, T., Reis, D., Van Wijck, R., & Evenhuis, H. (2012). Physical activity levels in older adults with intellectual disabilities are extremely low. *Research in Developmental Disabilities*, 33, 477–483. <https://doi.org/10.1016/j.ridd.2011.10.011>
- Howieson, J., & Clarke, K. (2013). Ensuring service users can access crucial information. *Learning Disability Practice*, 16(1), 22–25. <https://doi.org/10.7748/ldp2013.02.16.1.22.e664>
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288. <https://doi.org/10.1177/1049732305276687>
- Hsieh, K., Rimmer, J. H., & Heller, T. (2014). Obesity and associated factors in adults with intellectual disability. *Journal of Intellectual Disability Research*, 58(9), 851–863. <https://doi.org/10.1111/jir.12100>
- Jones, A., Tuffrey-Wijne, I., Bernal, J., Butler, G., & Hollins, S. (2006). Meeting the cancer information needs of people with learning disabilities: Experiences of paid caregivers. *British Journal of Learning Disabilities*, 35, 12–18. <https://doi.org/10.1111/j.1468-3156.2006.00400.x>
- Kagohara, D. M., Sigafoos, J., Achmadi, D., O'Reilly, M., & Lancioni, G. (2012). Teaching children with autism spectrum disorders to check the spelling of words. *Research in Autism Spectrum Disorders*, 6(1), 304–310. <https://doi.org/10.1016/j.rasd.2011.05.012>
- Kerr, S., Lawrence, M., Darbyshire, C., Middleton, A. R., & Fitzsimmons, L. (2013). Tobacco and alcohol-related interventions for people with mild/moderate intellectual disabilities: A systematic review of the literature. *Journal of Intellectual Disability Research*, 57(5), 393–408. <https://doi.org/10.1111/j.1365-2788.2012.01543.x>
- Kirby, S., & Hegarty, J. (2010). Breast awareness within an intellectual disability setting. *European Journal of Oncology Nursing*, 14(4), 328–336. <https://doi.org/10.1016/j.ejon.2010.03.005>
- Kuijken, N. M. J., Naaldenberg, J., Nijhuis-van der Sanden, M. W., & Van Schrojenstein-Lantman de Valk, H. M. J. (2016). Healthy living according to adults with intellectual disabilities: Towards tailoring health promotion initiatives. *Journal of Intellectual Disability Research*, 60(3), 228–241. <https://doi.org/10.1111/jir.12243>
- Lambert, V. A., & Lambert, C. E. (2012). Qualitative descriptive research: An acceptable design. *Pacific Rim International Journal of Nursing Research*, 16(4), 255–256.
- Lunsky, Y., Straike, A., & Armstrong, S. (2003). Women be healthy: Evaluation of a women's health curriculum for women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 16(4), 247–253. <https://doi.org/10.1046/j.1468-3148.2003.00160.x>
- MacArthur, C. A., Konold, T. R., Glutting, J. J., & Alamprese, J. A. (2010). Reading component skills of learners in adult basic education. *Journal of Learning Disabilities*, 43(2), 108–121. <https://doi.org/10.1177/0022219409359342>
- MacBride, M., Pruthi, S., & Bevers, T. (2012). The evolution of breast self-examination to breast awareness. *Breast Journal*, 18(6), 641–643. <https://doi.org/10.1111/tbj.12023>
- McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Mulryan, N., Andrews, V., Foran, S., & McCallion, P. (2011). Growing older with an intellectual disability in Ireland 2011: First results from the intellectual disability supplement of the Irish longitudinal study on ageing. Dublin, Ireland: School of Nursing & Midwifery, Trinity College, Dublin.
- McDonald, K. E., Kidney, C. A., & Patka, M. (2013). 'You need to let your voice be heard': Research participants' views on research. *Journal of Intellectual Disability Research*, 57(4), 216–225. <https://doi.org/10.1111/j.1365-2788.2011.01527.x>
- McGuire, B. E., Daly, P., & Smyth, F. (2007). Lifestyle and health behaviours of adults with an intellectual disability. *Journal of Intellectual Disability Research*, 51(7), 497–510. <https://doi.org/10.1111/j.1365-2788.2006.00915.x>
- McIlpatrick, S., Taggart, L., & Truesdale-Kennedy, M. (2011). Supporting women with intellectual disabilities to access breast cancer screening: A healthcare professional perspective. *European Journal of Cancer Care*, 20(3), 412–420. <https://doi.org/10.1111/j.1365-2354.2010.01221.x>
- Mellard, D. F., & Patterson, M. B. (2008). Contrasting adult literacy learners with and without specific learning disabilities. *Remedial and Special Education*, 29(3), 133–144. <https://doi.org/10.1177/0741932508315053>
- Mencap. (2002). Mencap guidelines for accessible writing: Am I making myself clear? <http://www.accessibleinfo.co.uk/pdfs/making-myself-clear.pdf> (Accessed 20th April 2016)
- Mittler, P. (2015). The UN convention on the rights of person with disabilities: Implementing a paradigm shift. *Journal of Policy and Practice in Intellectual Disabilities*, 12(2), 79–89. <https://doi.org/10.1111/jppi.12118>
- NALA. (2016). Literacy in Ireland. <https://www.nala.ie/literacy> (Accessed 8th March 2016)
- National Disability Authority. (2009). Ethical guidance for research with people with disabilities. <http://nda.ie/nda-files/Ethical-Guidance-for-Research-with-People-with-Disabilities.pdf> (Accessed 2nd February 2015)
- National Federation of Voluntary Bodies. (2016). Basic ethical principles in conducting research. http://www.fedvol.ie/How_To_and_Checklists/Default.1366.html (Accessed: 2nd January 2016)
- O'Mahony, M., Comber, H., Fitzgerald, T., Corrigan, M. A., Fitzgerald, E., Grunfeld, E. A., Flynn, M. G., & Hegarty, J. (2017). Interventions for raising breast cancer awareness in women. *Cochrane Database of Systematic Reviews*, 2, 1–34. <https://doi.org/10.1002/14651858.CD011396.pub2>
- O'Regan, P., & Drummond, E. (2008). Cancer information needs of people with intellectual disability: A review of the literature. *European Journal of Oncology Nursing*, 12, 142–147. <https://doi.org/10.1016/j.ejon.2007.12.001>
- Ottmann, G., & Crosbie, J. (2013). Mixed method approaches in open-ended, qualitative, exploratory research involving people with intellectual disabilities: A comparative methods study. *Journal of Intellectual Disabilities*, 17(3), 182–197. <https://doi.org/10.1177/1744629513494927>
- Parish, S. L., Rose, R. A., Lukem, K., Swaine, J. G., & O'Hare, L. (2012). Cancer screening knowledge changes: Results from a randomised control trial of women with development disabilities. *Research on Social Work Practice*, 22(1), 43–53. <https://doi.org/10.1177/1049731511415550>
- Reidy, M., Denieffe, S., & Foran, S. (2018). Exploring breast cancer and screening awareness among Irish women with intellectual disabilities. *British Journal of Learning Disabilities*, 46(3), 193–201. <https://doi.org/10.1111/bld.12225>

- Sandelowski, M. (2000). Focus on research methods - Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334–340. [https://doi.org/10.1002/1098-240X\(200008\)23:4<334::AID-NUR9>3.0.CO;2-G](https://doi.org/10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G)
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health*, 33(1), 77–84. <https://doi.org/10.1002/nur.20362>
- Satge, D., Axmon, A., Tretarre, B., Sandberg, M., & Ahlstrom, G. (2020). Cancer diagnoses among older people with intellectual disability compared with the general population: A national register study. *Journal of Intellectual Disability Research*, 64(8), 579–588. <https://doi.org/10.1111/jir.12734>
- Satge, D., Sauleau, E. A., Jacot, W., Raffi, F., Azema, B., Bouyat, J. C., & Assaf, N. E. H. (2014). Age and stage at diagnosis: A hospital series of 11 women with intellectual disability and breast carcinoma. *BioMed Central Cancer*, 14(150), 1–6. <https://doi.org/10.1186/1471-2407-14-150>
- Sisirak, J., & Marks, B. (2015). Health and wellness strand: Recommendations from National Goals Conference 2015. *Inc*, 3(4), 242–249. <https://doi.org/10.1352/2326-6988-3.4.242>
- Skivington, K., Matthews, L., Simpson, S. A., Craig, P., Baird, J., Blazeby, J. M., Boyd, K. M., Craig, N., French, D. P., McIntosh, E., Petticrew, M., Rycroft-Malone, J., White, M., & Moore, L. (2021). Framework for the development and evaluation of complex interventions: Gap analysis, workshop and consultation-informed update. *Health Technology Assessment*, 25(57), 1–132. <https://doi.org/10.3310/hta25570>
- Swaine, J. G., Parish, S. L., Luken, K., Son, E., & Dickens, P. (2014). Test of an intervention to improve knowledge of women with intellectual disabilities about cervical and breast cancer screening. *Journal of Intellectual Disability Research*, 58(7), 651–663. <https://doi.org/10.1111/jir.12062>
- Taggart, L., Truesdale-Kennedy, M., & McIlpatrick, S. (2011). The role of community nurses and residential staff in supporting women with intellectual disability to access breast screening services. *Journal of Intellectual Disability Research*, 55(1), 41–52. <https://doi.org/10.1111/j.1365-2788.2010.01345.x>
- Truesdale-Kennedy, M., Taggart, L., & McIlpatrick, S. (2011). Breast cancer knowledge among women with intellectual disabilities and their experiences of receiving breast mammography. *Journal of Advanced Nursing*, 67(6), 1294–1304. <https://doi.org/10.1111/j.1365-2648.2010.05595.x>
- Tuffrey-Wijne, I., Bernal, J., & Hollins, S. (2010). Disclosure and understanding of cancer diagnosis and prognosis for people with intellectual disabilities: Findings from an ethnographic study. *European Journal of Oncology Nursing*, 14(3), 224–230. <https://doi.org/10.1016/j.ejon.2010.01.021>
- Tuffrey-Wijne, I., Giatras, N., Butler, G., & Cresswell, A. (2012). People with intellectual disabilities who are affected by a relative or friend with cancer: A qualitative study exploring experiences and support needs. *European Journal of Oncology Nursing*, 16, 512–519. <https://doi.org/10.1016/j.ejon.2012.01.002>
- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, 15, 398–405. <https://doi.org/10.1111/nhs.12048>
- Walsh, S., O'Mahony, M., Hegarty, J., Farrell, D., Taggart, L., Kelly, L., Sahm, L., Byrne, A., Corrigan, M., Caples, M., Martin, A. M., Tabirca, S., Corrigan, M. A., & Lehane, E. (2021). Defining breast cancer awareness and identifying barriers to breast cancer awareness for women with an intellectual disability: A review of the literature. *Journal of Intellectual Disabilities*, 174462952199954(online first). <https://doi.org/10.1177/1744629521999548>
- Walsh, S., O'Mahony, M., Lehane, E., Farrell, D., Taggart, L., Kelly, L., Sahm, L., Byrne, A., Corrigan, M., Caples, M., Martin, A. M., Tabirca, S., Corrigan, M. A., & Hegarty, J. (2021). Cancer and breast cancer awareness interventions in an intellectual disability context: A review of the literature. *Journal of Intellectual Disabilities*, 25(1), 131–145. <https://doi.org/10.1177/1744629519850999>
- Wilkinson, J. E., & Cerreto, M. C. (2008). Primary care for women with intellectual disabilities. *Journal of the American Board of Family Medicine*, 21(3), 215–222. <https://doi.org/10.3122/jabfm.2008.03.070197>
- Wilkinson, J. E., Deis, C. E., Bowen, D. J., & Bokhour, B. G. (2011). 'It's easier said than done': Perspectives on mammography from women with intellectual disabilities. *Annals of Family Medicine*, 9(2), 142–147. <https://doi.org/10.1370/afm.1231>
- Willems, M., Hilgenkamp, T. I. M., Havik, E., Waninge, A. N., & Melville, C. A. (2017). Use of behaviour change techniques in lifestyle change interventions for people with intellectual disabilities: A systematic review. *Research in Developmental Disabilities*, 60, 256–268. <https://doi.org/10.1016/j.ridd.2016.10.008>
- World Health Organisation (WHO). (2021). Breast Cancer. Breast cancer (who.int) (Accessed 5th June 2021)
- Wyatt, D., & Talbot, P. (2013). What knowledge and attitudes do paid caregivers of people with a learning disability have about cancer? *European Journal of Cancer Care*, 22, 300–307. <https://doi.org/10.1111/ecc.12029>

How to cite this article: Walsh, S., Hegarty, J., Lehane, E., Farrell, D., Taggart, L., Kelly, L., Sahm, L., Corrigan, M., Caples, M., Martin, A. M., Tabirca, S., Corrigan, M. A., & O'Mahony, M. (2022). Determining the need for a breast cancer awareness educational intervention for women with mild/moderate levels of intellectual disability: A qualitative descriptive study. *European Journal of Cancer Care*, 31(4), e13590. <https://doi.org/10.1111/ecc.13590>