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## **Title Page**

Review Article

### **Cancer and Breast Cancer Awareness Interventions in an Intellectual Disability Context: A Review of the Literature**

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## Anonymous Main Document

Review Article

### **Cancer and Breast Cancer Awareness Interventions in an Intellectual Disability Context: A Review of the Literature**

#### *Abstract*

**Background:** Women with an intellectual disability (ID) have a similar risk of developing breast cancer as women in the general population yet present with later stage breast cancers, which have poorer outcomes.

**Aim:** To identify whether there is a need to develop a breast cancer awareness intervention for women with an ID.

**Methods:** Interventions aimed at increasing cancer awareness and breast cancer awareness for people with an ID were identified and critically appraised.

**Results:** Five interventions to increase cancer awareness or breast cancer awareness in people with an ID were identified.

**Conclusion:** The review highlighted the paucity of theoretically underpinned breast cancer awareness interventions specifically aimed at women with an ID. Facilitating breast cancer awareness for women with an ID could potentially lead to earlier presentation of potential symptoms of breast cancer, earlier treatment, better prognosis and ultimately, improved survival.

**Funding:** This research was funded by the Health Research Board (PDG/2015/2)

**Key Words:** Breast cancer awareness, cancer awareness, intellectual disability, intervention, review

**What this paper adds?** This paper establishes that there is a need for an intervention underpinned by theory to increase breast cancer awareness in women with an ID.

## 1. Introduction-Background

Globally, breast cancer is the second most common cause of death from cancer in women with the lifetime risk of developing breast cancer for the general population at 12% (National Cancer Registry Ireland, 2016; Cancer Research UK, 2014; National Cancer Institute, 2014). The two most important risk factors for developing a breast cancer are being female and aging (American Cancer Society, 2015; Kharboush *et al.*, 2011; Allen *et al.*, 2010). Demographic trends suggest that the number of people with an intellectual disability (ID) is increasing with a corresponding increase in the older demographic profile (Collins *et al.*, 2014; Reidy *et al.*, 2014). Therefore, the numbers who are at risk of developing cancer including breast cancer are also increasing (Satge *et al.*, 2014; Hanna *et al.*, 2011).

Women with an ID are considered to have the same risk of developing breast cancer as women in the general population (Reidy *et al.*, 2014; Truesdale-Kennedy *et al.*, 2011; Wilkinson & Cerreto, 2008). However, there is growing evidence to suggest that women with an ID are more likely to experience a greater number of risk factors for breast cancer, thus placing them at an increased risk of developing breast cancer when compared with women in the general population (Taggart *et al.*, 2011; Parish *et al.*, 2012; Lalor & Redmond, 2009). These risk factors include: nullparity, low levels of exercise and higher rates of obesity (Burke *et al.*, 2014; Hsieh *et al.*, 2014; Hilgenkamp *et al.*, 2012; Parish *et al.*, 2012; McCarron *et al.*, 2011; Lalor & Redmond, 2009). Furthermore, women with an ID also possess limited knowledge about breast awareness and breast cancer (Truesdale -Kennedy *et al.*, 2011). Consequently, women with an ID present with later stage breast cancers, which ultimately have poorer clinical outcomes (Satge *et al.*, 2014; Taggart *et al.*, 2011). By improving breast cancer awareness, including the early recognition of signs and symptoms of breast cancer, an environment for early cancer detection in women with an ID could be supported (Satge *et al.*, 2014). To assess what is needed to improve breast cancer awareness in women with an ID, a review of current interventions, to establish their efficacy, was deemed necessary.

This paper will identify, describe and critically appraise interventions that focused on raising cancer awareness or breast cancer awareness in the context of people with an ID.

## 2. Methods

### 2.1 Data Sources

The electronic databases CINAHL, Pubmed, and PsycInfo were searched within a 12-year time limit (2006-2018). The PICO framework (Patient, Intervention, Comparison, and Outcome) was used as a guide in formulating questions in order to identify relevant literature (Yensen, 2013).

### 2.2 Search strategy

An initial search was conducted in order to examine broader literature on cancer awareness interventions within an ID context. Four search strings (S2, S3, S4, S5) were combined with 'AND', with the following limits set: English language, abstract and years 2006-2018. A second search was carried out to examine literature specific to breast cancer awareness interventions within an ID context. All five search strings (S1, S2, S3, S4 and S5) were combined with 'AND', using the same limits previously mentioned.

- S1 Breast
- S2 Cancer OR lesion OR malignancy OR neoplasm OR carcinoma OR tumor OR tumour
- S3 Awareness, OR aware\* OR knowledge
- S4 intervention OR education OR program\* OR programme OR "health promotion" OR promotion OR empowerment
- S5 "Intellectual disability" OR "intellectual disabilities" OR "learning disability" OR "learning disabilities" OR "mental retardation" OR "mental handicap" OR "developmental disability" OR "developmental disabilities"

Studies were excluded if they did not relate to people with an ID, their carers or healthcare professionals (HCP's) in the context of cancer awareness or breast cancer awareness. Studies in which an intervention was not implemented were also excluded.

### 2.3 Quality Assessment

Critical Appraisal Skills Programme (CASP, 2016) checklists were used in the quality assessment of the included papers and guided the development of the data extraction (Table 1). Member checking of the CASP checklists utilised was undertaken to ensure credibility of the quality assessment of the included papers. The CASP checklists encourage the researcher to

address three broad, but essential, issues when appraising a study: validity of the results, what the results are and, will the results help locally (CASP, 2016). The data extraction table presents each study separately outlining a description of the intervention, outcomes which were assessed, and the impact of the intervention.

#### *2.4 Search Outcome (Figure 1)*

Following an eligibility review of both searches and removal of duplicate articles, 79 records were examined. Following peer checking of the search strategy, the abstracts of these records were reviewed and 66 were removed, as they did not include an intervention on cancer awareness or breast cancer awareness. Finally, the texts of the remaining 13 papers were reviewed in full, and assessed for eligibility.

A total of five studies met the inclusion criteria; two RCT's from the USA (Swaine *et al.*, 2014; Parish *et al.*, 2012), two evaluation studies from the UK (Howieson & Clarke, 2013; Gilbert *et al.*, 2007) and, one feasibility study from the USA (Greenwood *et al.*, 2014).

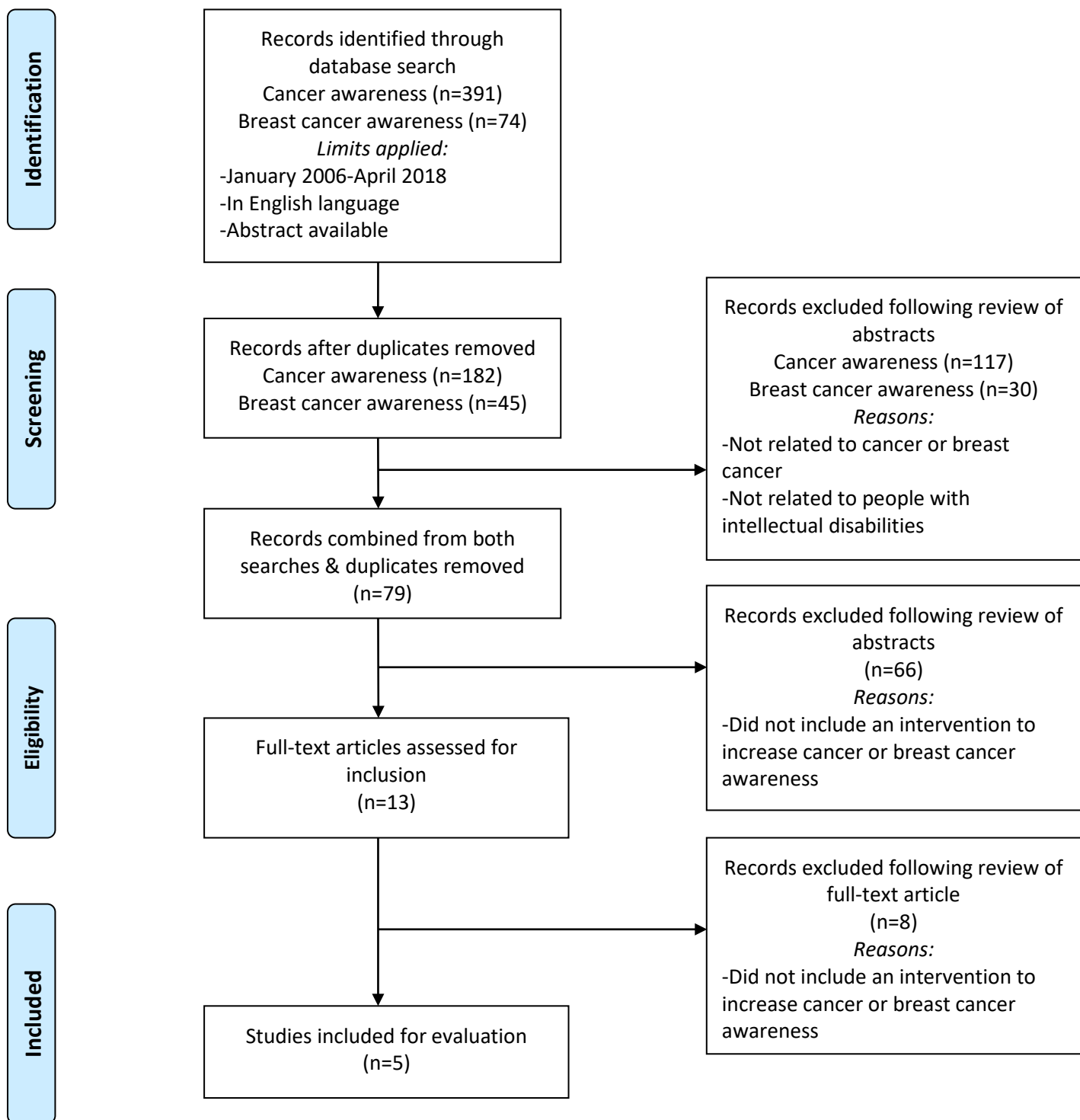


Figure 1: PRISMA (Moher *et al.*, 2009) flowchart illustrating the search outcomes on the literature for existing cancer awareness and breast cancer awareness interventions in an ID context



### 3. Results

#### 3.1 General Findings

Of the five studies included, two randomised control trials (RCT's) examined the success of a cervical and breast cancer screening educational intervention specifically developed for women with an ID (Swaine *et al.*, 2014; Parish *et al.*, 2012). Three studies evaluated the effectiveness of health education information on cancer related topics, including breast cancer, developed specifically for people with an ID (Greenwood *et al.*, 2014; Howieson & Clarke, 2013; Gilbert *et al.*, 2007).

Three of the studies were conducted in the USA (Greenwood *et al.*, 2014; Swaine *et al.*, 2014; Parish *et al.*, 2012) whilst the remaining two studies were conducted in the UK (Howieson & Clarke, 2013; Gilbert *et al.*, 2007).

Only two of the studies specified the level of ID (Swaine *et al.*, 2014; Parish *et al.*, 2012) but all five made reference to verification of ID either via medical records or being in receipt of services for people with an ID (Greenwood *et al.*, 2014; Swaine *et al.*, 2014; Howieson & Clarke, 2013; Parish *et al.*, 2012; Gilbert *et al.*, 2007). The number of participants with an ID varied greatly (from n=5 to n=198) with one study (Howieson & Clarke, 2013) providing no detail about the exact number of participants with an ID. The two RCT's determined their sample size through power calculations (Swaine *et al.*, 2014; Parish *et al.*, 2012).

#### 3.2 Intervention Description

The two RCT's "Women Be Healthy" (WBH1-two-arm study) and a revised version "Women Be Healthy 2" (WBH2- three-arm study) tested the effectiveness of an educational intervention to increase the knowledge of women with an ID on cervical and breast cancer screening (Swaine *et al.*, 2014; Parish *et al.*, 2012). The remaining three studies evaluated the effectiveness of health education information on cancer related topics developed specifically for people with an ID (Greenwood *et al.*, 2014; Howieson & Clarke, 2013; Gilbert *et al.*, 2007). One of the studies evaluated a written communication pack about living with cancer and health promotion topics (Gilbert *et al.*, 2007) whilst the second evaluated easy read booklets, a DVD and a website about cancer screening programmes (Howieson & Clarke, 2013). The final study evaluated the

effectiveness of a DVD in preparing women with an ID for a breast screening mammogram (Greenwood *et al.*, 2014).

While it is possible that these educational interventions were underpinned by theoretical frameworks, this was not reported in any of the studies. However, two studies indicated that their educational information was based on “total communication” (Howieson & Clarke, 2013; Gilbert *et al.*, 2007) which is an approach that supports the use of a variety of communication methods e.g. signs, symbols, pictures etc.

### 3.3 Outcomes Assessed

As this review is centred around interventions that focused on raising cancer awareness or breast cancer awareness in the context of ID, the interventions were specifically reviewed to determine if the outcomes included breast cancer awareness and knowledge about cancer.

Three of the five studies carried out individual, pre and post intervention assessments (Greenwood *et al.*, 2014; Swaine *et al.*, 2014; Parish *et al.*, 2012). Breast cancer awareness was assessed in two of these studies via questions about “*whose responsibility it is do a breast examination*” and “*what to do if a lump is found*” (Swaine *et al.*, 2014; Parish *et al.*, 2012). Knowledge about cancer was assessed in three studies via questions about the “*definition of cancer*”, “*purpose and frequency of mammography*” in addition to “*knowledge of cervical cancer screening*” (Greenwood *et al.*, 2014; Swaine *et al.*, 2014; Parish *et al.*, 2012). The remaining two studies relied on participant feedback via questionnaires, but response rates were reported as low and specific questions asked were not outlined (Howieson & Clarke, 2013; Gilbert *et al.*, 2007). So it can be surmised, that no standardised measures were used across the five interventions.

### 3.4 Impact of the Interventions

Knowledge gains were reported in three of the five studies (Greenwood *et al.*, 2014; Swaine *et al.*, 2014; Parish *et al.*, 2012). Control groups in both RCT’s (Swaine *et al.*, 2014; Parish *et al.*, 2012) received no education or change in their normal daily routine, however, both control groups demonstrated significant knowledge gains ( $p < 0.05$ ) on “*what to do if a lump is found*” suggesting that there was transfer of knowledge between participants. This may be due to contact between the participants outside of the study context as each site had equal numbers of

participants in both control groups and intervention groups. In both trials, there were significant improvements for the “WBH1” intervention groups on knowledge of the “*definition of and frequency of mammography*” ( $p < 0.01$ ) but no differences were seen regarding “*whose job it is to do a breast exam*” or “*what to do if a lump is found*” (Swaine *et al.*, 2014; Parish *et al.*, 2012). However, the revised educational intervention group “WBH2”, showed significant differences on only one out of the four components of breast cancer awareness that were assessed i.e. “*what to do if you find a lump*” ( $p < 0.05$ ). This indicates that the original shorter educational intervention “WBH1” (Parish *et al.*, 2012) was more successful in increasing knowledge about breast cancer screening. This may be because the changes to the “WBH2” intervention group were primarily to do with cervical cancer screening. Additionally, the “WBH2” group size was relatively small in comparison, which may reflect the differences in results.

The study which tested the feasibility of a DVD-based intervention to promote preparedness for mammography in women ( $n=46$ ) with an ID (Greenwood *et al.*, 2014) reported knowledge increases regarding the purpose of (70.2% pre-test; 80% post-test) and frequency of mammography (63.8% pre-test; 75.5% post-test). However, it is not reported whether these knowledge differences were statistically significant. It is important to note that the majority of participants ( $n=92.4\%$ ) had at least one mammogram prior to this intervention which would affect the pre-test knowledge.

The remaining two studies reported positive feedback in relation to the health information received about cancer and cancer screening programmes in addition to the communication aids used (Howieson & Clarke, 2013; Gilbert *et al.*, 2007). However, response rates were low and methods of obtaining feedback about the health information were not fully reported.

Table 1: Sample of the data extraction table detailing existing cancer awareness and breast cancer awareness interventions

<b>Intervention details</b> Authors (Date) Country i. Type of study/design ii. Sample details	<b>Q.1</b> i. Description of intervention ii. Feature/components of intervention (how & who) iii. Underpinning theory (if any)	<b>Q.2 Outcomes assessed/how</b> i. Breast cancer awareness ii. Knowledge	<b>Q.3 Impact of intervention</b> i. Breast cancer awareness ii. Knowledge iii. Measure of confidence
<b>Intervention 1:</b> Women Be Healthy Parish <i>et al.</i> , (2012) USA i. Randomised controlled trial (RCT) ii. Women with a mild-moderate ID (n=175). .	i. To measure the success of the “Women be Healthy” educational intervention in improving the knowledge levels of women with an ID about cervical and breast cancer screening ii. Control group (n=84): no change to daily activities at each partner site Intervention group (n=91): 8 weekly 90 minute sessions which included role play, group & individual activities, anxiety reduction strategies and visits to physician’s office iii. NR	Baseline knowledge survey and post-test computer assisted face-to-face individual interviews i. Who is responsible for breast examination, what to do if a lump is found ii. Definition of cancer, definition & frequency of mammogram, knowledge of cervical cancer screening	i. No statistically significant differences for intervention group on whose job it is to do a breast exam and what to do if a lump is found. ii. Significant differences in the intervention group on knowledge for the definition of mammogram (p<0.01) and frequency of mammogram (p<0.01) iii. Control group showed significant differences on what to do if a lump is found (p <0.05) which indicates there may have been knowledge transfer between participants as nearly all sites had equal numbers women in the control group and intervention groups
<b>Intervention 2:</b> Women Be Healthy 2 Swaine <i>et al.</i> , (2014) USA i. Randomised controlled trial ii. Women with a mild, moderate & severe ID (n=198)	i. To compare the effectiveness of the existing cervical and breast cancer screening educational intervention “Women be Healthy” and a revised, extended intervention “Women be Healthy 2” ii. Control group(n=65): no change to daily activities at each partner site Intervention group (n=98) participated in the “Women be Healthy” educational intervention Delayed intervention group (n=35) participated in the “Women be Healthy 2” educational intervention: 11 twice-weekly sessions. Additional information on cervical cancer, hands-on activities and resource material. Role-play was removed from this revised programme. iii. NR	Face-to-face, computer assisted individual interviews were conducted pre and post the intervention. i. Who is responsible for breast examination, what to do if a lump is found ii. Definition of cancer, definition & frequency of mammogram, knowledge of cervical cancer screening	i. No statistically significant differences for the intervention group “Women be Healthy” on whose job it is to do a breast exam and what to do if a lump is found. Statistically significant differences were seen for the delayed intervention group “Women be Healthy 2” on what to do if a lump is found (p<0.05) but no statistically significant difference seen on whose job it is to do a breast exam. ii. Significant differences were seen in the intervention group “Women be Healthy” on knowledge of the definition of mammogram (p<0.01) and frequency of mammogram (p<0.01). No significant differences were seen in the delayed intervention group “Women be Healthy 2” on knowledge of the definition of mammogram or frequency of mammogram. iii. Control group showed significant differences on what to do if a lump is found (p <0.05) which indicates there may have been knowledge transfer between participants as women had contact with each other outside of the interventions

<b>Intervention details</b> Authors (Date) Country i. Type of study/design ii. Sample details	<b>Q.1</b> i. Description of intervention ii. Feature/components of intervention (how & who) iii. Underpinning theory (if any)	<b>Q.2 Outcomes assessed/how</b> i. Breast cancer awareness ii. Knowledge	<b>Q.3 Impact of intervention</b> i. Breast cancer awareness ii. Knowledge iii. Measure of confidence
<b>Intervention 3:</b> Living with Cancer Gilbert <i>et al.</i> , (2007) UK i. Evaluation study of educational material ii. People with an ID (n=5) (Level of ID not specified)  Postal questionnaire (n=116)  Follow-up telephone interviews (n=10), a purposive sample from questionnaires returned was used.	i. To provide a holistic view of the effectiveness of the “Living with Cancer” communication pack from four different sources (mapping dissemination of materials, focus groups with people with ID, postal questionnaires to organisations that received the pack, follow-up telephone interviews with respondents to the postal questionnaires)  ii. “Living with Cancer” consists of two parts: health promotion and the cancer journey. Additional sections on: how to use the pack, principles underpinning the total communication techniques approach, tools related to expressing pain and symptom control and 25 sets of symbols (11 associated with health promotion and 14 to support the cancer journey).  iii. NR	i. Breast cancer awareness was not specifically assessed.  ii. Knowledge gains were not specifically assessed.	i. Breast cancer awareness was not specifically assessed.  ii. Knowledge gains were not specifically assessed.  iii. NR
<b>Intervention 4:</b> Cancer screening programmes Howieson & Clarke (2013) UK i. Development and evaluation of easy read booklets & total communication aid. ii. Learning disability nurses (n=2) Working group ( number of participants not specified) Focus groups (n=3) consisting of people with an ID ( number of participants or level of ID not specified)	i. To develop and appraise a range of easy read booklets, DVD’s, a website and a total communication aid to improve the accessibility of information for people with an ID and staff involved in their care in relation to screening programmes.  ii. Focus groups (n=3) advised on the layouts, pictures and language used in the easy read leaflets, booklets and total communication aid in addition to reviewing existing DVD’s in order to improve them.  The working group ensured information was accurate and evidence based.  iii. NR	i. Breast cancer awareness was not specifically assessed.  ii. Knowledge gains were not specifically assessed.	i. Breast cancer awareness was not specifically assessed.  ii. Knowledge gains were not specifically assessed.  iii. NR
<b>Intervention 5:</b> DVD about Mammography Greenwood <i>et al.</i> , (2014) USA i. Feasibility study ii. A convenience sample of women with an ID (n=53) aged 37 and above (level of ID not specified)	i. To test the feasibility of a DVD based health promotion intervention to increase the “preparedness” for mammography in women with an ID.  ii. A brief DVD featuring an actor with an ID who takes viewers through the process of going for a mammogram from start to finish highlighting any barriers that may arise.  iii. NR	Verbal face-to-face, individual interviews were conducted pre and post the intervention.  i. Breast cancer awareness was not specifically assessed.  ii. Knowledge about the purpose and frequency of mammography was assessed	i. Breast cancer awareness was not specifically assessed.  ii. Knowledge increases seen for the purpose of a mammogram (n= 70.2% pre-test; 80% post-test) and frequency of mammography (n= 63.8% pre-test; 75.5% post-test). Not known, if these were statistically significant.  iii. Majority of participants (n=92.5%) had at least one mammogram prior to this intervention which would affect pre-test knowledge.

#### 4. Discussion

Five interventions were identified which aimed to increase cancer awareness or breast cancer awareness in people with an ID, none of which focused solely on breast cancer awareness. Despite this, the WBH group educational sessions proved to be successful in educating women with a mild/moderate ID about breast and cervical cancer screening in two RCT's (Swaine *et al.*, 2014; Parish *et al.*, 2012). At least one care staff member from each recruitment site was trained in the delivery of the interventions. Groups consisted of 6-8 women and 60-90 minute educational sessions that were delivered over 8-12 weeks. Although not assessed over a long timeframe, short-term knowledge gains were seen for several components of the programmes. This tentatively suggests that a breast cancer awareness intervention could be effective if delivered in a similar manner.

The aforementioned RCT's (Swaine *et al.*, 2014; Parish *et al.*, 2012) used a multi-modal, hands-on approach in their educational session. Similarly, the remaining three interventions utilised a combination of total communication techniques (Howieson & Clarke, 2013; Gilbert *et al.*, 2007), easy read materials (Howieson & Clarke, 2013; Gilbert *et al.*, 2007) and DVD's (Greenwood *et al.*, 2014; Howieson & Clarke, 2013). The feedback from all three of these studies was positive, highlighting the need for, and interest in, such educational materials. Furthermore, some of the educational materials in two of the studies included easy read booklets and DVD's specifically about breast awareness, healthy eating, weight and exercise which constitute some elements of breast cancer awareness (Howieson & Clarke, 2013; Gilbert *et al.*, 2007).

The importance of the inclusion of the carers and HCP's working in an ID setting in any educational intervention has been well established in the literature (Bergstrom *et al.*, 2014; Oldrieve & Waight, 2013; Truesdale-Kennedy *et al.*, 2011). Regardless, it appears that the previous RCTs did not provide education for the carers or the HCPs working in an ID setting in the educational programmes, with the exception of the care staff recruited for the delivery of the intervention (Swaine *et al.*, 2014; Parish *et al.*, 2012). Similarly, information was provided to the carers and HCPs regarding the dissemination of the accessible educational information in two of the studies (Howieson & Clarke, 2013; Gilbert *et al.*, 2007). The wider involvement of carers and HCPs in educational interventions will allow for any learning to be put into practice in everyday life (Bergstrom *et al.*, 2014). It will potentially afford the carers and HCP's the skills, knowledge and confidence required to empower women with an ID in

being breast cancer aware and making healthier lifestyle choices (Bergstrom *et al.*, 2013; Wyatt & Talbot, 2013; Hanna *et al.*, 2011). However, it may be more appropriate to have a separate educational session for the carers and HCP's to ensure the autonomy of the woman with an ID is maintained (Bergstrom *et al.*, 2014).

Health promotion interventions for people with an ID are poorly developed and are rarely underpinned by any theory (Willems *et al.*, 2017; Kerr *et al.*, 2013; Taggart *et al.*, 2011). Corroborating these findings, the five studies identified in the current review did not appear to be based on any learning or behaviour change theories (Greenwood *et al.*, 2014; Swaine *et al.*, 2014; Howieson & Clarke, 2013; Parish *et al.*, 2012; Gilbert *et al.*, 2007). However, the literature has indicated that, in order to be effective, interventions designed to change behaviour should be theory-based which would allow for an understanding of the personal and environmental factors that influence behaviour and behaviour change (Willems *et al.*, 2017; Davis *et al.*, 2015; Kerr *et al.*, 2013). A scoping review identified 82 theories of behaviour and behaviour change that were relevant to public health interventions (Davis *et al.*, 2015). However, almost two thirds (n=174) of the articles reviewed (n=276) by Davis *et al.* (2015) were linked to four theories: the Transtheoretical Model of Change (n=91), the Theory of Planned Behaviour (n=36), Social Cognitive Theory (n=29) and the Information-Motivation-Behavioural-Skills Model (n=18).

Previous studies using cluster randomised controlled designs, which were based on the "Social Cognitive Theory" (Bandura, 2004) and the "Transtheoretical Model of Change" (Prochaska & DiClemente, 1983) aimed to promote diet and physical activity in people with ID, reported mixed results (Melville *et al.*, 2015; Bergstrom *et al.*, 2013; Elinder *et al.*, 2010). Reasons suggested for the ineffectiveness of one of the programmes, were the difficulties participants experienced with self-monitoring and goal setting (Melville *et al.*, 2015). Ultimately, the authors believed that the behaviour change techniques were too complex for most of the participants with an ID.

Furthermore, a systematic review that examined the use of behaviour change techniques in lifestyle change interventions for people with an ID, primarily nutrition and exercise, identified 45 relevant studies (Willems *et al.*, 2017). Some of the behaviour change techniques were consistent with two common facilitators of health behaviours reported in previous studies i.e. social support and motivation. Although behaviour change techniques

can be considered complex, if adapted to suit the participants' needs, they may be effective in lifestyle change interventions (Willems *et al.*, 2017; Melville *et al.*, 2015).

Given the complexities of engaging women with an ID in learning, any single behaviour change theory may not be entirely suitable to underpin an intervention to increase breast cancer awareness in this population. French *et al.* (2012) have suggested utilising a “broadly based theoretical framework” such as the Theoretical Domains Framework (TDF) in attempting to change health behaviours. This four-step approach is a combination of a broad range of behaviour change theories that incorporate behaviour change techniques in attempting to overcome barriers to behaviour change (Steinmo *et al.*, 2016; French *et al.*, 2012). Therefore, it may be a suitable theoretical framework to underpin a breast cancer awareness educational intervention. Furthermore, Willems *et al.* (2017) highlighted that both the use of a theoretical framework to underpin lifestyle change interventions and the tailoring of interventions specifically for individuals with an ID would enhance the effectiveness of the intervention. Given the evidence presented, this is worth considering when developing a breast cancer awareness educational intervention particularly due to the obvious lack of interventions underpinned by theories specifically aimed at people with an ID. In addition, there is a need to unpack intervention processes and outcomes, which can be accomplished by using a logic model. This will map out the links between the intervention, outcomes and impacts in order to develop a summarised understanding of how a complex intervention works or does not work.

Considering the lack of interventions focusing solely on breast cancer awareness specifically aimed at women with an ID, it was necessary to look at interventions aimed at women in the general population. Notably, a recent Cochrane systematic review identified that there was a similar lack of interventions aimed to increase breast cancer awareness for women in the general population (O'Mahony *et al.*, 2017). The authors of this Cochrane review, which assessed the effectiveness of interventions for raising breast cancer awareness in women in the general population, found that only two RCT's (Eskandari-Torbaghan *et al.*, 2014; Forbes *et al.*, 2011) met the inclusion criteria (O'Mahony *et al.*, 2017). The Promoting Early Presentation (PEP) intervention aimed at increasing breast cancer awareness in women aged 67-70years (n=867) at their final routine mammogram (Forbes *et al.*, 2011). The Zahedan University of Medical Sciences (ZUMS) study aimed to improve breast cancer preventative behaviours in women aged 35-39years (n=130) (Eskandari-Torbaghan *et al.*, 2014). Both



interventions used written information to educate women. The ZUMS study also utilised Microsoft Power-Point presentations, videos and a compact disc to deliver their educational material.

Although the authors of the review advised caution when interpreting the findings of the review due to the low-moderate quality of the studies, they concluded that a brief intervention could potentially increase women's breast cancer awareness (O'Mahony *et al.*, 2017). Given the lack of interventions to increase breast cancer awareness for women in the general population, the paucity of cancer awareness and breast cancer awareness interventions specifically aimed at women with an ID is not surprising.

## **5. Conclusion & Recommendations**

An extensive review of the literature has highlighted that there is a dearth of cancer awareness and breast cancer awareness interventions specifically aimed at women with an ID. There were no interventions focusing solely on breast cancer awareness for women with an ID identified in the review. There is a similar shortage of quality interventions to increase breast cancer awareness amongst women in the general population (O'Mahony *et al.*, 2017).

To address this notable gap in research, there is an urgent need for an intervention underpinned by theory to increase breast cancer awareness in women with an ID. However, prior to developing such an intervention it is important to firstly engage with key stakeholders including women with an ID and their carers, to gain their perspectives on the processes and content required to underpin an intervention. This would help to ensure that the specific needs of women with an ID would be at the core of an educational intervention for breast cancer awareness thus, aiding its successful implementation.

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