Defining Breast Cancer Awareness and Identifying Barriers to Breast Cancer Awareness for Women with an Intellectual Disability: A Review of the Literature

Abstract

Introduction

Incidence rates for developing breast cancer are similar for women regardless of intellectual ability. However, women with an intellectual disability present with advanced breast cancers, which often have a poor prognosis.

Method

A structured narrative review of the literature was performed to explore the concepts of breast awareness and breast cancer awareness and subsequently, identify barriers to breast cancer awareness encountered by women with an intellectual disability.

Results

A total of 22 studies involving people with varying levels of intellectual disability informed this review. The barriers to breast cancer awareness encountered by women with an intellectual disability include: lack of their understanding, the role of the carer and literacy issues.

Conclusion

Identifying the barriers to breast cancer awareness for women with an intellectual disability will help to facilitate breast cancer awareness which has the potential to result in better long-term outcomes through an early diagnosis of breast cancer.

Keywords: Barriers, Breast awareness, Breast cancer awareness, Facilitators, Intellectual disabilities

1. Background

An intellectual disability (ID) is defined as limitations in intellectual functioning and adaptive behavior expressed in practical, social and conceptual skills, which develops before the age of 18 years (American Association of Intellectual and Developmental Disabilities, 2013). Recent studies of the population suggest trends that the number of people with an intellectual disability (ID) is increasing with a corresponding increase in the elderly demographic. (Albuquerque & Carvalho, 2020; Bates & Triantafyllopoulou, 2019; Walsh *et al.,* 2019; O'Leary *et al.,* 2018; Reidy *et al.,* 2018; Seaton *et al.,* 2018; National Intellectual Disability Database, 2017; Collins *et al.,* 2014; Reidy *et al.,* 2014). As a result, the number of people with an intellectual disability who are at risk of developing cancer is increasing, including breast cancer (Satge et al., 2020;

Bates & Triantafyllopoulou, 2019; O'Leary *et al.,* 2018; Reidy *et al.,* 2018; Satge *et al.,* 2014; Hanna *et al.,* 2011). Incidence rates for developing breast cancer are similar for women regardless of intellectual ability (Satge et al., 2020; Reidy *et al.,* 2014; Willis, 2013; Truesdale-Kennedy *et al.,* 2011; Wilkinson & Cerreto, 2008). However, it has been reported that breast cancer awareness knowledge levels are low amongst women with an intellectual disability (Reidy *et al.,* 2018; Truesdale -Kennedy *et al.,* 2011). Consequently, women with an intellectual disability often present with advanced breast cancers, which often have a poor prognosis (Satge et al., 2020; Seaton *et al.,* 2018; Satge *et al.,* 2014; Taggart *et al.,* 2011). An increase in breast cancer awareness knowledge among this cohort of women could result in an earlier diagnosis in breast cancer with potentially more favourable long-term outcomes (Walsh *et al.,* 2019; Satge *et al.,* 2014).

The aims of this structured narrative review are to: (i) critically explore the literature surrounding the concepts of breast awareness and breast cancer awareness and (ii) identify the barriers to breast cancer awareness for women with an intellectual disability. The review findings are intended to assist in identifying the learning needs of women with an intellectual disability in relation to breast cancer awareness.

2. Methods

2.1 Data Sources

The electronic databases CINAHL, Pubmed, PsychInfo and the Cochrane Database of Systematic Reviews were searched for relevant literature initially within a 10-year time limit (2006-2016) and subsequently updated (2006-2020) as part of a higher education programme. The PICO framework (Patient, Intervention, Comparison, and Outcome) guided the formulation of questions to assist with identifying relevant literature (Yensen, 2013) which

would identify the barriers (outcome) to breast cancer awareness (intervention) for women with an intellectual disability (patient).

2.2 Search strategy

Due to the numerous aspects of breast awareness and breast cancer awareness, several search strings were utilised to explore these concepts. All search strings were utilised in various combinations to ensure literature saturation. When combining search strings with (AND), the following limits were set: English language, abstract and years 2006-2020. The literature search was an iterative process. Reference lists of relevant publications were also used to identify other potentially relevant publications. Duplicate papers were removed. The search strings utilised for the literature review were as follows:

- S1 Breast
- S2 Cancer OR lesion OR malignancy OR neoplasm OR carcinoma OR tumor OR tumour
- S3 Awareness, OR aware* OR knowledge
- S4 Intellectual disability OR intellectual disabilities OR learning disability OR learning disabilities OR mental retardation OR mental handicap OR developmental disability OR developmental disabilities
- S5 Risk OR risks OR cause OR causes OR risk factor OR risk factors
- S6 Non-modifiable OR un-modifiable OR unmodifiable OR unchangeable OR un-changeable
- S7 Modifiable OR preventable OR prevent* OR changeable OR adaptable
- S8 Barrier OR barriers OR block OR prevent* OR prevention OR preventive OR obstruct*

- S9 Literacy OR reading OR learn* OR learning OR knowledge OR education

During the review of the literature, it became apparent that "literacy issues" was an area which required further exploration so search string (S9) was developed to glean more articles to inform the review.

2.3 Eligibility Criteria

Publications were eligible if they met the following inclusion criteria: (a) population included women in the general population or women with any level of intellectual disability; (b) breast awareness or breast cancer awareness including signs and symptoms of breast cancer, risk factors for breast cancer, breast screening mammography; (c) barriers or facilitators to breast cancer awareness in an intellectual disability context; (d) health literacy in an intellectual disability context.

Once the search strategy was peer-reviewed (JH & MOM), titles and abstracts were assessed for inclusion against the eligibility criteria, followed by a full-text review. Key data in terms of breast awareness and breast cancer awareness were initially extracted. Following this key data in terms of barriers to breast cancer awareness in an intellectual disability context were extracted from 22 relevant studies (see table 1). Data were extracted (SW) and reviewed by two team members (JH & MOM) for accuracy with consensus reached through discussion. As this is a narrative review, the Critical Appraisal Skills Programme CASP (2016) checklists acted as informal guidance in the objective reviewing of the strength of the evidence for a novice researcher; therefore the formal reporting of the strength of the evidence has not been provided in this review. A list of themes from each paper was compiled to discover recurring themes. This resulted in the identification of three themes under the heading "concept of breast awareness and breast cancer awareness"; (i) defining breast awareness and breast cancer

awareness, (ii) breast cancer risk factors and (iii) breast screening mammography. Similarly, under the heading "barriers to breast cancer awareness for women with an intellectual disability" three themes were identified; (i) lack of understanding, (ii) role of the carer and (iii) literacy issues.

3. Concepts of Breast Awareness and Breast Cancer Awareness

Historically, women were encouraged to carry out monthly breast self-examinations to detect any changes in the breast (MacBride *et al.,* 2012). However, since the results of two RCT's (Thomas *et al.,* 2002; Semiglazov *et al.,* 1999) have been published, the focus has shifted to the broader construct of breast awareness (MacBride *et al.* 2012). Breast awareness is a concept which is closely linked with breast cancer awareness (O'Mahony *et al.,* 2017) so consequently requires further clarification.

3.1 Defining Breast Awareness and Breast Cancer Awareness

Breast awareness occurs during the normal activities of daily living and involves a woman being aware of how her breasts look and feel normally, as well as knowing what changes to expect during her lifetime (Kennerly, 2015; BreastCheck, 2011; Harmer, 2008; Irish Cancer Society, 2008; Thornton & Pillarisetti, 2008). However, breast cancer awareness is slightly more complex as it also encompasses knowledge of signs and symptoms of breast cancer, risk factors for developing breast cancer in addition to attendance at breast screening mammography as appropriate (Chao et al., 2020; Kaushal et al., 2019; Irish Cancer Society, 2008; Peacey *et al.,* 2006).

3.2 Breast Cancer Risk Factors

Risk factors for developing breast cancer are described as either non-modifiable or modifiable risk factors.Ageing and being female are considered to be the two most imperative non-modifiable risk factors (Chao *et al.,* 2020; Kaushal *et al.,* 2019; Hayes *et al.,* 2013; Kharboush *et al.,* 2011; Allen *et al.,* 2010). Other non-modifiable factors which increase the risk of developing breast cancer include a family history of breast cancer, early age at menarche, later age at menopause, nulliparity, having the first child after 35years of age in addition to mammographically dense breast tissue (Chao et al., 2020; Rainey *et al.,* 2020; American Cancer Society, 2015; Ryan *et al.,* 2015; Irish Cancer Society, 2014; Manning *et al.,* 2013; Nelson *et al.,* 2012).

Modifiable risk factors which increase one's personal risk of developing breast cancer include a high alcohol consumption, lack of physical activity, obesity post-menopause, use of oral contraceptives and hormone replacement therapy (Rainey et al., 2020; American Cancer Society, 2015; Irish Cancer Society, 2014; Tazhibi & Feizi, 2014; Kratzke *et al.,* 2013; Zeinomar & Moslehi, 2013; Cibulka, 2011; Kharboush *et al.,* 2011; Lalor & Redmond, 2009; Peacey *et al.,* 2006). There is also evidence in the literature to suggest that breastfeeding reduces one's risk of developing breast cancer (Anothaisintawee *et al.,* 2013; Nelson *et al.,* 2012; Pechlivani & Vivilaki, 2012).

At least one quarter of breast cancers can be linked with modifiable risk factors (Ryan *et al.,* 2015; Wilson *et al.,* 2013). Therefore, it is important for women to be aware of the modifiable risk factors for developing breast cancer as it may influence their lifestyle choices which increase or decrease their personal risk of developing breast cancer (Sherman & Lane, 2015; Kratzke *et al.,* 2013). As stated previously, an additional component of breast cancer awareness

is attendance at breast screening mammography as appropriate (Chao et al., 2020; Irish Cancer Society, 2008).

3.3 Breast Screening Mammography

Mammography continues to be the foundation of population-based breast cancer screening and attendance is recommended every two years from 50-69years (Lauby-Secretan *et al.,* 2015; Balaji, 2014; Haakinson *et al.,* 2010; Perry *et al.,* 2006). Although, there are those who continue to question its effectiveness in reducing breast cancer mortality (Gotzsche & Jorgensen, 2013; Coldman & Philips, 2011; Harris *et al.,* 2011; Jatoi, 2011), there is continued evidence supporting the viability of breast screening programmes whilst also acknowledging the negative impacts of breast screening mammography (Lauby-Secretan *et al.,* 2015; Marmot *et al.*, 2013).

Ultimately, by increasing breast cancer awareness, it is hoped that women will present earlier with potential symptoms leading to an earlier diagnosis and treatment which have potential to improve survival rates from breast cancer (Ruddy *et al.,* 2014; Forbes *et al.,* 2010; Linsell *et al.,* 2010). This applies to women of all abilities. Unfortunately for women with an intellectual disability, barriers exist to becoming breast cancer aware. Once they have been identified it may then be possible to overcome such barriers in order to facilitate an environment for breast cancer awareness. Figure 1 presents the key aspects of breast awareness and breast cancer awareness, in addition to the associated outcomes, as identified from the review. It is important to note the key aspects of each concept prior to reviewing breast cancer awareness within an intellectual disability context as there are further considerations required for women with an intellectual disability which will be elaborated in the next section.

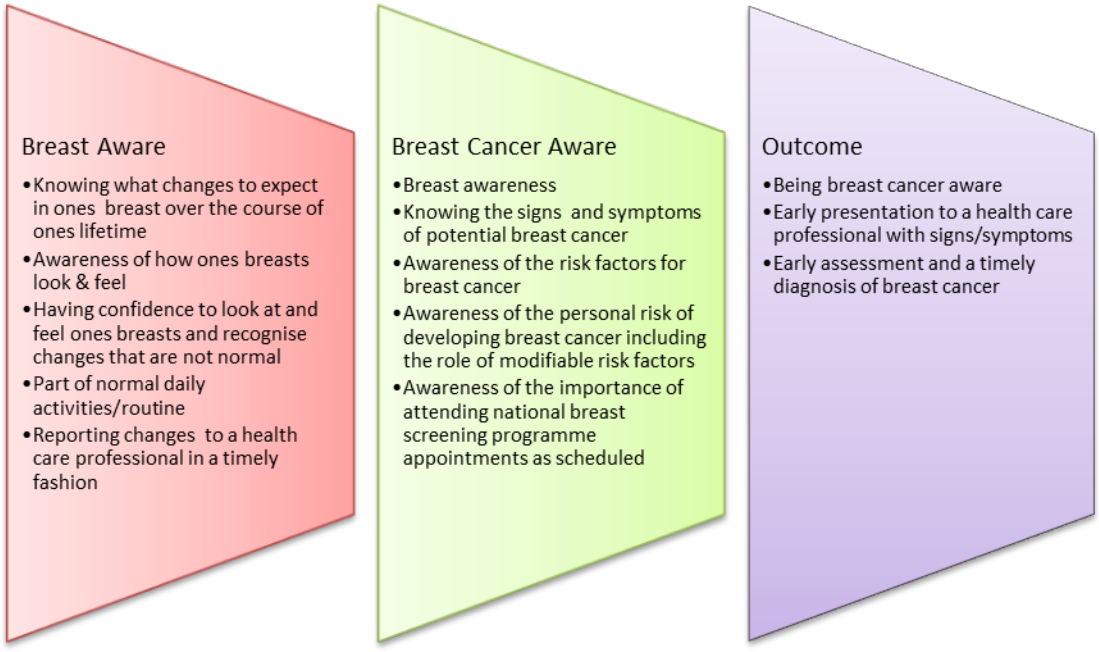

Figure 1: Summary of key points of breast cancer awareness

4. Barriers to Breast Cancer Awareness for Women with an Intellectual Disability

Barriers to breast cancer awareness which exist for women with an intellectual disability include a lack of understanding, carer attitudes and carer knowledge, literacy skills and availability of health information (Plourde *et al.,* 2018; Satge *et al.* 2014; Hanna *et al.,* 2011; McIlfatrick *et al.,* 2011; Taggart *et al.,* 2011). Further exploration of these barriers will identify what needs to be implemented to transform these barriers into facilitators for breast cancer awareness. This will ensure women with an intellectual disability are afforded the same opportunities as women in the general population in becoming breast cancer aware.

4.1 Lack of Understanding

Women with an intellectual disability may not participate in active breast cancer awareness due to their level of cognitive function, lack of motor skills or equally may not understand the need for breast awareness (Reidy *et al.,* 2018; McIlfatrick *et al.,* 2011; Taggart *et al.,* 2011;

Davies & Duff, 2001). Additionally, in several studies, women with an intellectual disability have been reported to display a lack of understanding of breast cancer signs, symptoms and risk factors (Reidy *et al.,* 2018; Satge *et al.,* 2014; McIlfatrick *et al.,* 2011; Taggart *et al.,* 2011; Davies & Duff, 2001). Furthermore, feelings of embarrassment and worry have been reported as deterrents in reporting potential symptoms to a doctor or carer (Reidy *et al.,* 2018). The inability to self-examine one's breasts in addition to a lack of understanding of breast cancer signs, symptoms and risk factors could be classified as barriers for women with an intellectual disability becoming breast cancer aware. However, it must be noted the years in which majority of these studies took place (2001-2011); there may not have been an emphasis on the importance of breast cancer awareness practices for women with an intellectual disability.

As women with an intellectual disability are a vulnerable group, the nature of clinical breast examination leads to barriers for healthcare professionals (HCP's) in carrying out breast examinations (Collins *et al.,* 2014; Taggart *et al.,* 2011). A lack of clarity exists on whether clinical breast examinations by carers are appropriate and with whom the responsibility should lie, with the role of general practitioners being cited as a potential option (Collins *et al.,* 2014; Lalor & Redmond, 2009). Furthermore, limited ethical guidelines and staff training are available, highlighting the need for women with an intellectual disability to become breast cancer aware themselves (Collins *et al.,* 2014; Hanna *et al.,* 2011; Lalor & Redmond, 2009).

Breast screening mammography uptake in women with an intellectual disability is commonly documented as being below the optimum level and remains under reported (Plourde *et al.,* 2018; Swaine *et al.,* 2013; Wyatt & Talbot, 2013; Parish *et al.,* 2012; Taggart *et al.,* 2011; Truesdale-Kennedy *et al.,* 2011; Wilkinson *et al.,* 2011; Lalor & Redmond, 2009). Barriers to attendance at screening mammography for women with an intellectual disability have been reported by HCP's due to cognitive and communication deficits, level of understanding in

addition to ability to consent, mobility and physical health (Bates & Triantafyllopoulou, 2019; McIlfatrick *et al.,* 2011; Lalor & Redmond, 2009). Additionally, negative emotions such as fear, anxiety, discomfort and pain have been reported by carers as reasons why women with an intellectual disability have refused to attend their screening mammography appointment (Bates & Triantafyllopoulou, 2019; Taggart *et al.,* 2011). Upon questioning, women with an intellectual disability have described similar feelings of fear, stress, embarrassment and anxiety in addition to a lack of knowledge and understanding about mammography (Swaine *et al.,* 2014; Parish *et al.*, 2012; Truesdale-Kennedy *et al.,* 2011; Wilkinson *et al.,* 2011). Despite this, their motivation for having at least one mammogram was derived from the "need to fit in" with women in the general population (Wilkinson *et al.,* 2011).

Based on the above discussion of potential barriers to breast cancer awareness, it is clear women with an intellectual disability will require an element of assistance/support thus, reinforcing the important role of the carer, in this regard (Byrnes *et al.,* 2020; Swaine *et al.,* 2013).

4.2 Role of the Carer

Primary carers of women with an intellectual disability, whether they are paid or familial, have a crucial role in promoting the health of these women (Reidy *et al.,* 2018; Wyatt & Talbot, 2013). They are often the main support network for a woman with an intellectual disability; not only do they support and care for the woman but also play a key role in interpreting and relaying information between the woman with an intellectual disability and the HCP's (Reidy *et al.,* 2018; Forbat & McCann, 2010). Furthermore, people with an intellectual disability have identified the need for carers to embrace a supportive role as opposed to a caring role (Abbott & McConkey, 2006). A lack of knowledge or understanding amongst carers of women with an intellectual disability has been linked with negative carer attitudes towards cancer and cancer

prevention (Bates & Triantafyllopoulou, 2019; Wyatt & Talbot, 2013). There are contrasting findings in the literature with two studies reporting that carers believe women with an intellectual disability are not at risk of developing breast cancer (Cobigo *et al.,* 2013) whilst one study reported that carers believe people with an intellectual disability have similar cancer diagnosis rates as the general population (Wyatt & Talbot, 2013). Consequently, carer attitudes to cancer screening and prevention may influence the care of people with an intellectual disability and potential health promotion opportunities may be missed (Wyatt & Talbot, 2013; McIlfatrick *et al.,* 2011).

As women with an intellectual disability are living longer and their risk of developing breast cancer increases, carers' knowledge about breast cancer risks, signs and symptoms will become more important (Reidy *et al.,* 2018; Wyatt & Talbot, 2013; Taggart *et al.,* 2011). The literature has again reported contrasting findings with one study identifying that carers lack awareness of risk factors for developing cancer (Hanna *et al.,* 2011). In contrast, two studies reported that carers demonstrated a good awareness of the risk factors for developing breast cancer and good knowledge about cancer risk-reducing behaviours in addition to the importance of early detection and screening (Wyatt & Talbot, 2013; McIlfatrick *et al.,* 2011). Despite these latter two studies portraying that carers possess an awareness of breast cancer risks, signs and symptoms, it appears that a lack of confidence is preventing carers from sharing this knowledge through educating women with an intellectual disability about breast cancer awareness. Consequently, this may impact the integral role of carers in supporting women with an intellectual disability in accessing breast screening mammography.

An additional barrier to screening mammography for women with an intellectual disability has been reported by studies as carers' personal attitudes to breast screening mammography (Byrnes *et al.,* 2020; McIlfatrick *et al.,* 2011; Rees, 2011; Truesdale-Kennedy *et al.,* 2011).

Several studies have identified that carers received little or no formal training about cancer screening, cancer awareness and cancer health promotion activities for people with an intellectual disability (Wyatt & Talbot, 2013; Hanna *et al.,* 2011; Rees, 2011). Consequently, the main sources of knowledge came from the carers' personal experiences and health promotion campaigns (Seaton *et al.,* 2018; Wyatt & Talbot, 2013; Rees, 2011). Without appropriate training for carers, there is a risk that people with an intellectual disability will be provided with inaccurate information regarding breast cancer awareness and screening (Willis, 2016; Rees, 2011).

Carers also have an integral role in the promotion of healthier lifestyles for women with an intellectual disability in an attempt to reduce their risk of developing breast cancer. The importance of support from carers in promoting healthier lifestyle choices, particularly for people with a mild intellectual disability living independently in the community, as opposed to those in institutional care, is reiterated by several authors (Hseih *et al.,* 2014; De Winter *et al.,* 2012; Hanna *et al.,* 2011). Furthermore, studies have highlighted the need for further education for both the carers and the women with an intellectual disability on healthier eating habits, the importance of physical activity and the long-term negative impact of an unhealthy lifestyle (O'Leary *et al.,* 2018; Hseih *et al.,* 2014; De Winter *et al.,* 2012; Hanna *et al.,* 2011).

Nevertheless, what is clear from the literature is that there is an imperative role for carers to play in empowering women with an intellectual disability in being breast cancer aware (Wilkinson *et al.,* 2014; McIlfatrick *et al.,* 2011). Ultimately, the goal should be to encourage women with an intellectual disability to assume ownership of their own health and play an active role in their healthcare decisions (Reidy *et al.,* 2018; Bergstrom *et al.,* 2014; Swaine *et al.,* 2013; Parish *et al.,* 2012). In order to promote empowerment, carers need to be equipped with the relevant knowledge, skills and strategies to facilitate education and choice where

understanding and communication can be an issue for women with an intellectual disability (Wyatt & Talbot, 2013). Therefore, it is essential to include carers in any efforts to improve breast cancer awareness in this cohort of women (Willis, 2016; McIlfatrick *et al.,* 2011). Empowering women with an intellectual disability to be breast cancer aware requires education about the importance of breast cancer awareness, ways to communicate effectively with HCPs and ways to manage their fears and anxieties (Parish *et al.,* 2012). Empowerment of the individual with an intellectual disability may be facilitated through person-centred planning and ensuring information is presented in a variety of formats to suit their literacy ability (Bergstrom *et al.,* 2014).

4.3 Literacy Issues

Literacy encompasses the skills one requires to be able to participate fully in society and includes listening, speaking, reading, writing, numeracy and using everyday technology to communicate and handle information (NALA, 2016; Hock, 2012). Health literacy has been defined as; *"the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions"* (Institute of Medicine, 2004, pg.20). A strong link has been found between literacy and health (Wilson, 2003) and between health literacy and outcomes (Gatti *et al.,* 2009). Adults with learning disabilities are known to have lower literacy levels than those without learning disabilities (Albuquerque & Carvalho, 2020; MacArthur *et al.,* 2010; Mellard & Patterson, 2008).

Studies have determined that adults with learning disabilities score significantly lower in areas such as reading comprehension ($p<0.001$), functional reading skills ($p<0.001$), general intelligence ($p<0.05$), decoding ($p<0.001$), word recognition ($p<0.001$), spelling ($p<0.001$), and fluency ($p=0.012$) when compared with adults without a learning disability (MacArthur *et*

al., 2010; Mellard & Patterson 2008). Furthermore, levels of intellectual disability will also impact a person's ability to understand information and communicate effectively. It has been reported that people with mild intellectual disability possess a higher capacity to communicate and interpret communication than those with moderate intellectual disability (Dordevic *et al.,* 2016). This is important to note when educating women about breast cancer awareness in order to meet the needs of the individual.

Consequently, communication difficulties and low literacy levels act as barriers for women with an intellectual disability in becoming breast cancer aware (Byrnes *et al.,* 2020; Bates & Triantafyllopoulou, 2019). Communication difficulties, a lack of knowledge and accessible information on breast cancer risks, preventions and screening mammography prohibit women with an intellectual disability having the ability to communicate effectively and seeking timely advice from health care providers (Parish *et al.,* 2012; McIlfatrick *et al.,* 2011). Moreover, a low level of health literacy is linked with poorer health outcomes (Bergstrom *et al.,* 2014). Therefore, to improve health behaviours including breast cancer awareness, health literacy needs to be addressed for women with an intellectual disability.

However, a lack of user friendly, accessible information about cancer has been widely reported to be a barrier to good quality care for women with an intellectual disability (Byrnes *et al.,* 2020; Hanna *et al.,* 2011; Taggart *et al.,* 2011). When attempting to improve health literacy and health behaviours for adults with an intellectual disability there is a need to set individual goals and modify delivery methods whilst creating an individualised supportive context (Bergstrom *et al.,* 2014; Mellard & Patterson, 2008). Widely used formats for delivering accessible information include: easy-read information, pictures using talking mats, audio and DVD systems, computer software and internet based systems (Oldrieve & Waight, 2013). However, presently the majority of advertisements and information about breast cancer and

screening require a literacy level which women with an intellectual disability may lack (Byrnes *et al.,* 2020; Taggart *et al.,* 2011; Wilkinson *et al.,* 2011; Wilkinson & Cerreto, 2008).

Therefore, it can be hypothesised that empowering women with an intellectual disability through improved health literacy, will result in improved health outcomes in the context of breast cancer awareness. As previously stated, carers/staff play an integral role in supporting and maintaining new skills acquired by individuals with an intellectual disability (Bergstrom *et al.,* 2014; Hanna *et al.,* 2011; Truesdale-Kennedy *et al.,* 2011). For this reason, additional staff training/education may be required to facilitate access to appropriate health information (Oldrieve & Waight, 2013).

In summary, several key barriers to breast cancer awareness for women with an intellectual disability have been outlined. If these barriers are addressed, they are likely to become facilitators for breast cancer awareness which in turn will assist in reducing health disparities for women with an intellectual disability. Figure 2 presents a summary of the facilitators of breast cancer awareness in an intellectual disability context.

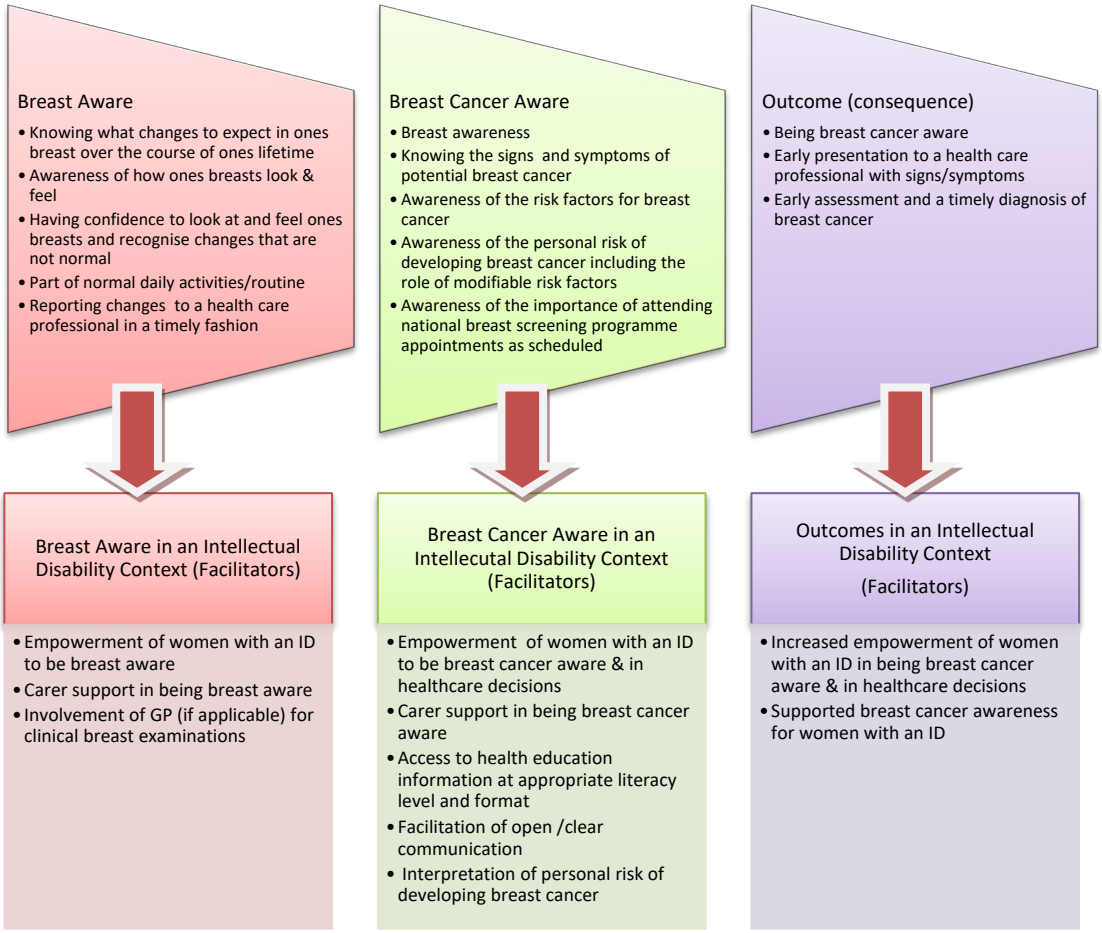

Figure 2: Summary of the facilitators of breast cancer awareness in an intellectual disability context

5. Limitations

There are some limitations to the current review. This is a narrative review, rather than a systematic review, however a systematic and comprehensive search strategy was undertaken using multiple databases and searching of grey literature to identify all eligible studies for the review. Data were extracted by one author (SW), rather than two authors independently, however peer reviewing of extracted data and the formulation of themes occurred. It must be acknowledged that other reviewers may highlight different themes or grouping of the studies. Furthermore, peer-reviewing included peers and mentors; however the inclusion of a wider stakeholder group, including people with intellectual disabilities and their care givers, could have further strengthened the review process.

6. Conclusion

When compared to women in the general population, women with an intellectual disability have a comparable risk of developing breast cancer and are exposed to similar risk factors. However, women with an intellectual disability present with advanced breast cancers, which often have a poor prognosis. This has been attributed to poor attendance at screening mammography, communication difficulties and ultimately, a lack of breast cancer awareness by women with an intellectual disability.

Barriers to breast cancer awareness for women with an intellectual disability include a lack of understanding about breast cancer, role of the carer, literacy skills and availability of health information. Additionally, limited ethical guidelines and training prevent carers from performing clinical breast examinations for women with an intellectual disability. Barriers to attendance at screening mammography for women with an intellectual disability have been documented as cognitive and communication deficits, level of understanding in addition to ability to consent, mobility issues, physical health, fear, anxiety, discomfort and pain.

Primary carers play a crucial health promotion role in supporting women with an intellectual disability in becoming breast cancer aware. However, carers need to be empowered in such a role through appropriate training and education. This will assist them to empower women with an intellectual disability through person-centred planning; ensuring information is presented in a variety of formats to suit women's literacy ability. In order to dispel existing barriers for women with an intellectual disability in becoming breast cancer aware, it is important to not only improve health literacy through accessible health education information but equally to empower women with an intellectual disability in making informed choices and gaining control over their healthcare decisions. Facilitating breast cancer awareness for women with an

intellectual disability has the potential to result in better long-term outcomes through an early diagnosis of breast cancer.

References

Abbott, S. & McConkey, R. (2006) The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities,* 10(3), 275-287.

Albuquerque, C.P. & Carvalho, A.C. (2020) Identification of needs of older adults with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities,* 17(2), 123-131.

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.

American Association of Intellectual and Developmental Disabilities (2013) *Definition of Intellectual Disability.* Available from http://aaidd.org/intellectual-disability/definition#.VYMK2btRFlY (Accessed: 15th June 2019).

American Cancer Society (2015) *What are the risk factors for breast cancer?* Available from: http://www.cancer.org/cancer/breastcancer/detailedguide/breast-cancer-risk-ccccccccccccccccffactors (Accessed: 10th June 2015).

Anothaisintawee, T., Wiratkapun, C., Lerdsitthichai, P., Kasamesup, V., Wongwaisayawan, S., Srinakarin, J., Hirunpat, S., Woodtichartpreecha, P., Boonlikit, S., Teerawattananon, Y. & Thakkinstian, A. (2013) Risk factors of breast cancer: A systematic review and meta-analysis. *Asia-Pacific Journal of Public Health*, 25(5), 368-387.

Balaji, S. (2014) Breast cancer screening: options beyond the mammogram. *Harvard Women's Health Watch,* 8, 3-4.

Bates, C. & Triantafyllopoulou, P. (2019) Exploring the impact of mental capacity on breast screening for women with intellectual disabilities. *Health and Social Care in the Community,* 27, 880–888.

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.

BreastCheck (2011) *Make time for your breast health.* Available from http://www.breastcheck.ie/sites/default/files/bcheck/documents/maketimeleaflet.pdf (Accessed: 10th June 2015).

Byrnes, K., Hamilton, S., McGeechan, G.J., O'Malley, C., Mankelow, J. & Giles, E.L. (2020) Attitudes and perceptions of people with a learning disability, family carers, and paid carer workers towards cancer screening programmes in the United Kingdom: A qualitative systematic review and meta-aggregation. *Journal of the Psychological, Social and Behavioral Dimensions of Cancer,* 29(3), 475-484.

Cibulka, N. (2011) Update on breast cancer screening. *The Journal for Nurse Practitioners,* 7(1), 67-68.

Chao, C.A., Huang, L., Visvanathan, K., Mwakatobe, K., Masalu, N. & Rositch, A.F (2020) Understanding women's perspectives on breast cancer is essential for cancer control: knowledge, risk awareness, and care-seeking in Mwanza, Tanzania. *BMC Public Health,* 20(930), 1-11.

Cobigo, V., Ouellette-Kuntz, H., Balogh, R., Leung, F., Lin, E. & Lunsky, Y. (2013) Are cervical and breast cancer screening programmes equitable? The case of women with intellectual and developmental disabilities. *Journal of Intellectual Disability Research,* 57(5), 478-488.

Coldman, A. & Philips, N. (2011) Population studies of the effectiveness of mammographic screening. *Preventative Medicine,* 53(3), 115-117.

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.

Critical Appraisal Skills Programme (CASP, 2016) CASP Checklists. Available from http://www.casp-uk.net/casp-tools-checklists (Accessed: 31st February 2016).

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.

De Winter, C.F., Bastiaanse, L.P., Hilgenkamo, T.I.M., Evenhuis, H.M. & Echteld, M.A. (2012) Overweight and obesity in older people with intellectual disability. *Research in Developmental Disabilities,* 33, 398-405.

Dordevic, M., Glumbic, N. & Brojcin, B. (2016) Paralinguistic abilities of adults with intellectual disability. *Research in Developmental Disabilities,* 48, 211-219.

Forbat, L. & McCann, L. (2010) Adults with intellectual disabilities affected by cancer: critical challenges for the involvement agenda. *European Journal of Cancer Care,* 19(1), 91-97.

Forbes, L., McNaughton Nicholls, C., Linsell, L., Graham, J., Tompkins, C. & Ramirez, A. (2010) Involving users in the design of a randomised controlled trial of an intervention to promote early presentation in breast cancer: qualitative study. *BMC Medical Research Methodology,* 10(110), 1-8.

Gatti, M.E., Jacobson, K.L., Gazmararian, J.A., Schmotzer, B., & Kripalani, S. (2009) Relationships between beliefs about medications and adherence. *American Journal of Health-System Pharmacy,* 66, 657–664.

Gotzsche, P. & Jorgensen, K. (2013) Screening for breast cancer mammography. *Cochrane Database of Systematic Review,* 6, 1-59.

Haakinson, D.J., Stucky, C.H., Dueck, A.C., Gray, R., Wasif, N., Apsey, H. & Pockaj, B. (2010) A significant number of women present with palpable breast cancer even with a normal mammogram within 1 year. *The American Journal of Surgery,* 200, 712-718.

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.

Harmer, V. (2008) Breast cancer part 1: awareness and common benign diseases. *British Journal of Nursing,* 17(15), 950-955.

Harris, R., Yeatts, J. & Kinsinger, L. (2011) Breast cancer screening for women aged 50-69 years: a systematic review of observational evidence. *Preventative Medicine,* 53, 108-114.

Hayes, J., Richardson, A. & Frampton, C. (2013) Population attributable risks for modifiable lifestyle factors and breast cancer in New Zealand women. *Internal Medicine Journal,* 1198-1204.

Hock, M.F. (2012) Effective literacy instruction for adults with specific learning disabilities: implications for educators. *Journal of Learning Disabilities,* 45(1), 64-78.

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.

Institute of Medicine. *Health Literacy: A Prescription to End Confusion.* Washington, DC: National Academies Press, 2004.

Irish Cancer Society (2008) *Preventing breast cancer*. Available from http://www.cancer.ie/cancer-information/breast-cancer/prevention (Accessed: 31st May 2015).

Irish Cancer Society (2014) *Understanding cancer of the breast.* Nursing Services of the Irish Cancer Society, Dublin.

Jatoi, I. (2011) The impact of advances on the efficacy of mammography screening. *Preventative Medicine,* 53, 103-104.

Kaushal, A., McCormick, K., Warburton, F., Burton, C., Ramirez, A.J. & Forbes, L.J. (2019) Promoting breast cancer awareness in older women during the seasonal flu vaccination campaign. *British Journal of Nursing*, 28(1), 43-49.

Kennerley, J. (2015) What's best for the breast? *KaiTiaki Nursing New Zealand*, 21(4), 26.

Kharboush, I.F., Ismail, H.M., Kandil, A.A., Mamdouh, H.M., Muhammad, Y.Y., El Sharkawy, O.G. & Sallam, H.N. (2011) Raising the breast health awareness amongst women in an urban slum area in Alexandria, Egypt. *Breast Care,* 6, 375-379.

Kratzke, C., Vilchis, H. & Amatya, A. (2013) Breast cancer prevention knowledge, attitudes, and behaviors among college women and mother-daughter communication. *Journal of Community Health*, 38(3), 560-568.

Lalor, A. & Redmond, R. (2009) Breast screening for post-menopausal women. *Learning Disability Practice,* 12(9), 28-33.

Lauby-Secretan, L., Scoccianti, C., Loomis, D., Benbrahim-Tallaa, L., Bouvard, V., Bianchini, F. & Straif, K. (2015) Breast cancer screening-viewpoint of the IARC Working Group. *The New England Journal of Medicine,* 372(24), 2353-2358.

Linsell, L., Forbes, L., Burgess, C., Kapari, M., Thurnham, A. & Ramirez, A. (2010) Validation of a measurement tool to assess awareness of breast cancer. *European Journal of Cancer,* 46, 1374-1381.

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.

MacBride, M., Pruthi, S. & Bevers, T. (2012) The evolution of breast self-examination to breast awareness. *Breast Journal*, 18(6), 641-643.

Marmot, M.G., Altman, D.G., Cameron, D.A., Dewar, J.A., Thompson, S.G. & Wilcox, M. (2013) The benefits and harms of breast cancer screening: an independent review. *British Journal of Cancer,* 108, 2205-2240.

Manning, M., Duric, N., Littrup, P., Bey-Knight, L., Penner, L. & Albrecht, T. (2013) Knowledge of breast density and awareness of related breast cancer risk. *Journal of Cancer Education,* 28, 270-274.

McIlfatrick, 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, 412-420.

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.

NALA (2016) *Literacy in Ireland.* Available from https://www.nala.ie/literacy (Accessed: 8th March 2016).

National Intellectual Disability Database (2017) *HRB Statistics Series 37: Annual Report of the National Intellectual Disability Database Committee 2017.* Available from http://www.hrb.ie/health-information-in-house-research/disability/nidd-publications (Accessed: 21st July 2020).

Nelson, H., Zakher, B., Cantor, A., Fu, R., Griffin, J., O'Meara, E., Buist, D., Kerlikowske, K., Van Ravesteyn, N., Trentham-Dietz, A., Mandelblatt, J. & Miglioretti, D. (2012) Risk factors for breast cancer for women aged 40 to 49 years. *Annals of Internal Medicine,* 156, 635-648.

O'Connor, T. (2012) *Health literacy in Ireland: benchmarking the present state of the art and examining future challenges and opportunities.* National Adult Literacy Agency, Dublin, Ireland.

O'Leary, L., Cooper, S.A. & Hughes-McCormack, L. (2018) Early death and causes of death of people with intellectual disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities,* 31, 325-342.

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.

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.

Peacey, V., Steptoe, A., Davidsdottit, S., Baban, A. & Wardle, J. (2006) Low levels of breast cancer risk awareness in young women: An international survey. *European Journal of Cancer,* 42, 2585-2589.

Pechlivani, E., & Vivilaki, V. (2012) Breastfeeding and breast cancer. *Health Science Journal,* 6(4), 610-617.

Perry, N., Broeders, M., De Wolf, C., Tornberg, S., Holland, R. & Von Karsa, L. (2006) *European guidelines for quality assurance in breast cancer screening and diagnosis,* 4th ed. Office for Official Publications of the European Communities, Luxembourg.

Plourde, N., Brown, H.K., Vigod, S. & Cobigo, V. (2018) The association between continuity of primary care and preventative cancer screening in women with intellectual disability. *American Journal on Intellectual and Developmental Disabilities,* 123(6), 499-513.

Rainey, L., Van der Waal, D., Jervaeus, A., Donnelly, L.S., Evans, D.G., Hammarström, M., Hall, P., Wengström, Y. & Broeders, M.J.M. (2020) European women's perceptions of the implementation and organisation of risk based breast cancer screening and prevention: a qualitative study. *BMC Cancer,* 20(247), 1-12.

Rees, G. (2011) Increasing access to cancer screening programmes. *Learning Disability Practice,* 14(7), 14-19.

Reidy, M., Denieffe, S. & Foran, S. (2014) Cancer screening in women with intellectual disabilities: An Irish perspective. *Journal of Intellectual Disabilities,* 18(1), 50-60.

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, 193-201.

Ruddy, K., Gelber, S., Tamimi, R., Schapira, L., Come, S., Meyer, Winer, E. & Partridge, A. (2014) Breast cancer presentation and diagnostic delays in young women. *Cancer,* 20-25.

Ryan, A.M, Cushen, S., Schellekens, H., Ni Bhuachalla, E., Burns, L., Kenny, U. & Power, D. (2015) Poor awareness of risk factors for cancer in Irish adults: results of a large survey and review of the literature. *The Oncologist,* 20, 372-378.

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.

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.

Seaton, M.B., Muraca, L., Devaney, J. & Angus, J.E. (2018) "I want to help, but what do you do in a situation like that?" Health care providers' qualitative perspectives on working with disabled women in breast cancer screening. *Journal of Medical Imaging and Radiation Services,* 49, 383-389.

Semiglazov, V.P., Moiseyenko, V.M., Manikhas, A.G., Protsenko, S.A., Kharikova, R.S., Seleznev, I.K., Popova, R.T., Migmanova, N.S., Orlov, A.A., Barash, N.I., Ivanova, O.A. & Ivanova, V.G. (1999) Interim results of a prospective randomised study of self-examination for early detection of breast cancer. *VoprOnkol,* 45, 265-271.

Sherman, S.M. & Lane, E.L. (2015) Awareness of risk factors for breast, lung and cervical cancer in a UK Student Population. *Journal of Cancer Education,* 30, 660-663.

Swaine, J.G., Parish, S.L. & Luken, K. (2013) Breast and cervical cancer screening for women with intellectual disabilities. *Health & Social Work,* 38(3), 183-186.

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.

Taggart, L., Truesdale-Kennedy, M. & McIlfatrick, 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.

Tazhibi, M. & Feizi, A. (2014) Awareness levels about breast cancer risk factors, early warning signs, screening and therapeutic approaches among Iranian adult women: A large population based study using latent class analysis. *BioMed Research International.* Available from http://dx.doi.org/10.1155/2014/306352 (Accessed: 5th November 2015).

Thomas, D.B., Gao,D.L., Ray, R.M., Wang, W.W., Allison, C.J., Chen, F.L., Porter, P., Wei Hu, Y., Lin Zhao, G., Da Pan, L., Wenjin, L., Wu, C., Coriaty, Z., Evans, I., Lin, M.G., Stalsberg, H. & Self, S. (2002) Randomized trial of breast self-examination in Shanghai: Final results. *Journal of the National Cancer Institute,* 94(19), 1445-1457.

Thornton, H. & Pillarisetti, R.R. (2008) Breast awareness and breast self-examination are not the same. What do these terms mean? Why are they confused? What can we do? *European Journal of Cancer,* 44, 2118-2121.

Truesdale-Kennedy, M., Taggart, L. & McIlfatrick, 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.

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.

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.

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.

Wilkinson. J., Greenwood, N., Tierney-Wang, C., White, L. & Culpepper, L. (2014) Measuring staff empowerment regarding health care for clients with intellectual disabilities. *International Journal of Family Medicine,* 2014, 1-6.

Willis, D. (2013) Breast screening: Participation of women with intellectual disabilities. *Learning Disability Practice,* 16(4), 24-26.

Willis, D. (2016) What influences women with intellectual disabilities to attend breast screening? Experiences of women who have and have not participated. *British Journal of Learning Disabilities,* 44, 269-276.

Wilson J.F., (2003) The crucial link between literacy and health. *Annals of Internal Medicine*, 139, 875–878.

Wilson, L.F., Page, A.N., Dunn, N.A., Pandeya, N., Protani, A.A. & Taylor, R.J. (2013) Population attributable risk of modifiable risk factors associated with invasive breast cancer in women aged 45-69 years in Queensland. *Maturitas,* 76, 370-376.

Wyatt, D. & Talbot, P. (2013) What knowledge and attitudes do paid carers of people with a learning disability have about cancer? *European Journal of Cancer Care,* 22, 300-307.

Yensen, J. (2013) Pico search strategies. *Online Journal of Nursing Informatics,* 17 (3). Available from http://ojni.org/issues/?p=2860 (Accessed: 2nd October 2015).

Zeinomar, N. & Moslehi, R. (2013) The effectiveness of a community-based breast cancer education intervention in the New York state capital region. *Journal of Cancer Education,* 28, 466-473.

Table 1: Extract of the study details which informed the literature review

1. Authors (Date), Country **2. Site of recruitment** **3. Sample details, level of ID**	**1. Study methodological approach** **2. Aim of study** **3. Data Collection**

1. Abbott & McConkey (2006), UK 2. Supported living or shared group homes 3. People with an ID (n=68), level of ID not specified	1. Qualitative Study 2. To identify barriers to social inclusion as perceived by people with an ID 3. Focus groups
1. Bergstrom *et al.* (2014), Sweden 2. Health course for people with mild/moderate ID 3. People with a mild/moderate ID (n=83)	1. Qualitative study 2. To explore the barriers and facilitators in health education for adults with ID 3. Unstructured observations, group discussions with course leaders & evaluation notes from course leaders
1. Davies & Duff (2001), UK 2. Community group homes 3. Women with an ID (n=58), level of ID not specified	1. Quantitative study 2. To explore the breast cancer awareness practices of women with an ID 3. Postal questionnaire
1. De Winter *et al.,* (2012), The Netherlands 2. Care organisations (n=3) 3. People with varying levels of ID (n=945)	1. Cross-sectional study 2. To establish the prevalence of overweight, obesity & body fat percentage in older people with an ID & compare to the general population 3. Medical record, general practitioners & psychologists input, physical examinations & pedometers
1. Dordevic *et al.,* (2016), Serbia 2. Day care centres & residential institutions 3. People with a mild ID (n=25) & moderate ID (n=35)	1. Quantitative study 2. To determine the ability level of paralinguistic production & comprehension in adults with an ID 3. Paralinguistic scale from "The assessment battery for communication"
1. Forbat & McCann (2010), UK 2. Advocacy organisation & service providers (n=23) 3. People with an ID (n=4), level of ID not specified	1. Qualitative study 2. To develop an advisory forum of adults with an ID affected by cancer & to inform the development of a research agenda 3. Semi-structured interviews
1. Hanna *et al.,* (2011), UK 2. Residential facilities for people with an ID (n=15) 3. Residential staff (n=40)	1. Exploratory descriptive study 2. To examine how care staff engaged in cancer prevention and health promotion activities on behalf of people with an ID 3. Postal survey
1. Hsieh *et al.* (2013), USA 2. Various care & support organisations 3. People with varying levels of ID (n=1,450),	1. Mixed methods study 2. To examine the prevalence of obesity in adults with an ID compared to the general population 3. Postal & online surveys
1. Lalor & Redmond (2009), Ireland 2. Residential care sites (n=3) 3. Primary carers of post-menopausal women with varying levels of ID (n=90)	1. Explorative descriptive study using quantitative methodology 2. To explore the extent of breast cancer screening for post-menopausal women with an ID living in residential care 3. Questionnaires
1. MacArthur *et al.,* (2010), USA 2. Adult basic education programmes (n=23) 3. People with learning disabilities (n=486)	1. Quantitative study 2. To investigate the reliability and construct validity of measures of reading component skills with a sample of adult basic education learners and to describe the performance of those learners on the measures 3. Use of 11 measures of reading component skills
1. McIlFatrick *et al.,* (2011), UK 2. Health & social care trusts (n=3) 3. Primary healthcare staff (n=8), Breast care staff (n=10)	1. Qualitative study 2. To explore the role of HCP's on supporting women with ID to access breast screening 3. Focus groups & telephone interviews with a semi-structured interview schedule
1. Mellard & Patterson (2008), USA 2. Adult education programmes 3. People with learning disabilities (n=89) & people without learning disabilities (n=222)	1. Quantitative study 2. To determine the differences between adult learners with learning disabilities and those without learning disabilities 3. Structured interviews & measures of reading comprehension, functional literacy & general intelligence
1. Parish *et al.,* (2012), USA 2. Community colleges, community rehabilitation programmes & vocational/residential organisations 3. Women with a mild-moderate ID (n=175)	1. Randomised controlled trial 2. 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 3. Baseline knowledge survey and post-test computer assisted face-to-face individual interviews

1. Plourde *et al.,* (2018), Canada 2. Healthcare database & disability support programme database 3. Women with an ID eligible for breast cancer screening (n=5,417)	1. Quantitative, retrospective population based cohort study 2. To examine the association between the level of primary care continuity and breast & cervical cancer screening rates in women with intellectual disability 3. Database searches
1. Rees (2011), UK 2. Community healthcare Trust (n=1) 3. HCP's (n=32)	1. Quantitative study 2. To assess the awareness of cancer screening programmes among frontline staff working with people with learning disabilities 3. Online questionnaire
1. Reidy *et al.,* (2018), Ireland 2. Intellectual disability service provider 3. Women with a mild-moderate ID (n=45)	1. Quantitative, cross-sectional descriptive 2. To explore breast cancer and screening awareness among Irish women with an ID 3. Questionnaire
1. Satge *et al.,* (2014), France 2. One hospital over 18 year period 3. Women with mild, moderate & severe ID (n=11)	1. Quantitative study 2. To evaluate the age at & stage of diagnosis of breast cancer in women with an ID 3. Medical health records & database search, interviews with HCP's involved in participants care
1. Swaine *et al.,* (2014), US 2. Community colleges, community rehabilitation programmes and residential organisations 3. Women with a mild, moderate & severe ID (n=198)	1. Randomised controlled trial 2. 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" 3. Face-to-face, computer assisted individual interviews were conducted pre and post the intervention
1. Taggart *et al.,* (2011), UK 2. Health & social care trusts (n=3) 3. Community ID nurses (n=16), Residential support staff (n=13)	1. Qualitative study 2. To examine how community nurses and residential staff support women with an ID to access breast screening services 3. Focus groups with a semi-structured interview schedule
1. Truesdale-Kennedy *et al.,* (2011), UK 2. Health & social care trusts (n=3) 3. Women with borderline to moderate ID (n=19)	1. Qualitative descriptive study 2. To explore breast cancer knowledge among women with an ID & their experiences of receiving breast mammography 3. Focus groups with a semi-structured interview schedule
1. Wilkinson *et al.,* (2011), USA 2. Community groups (n=4) 3. Women with an ID (n=27) , level of ID not specified	1. Qualitative study 2. To explore the perceptions & understanding of mammography for women with ID & the potential barriers to mammography 3. Semi-structured interviews
1. Wyatt & Talbot (2013), UK 2. Independent sector organisations (n=3) 3. Paid carers (n=324)	1. Exploratory study 2. To investigate the knowledge of and attitudes to cancer of paid carers of people with an ID 3. Questionnaire