Introduction

It is estimated that there are almost 60 million people worldwide with an intellectual disability (International Association for the Scientific Study of Intellectual Disabilities, 2002). Intellectual disability is characterised by significant limitations in both intellectual functioning and adaptive behaviour as expressed in practical, social and conceptual skills which originate before the age of 18 years (Schalock et al., 2010). The National Intellectual Disability Database (NIDD) reports that 27,324 people with intellectual disabilities were registered for service provision in Ireland in 2011; 8050 of those registered are women over the age of 20 years (Kelly, 2012).

In recent years there have been significant improvements in the life expectancy of people with intellectual disabilities, which are largely due to improved medical care, rehabilitation services and living conditions (Patja et al., 2000; International Association for the Scientific Study of Intellectual Disabilities, 2002; Sullivan et al., 2004a). The ageing of people with mild intellectual disabilities is equivalent to that of the general population and the age standardised incidence of cancers in people with intellectual disabilities is not significantly different to that of the general population (Patja et al., 2000; Patja et al., 2001; Sullivan et al., 2004a). This evolving demographic profile is expected to correlate with increases in cancer prevalence amongst people with intellectual disabilities (Wilkinson and Cerreto, 2008).
Cancer is a global term for a variety of diseases characterised by uncontrolled cellular growth, increased angiogenesis and/or decreased programmed cell death (Alberts and Hess, 2008). A key objective of cancer screening programmes is to reduce cancer mortality through early diagnosis and treatment (International Agency for Research on Cancer, 2013).

BreastCheck, the Irish national cancer screening service, introduced in 2000, invites eligible women aged 50-64 years with no symptoms of breast cancer to have a free mammogram biennially. The programme has a database register of age-eligible women compiled from information sourced from the Department of Social Protection and General Medical Services in accordance with national legislation. It is the first national screening service provider worldwide to offer a fully digitised mammography service which exhibits a significant improvement in image quality, especially in dense breast tissue. The target uptake at screening is 70%; in 2011 the screening rate was 72.2%. Over 125,000 women participated in the screening programme and 832 women had cancers detected (National Cancer Screening Service, 2013).

CervicalCheck was introduced in September 2008 and offers women between the age of 25 and 60 years the opportunity to have a free cervical smear test. The screening intervals are every three years for women aged 25-44 years and every five years for
women aged 45-60 years. It is estimated that cervical cancer screening can prevent at least 75% of cervical cancers in women aged 60 years and over and at least 45% of cervical cancers in women in their 30's (Cancer Research UK., 2013). In the first three years of the programme 60.9% of the eligible population were screened. Pre-cancerous abnormalities were detected in just over 8000 women, and 104 women were diagnosed with cervical cancer (National Cancer Screening Service, 2012).

**Aims**

The aims of this paper to are explore the cancer screening participation rates of women with intellectual disabilities in the Republic of Ireland; to examine the participation rates for women with intellectual disabilities in other countries; to consider the barriers facing Irish women with intellectual disabilities who attend screening and compare these experiences with those of women with intellectual disabilities internationally.

**Review strategy**

Electronic databases used in this paper included PUBMED, Wiley Online Library, Science Direct, PsychInfo, Academic Search Complete. The keywords used were cervical cancer; breast cancer; screening; learning disabilities; intellectual disabilities; developmental disabilities; women. The inclusion criteria included studies written in English related to breast and cervical screening in women with intellectual disabilities.
The literature review was restricted to the last 10 years (2003-2013). Initially, there were 40 articles retrieved in the five databases, however, a large volume of these articles were duplicated across the databases. A total of six papers met the inclusion criteria and were explored in the review. These studies explore breast and cervical cancer screening in women with and without intellectual disabilities nationally and internationally, see Table 1. In addition, Irish reports on breast and cervical cancer screening programmes statistics in the general population were reviewed.

**Results**

Three key themes evolved in the course of the literature review in the context of the aims of the paper. The first theme related to breast cancer and screening in Irish women with intellectual disabilities, the second theme concerned breast and cervical screening participation rates for women with intellectual disabilities in the international arena, and finally the barriers faced by Irish women with intellectual disabilities when attending screening compared to the international experience. Each theme will be discussed in the following sections.

**Theme 1: Breast cancer and screening in Irish women with intellectual disabilities**

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) is a large scale nationally representative study of Irish people with an
intellectual disability aged 40 years and over. In this study n=753, representing almost 9% of the target population with intellectual disabilities. Over half the participants were female with an average age of 54.7 years. The study has close harmonisation with the Irish Longitudinal Study of Ageing (TILDA), and facilitates the comparison of similarities and differences experienced by the general population and people with intellectual disabilities. In the IDS-TILDA study, Mc Carron et al. (2011), found that breast cancer incidence in Irish women with intellectual disabilities (29%) is comparable to the incidence in Irish women without intellectual disabilities (30%).

Lalor and Redmond (2009) undertook a survey to explore the extent of breast surveillance for breast cancer among post-menopausal women with intellectual disabilities living in three residential care settings in Ireland. The findings indicate that 67% of the 90 respondents had successfully completed mammography. This remains lower than the 72.2% uptake for women reported by BreastCheck (National Cancer Screening Service, 2013). The comparison of this convenience sample of post-menopausal women with intellectual disabilities with national norms relating to mammography uptake seems to indicate evidence of disparities in access to screening programmes. The highest successful completion of the mammogram was recorded in women with mild to moderate intellectual disabilities while in the severe to profound group, none of the women had successfully obtained a mammogram.
As the BreastCheck database register is compiled from information supplied by the Department of Social Protection and General Medical Services, it would be expected that all age eligible woman would be registered. Evidence of disparities in access to screening services for women with intellectual disabilities was apparent in this study as 14% of the age eligible women surveyed were not included on the BreastCheck register.

The authors of this paper are unable to discuss the cervical cancer screening uptake of women with intellectual disabilities in the Republic of Ireland due to the paucity of literature available on this topic.

**Theme 2: Contemporary research from Europe, United Kingdom and Canada on breast and cervical screening participation rates for women with intellectual disabilities.**

**Europe**

*POMONA II Health Indicators for People with Intellectual Disabilities: Using an Indicator Set (2005-2008)* was a European Commission public health project. It aimed to develop and test a set of health indicators specific to people with intellectual disabilities with the potential to increase the visibility of people with intellectual disabilities in health information surveys in member states in the EU. The data in this exploratory study represented a convenience sample to test an indicator set and may not
be deemed representative of people with intellectual disabilities nationally in the member states. However, the findings suggested evidence of disparities in gender specific screening tests for European women with intellectual disabilities; less than half the women with intellectual disabilities in the sample reported having a mammogram and less than one third of the women report participating in cervical cancer screening in the 14 member states in the relevant time periods (Noonan Walsh et al., 2008)

**United Kingdom**

In the UK, Osborn et al. (2012), undertook a retrospective cohort study to assess whether people with intellectual disabilities have poorer access to cancer screening using the Health Improvement Network (THIN) primary care research database. The active participants in THIN represented almost 6% of the UK population at the time of the study. The two cohort groups of interest were people with intellectual disability and a demographically similar group without intellectual disabilities.

With regard to breast screening in the UK, women with intellectual disabilities (n= 2956) were compared with women without intellectual disabilities (n= 17,354) in the Mammogram Cohort in 2009. The key finding in this cohort is that age eligible women with intellectual disabilities were still 35% less likely to have a mammogram than women without intellectual disabilities.
Women with intellectual disabilities (n=6254) were compared with women without intellectual disabilities (n=33,425) in the Cervical Cohort in the time period 2008-9. The key finding in this cohort is that age eligible women with intellectual disabilities were 45% less likely to have cervical cancer screening than women without intellectual disabilities.

**Canada**

A recently published study undertaken by Cobigo et al. (2013) and colleagues in Ontario, Canada investigated whether cervical and breast cancer screening programmes were equitable for women with intellectual disabilities. Two cohorts of adult women with and without intellectual disabilities living in Ontario who were eligible for health coverage in a twelve month period in 2009-2010 were created. All women with intellectual disabilities (n=16,663) and a random sample of 20% of the women without intellectual disabilities (n=1,352,366) were included in the cohorts.

The key findings in this study were that in Ontario the proportion of age eligible women with intellectual disabilities who did not receive a mammogram was one and a half times that of age eligible women without intellectual disabilities. The proportion of age eligible women with intellectual disabilities who were not screened for cervical cancer was almost twice that of age eligible women without intellectual disabilities.
Theme 3: Barriers faced by Irish women with intellectual disabilities when attending screening compared with the international experience.

D'Eath et al. (2005) undertook interviews with people with a range of disabilities including intellectual disabilities, parents and advocates in one health service area in Ireland (n=32, age range 21-77 years). Irish women with intellectual disabilities who had accessed screening perceived a number of barriers; among these were a lack of awareness among the personnel carrying out the procedure about people with intellectual disabilities; and abandonment of the test when the person found it difficult to cooperate during the procedure. People with physical disabilities had further concerns about environmental barriers particularly those surrounding positioning for a mammogram.

Lalor and Redmond (2009) established that Irish women with more severe intellectual disabilities have poorer access to breast cancer screening programmes, and these findings are reiterated in McCarron and colleagues (2011). Regrettably, women with intellectual disabilities often present with later, less treatable stages of cancer and have poorer outcomes (Sullivan et al., 2004a).

There is agreement concerning these perceived barriers to screening for Irish women with intellectual disabilities in the international literature. Concerns have been
expressed about physical disabilities and stature (Sullivan et al., 2004b; Biswas et al., 2005; Wilkinson et al., 2011); medical personal interactions with women with intellectual disabilities (Sullivan et al., 2004b; Rees, 2011; Wilkinson et al., 2011); painful experiences of procedure (Sullivan et al., 2004b; Biswas et al., 2005; Truesdale-Kennedy et al., 2011; Wilkinson et al., 2011); lack of understanding about the procedure resulting in stress and anxiety (Sullivan et al., 2004b; Truesdale-Kennedy et al., 2011; Wilkinson et al., 2011; Parish et al., 2012); poor provision of accessible information (Sullivan et al., 2004b; Truesdale-Kennedy et al., 2011; Wilkinson et al., 2011).

**Discussion**

In the IDS-TILDA study Mc Carron and colleagues (2011) found that breast cancer incidence in Irish women with intellectual disabilities is comparable to the incidence in Irish women without intellectual disabilities. This data clearly challenges the societal misconception uncovered by D’Eath and colleagues (2005) that Irish women with intellectual disabilities do not get cancer or need cancer screening.

Current Irish census data suggests a strong link between disability and poor health; of those reporting that they had bad or very bad health, 91.7% also reported having a disability including intellectual disabilities. There is a marked increase in health disparities between disabled and non-disabled individuals in Ireland after the age of 25.
years (Central Statistics Office, 2012). An Irish report on the impact of disability highlighted that a person with a disability present before the age of 25 years has an increased likelihood of having no qualification, a reduced chance of third level education and a reliance on a social welfare payment as their source of income (Gannon and Nolan, 2005).

Walsh et al. (2010) contend that socio-economic classification and education may offer insight into the individual’s ability to acquire and process health related information. Literacy challenges present a formidable barrier to people with intellectual disabilities to engage in and take ownership of their own health needs (Mc Carron et al., 2011). Walsh and colleagues conclude that differences in participation rates in the national cervical screening programme may persist in the short term, and uptake may depend on the women’s ability to organise a screening appointment (2010). Unfortunately this may result in Irish women missing the vital opportunity for the early detection and treatment of cancer. This presents a challenge to health professionals and services providing preventative breast and cervical cancer screening (Bouchardy Magnin, 2004).

Lalor and Redmond (2009) provided evidence that age eligible women with intellectual disabilities in the Republic of Ireland have lower participation rates that women in the general population in the breast cancer screening programme. This is similar to the international experience for women with intellectual disabilities who participate in
breast and cervical screening programmes (Noonan Walsh et al., 2008; Osborn et al., 2012; Cobigo et al., 2013). D’eath et al. (2005) reported that Irish women with intellectual disabilities who had accessed screening perceived a number of barriers including physical, environmental and attitudinal barriers which is reflected the experience of women with intellectual disabilities internationally.

There is a distinct lack of clarity in the Republic of Ireland on the participation rates of women with intellectual disabilities in breast and cervical cancer screening programmes. Walsh and colleagues (2010) did not provide any breakdown of the presence of an intellectual disability in their sample. BreastCheck and CervicalCheck do not separate screening uptake for women with intellectual disabilities from women in the general population (National Cancer Screening Service Communication Department, 2013).

Further research into the assessment of the cancer awareness of Irish women with intellectual disabilities and their participation in breast and cervical cancer screening programmes is recommended. Strategies need to be developed and evaluated which aim to increase participation in screening programmes by Irish women with intellectual disabilities. This is intended to lead to earlier diagnosis of breast and cervical cancer with better outcomes.
Limitations

The principal limitation of this review is the comparison of convenience samples of Irish women with intellectual disabilities with national norms for cancer screening uptake rates. The authors acknowledge that drawing inferences from this type of comparison may not be empirically sound as the convenience samples may not be deemed representative of Irish women with intellectual disabilities. However, given the limited evidence base available in an Irish context, these comparisons give valuable insight into the apparent inequalities in cancer screening uptake for Irish women with intellectual disabilities.

Conclusion

The health needs of Irish women with intellectual disabilities present a challenge to preventative health services including cancer screening services (Bouchardy Magnin, 2004). International recommendations encompass the provision of tailored health promotion for the women with intellectual disabilities and their carers to increase cancer awareness and improve participation rates in screening programmes (Mc Carron et al., 2011; Wilkinson et al., 2011; Parish et al., 2012; Cobigo et al., 2013). In this context it is opportune to assess the breast and cervical cancer awareness and screening awareness amongst Irish women with intellectual disabilities.
Recommendations

It is timely to investigate the reasons for the differences in screening services uptake for these women when compared to the general population in Ireland. The implementation and evaluation of a tailored health education programme for Irish women with intellectual disabilities may offer a potential solution to achieve earlier detection and reduce the unnecessary deaths of women with intellectual disabilities from breast and cervical cancer.
References


