

Cancer prevention and health promotion for people with intellectual disabilities: an exploratory study of staff knowledge

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Abstract

Background As people with intellectual disabilities (ID) are living longer, their chances of developing cancer also increases. However, recognising the early signs and symptoms of cancer in a population with cognitive impairment and communication difficulties poses difficulties for both family carers and professional care staff. Engagement in health promotion and cancer prevention activities is also a challenge; yet, people with ID have an equal right to these important public services as other members of the population.

Aims The aim of this study was to examine how care staff engaged in cancer prevention and health promotion activities on behalf of people with ID.

Methods This was an exploratory descriptive study using a postal survey design employing a questionnaire. Fifteen residential facilities for adults with ID were targeted within one geographic region of the UK. In total, 40 residential staff completed a questionnaire about their knowledge of the risk and protective factors of stomach, breast, cervical and testicular cancer. Staff then completed questionnaires regarding 90 adults with ID, recording details

about body mass index (BMI), lifestyle choices (i.e. smoking, dietary intake), *Helicobacter pylori* testing, family history of cancer and staff's health promotion and cancer prevention activities with these individuals.

Findings The women with ID were reported to have significantly higher BMIs than the men with ID and only two people with ID had been tested for the *H. pylori* infection: potential risk factors for developing breast and stomach cancer, respectively. The majority of the staff reported that they did not receive training in cancer prevention. Likewise, the majority of the staff reported that they were unaware of the family histories of the people with ID in their care. Reports varied with how staff engaged with people with ID regarding stomach, breast, cervical and testicular cancer health promotion activities and cancer screening opportunities.

Discussion Findings of this study show that health promotion and cancer prevention activities for people with ID may be less than optimal. The importance of staff training in order to raise knowledge and awareness is highlighted. Educating both staff and people with ID about the early signs and symptoms of cancer and the importance of a healthy lifestyle as a protective factor may help lead to more informed healthier lifestyle choices and lower cancer risk and morbidity.

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Keywords cancer, health promotion, intellectual disability, risk factors, staff education

Background

People with intellectual disabilities (ID) suffer from significantly more health problems than the general population and are much more likely than other citizens to have significant health risks and major health problems (Department of Health 2001; MENCAP 2004; Disability Rights Commission 2006; Taggart *et al.* 2007). Furthermore, there is considerable evidence that people with ID are not receiving the same level of health care as other members of society. For example, health screening medical checks are given less often to people with ID than the general population (Evenhuis *et al.* 2000); yet, the Disability Discrimination Act (HMSO 1995, 2005) places duties on the UK public sector not to discriminate against disabled people across the whole range of its public activities and access to health promotion and illness prevention services would be included within this remit.

The Disability Rights Commission (2004) reported that in the UK 'four times as many people with learning disabilities die of preventable causes as people in the general population'. There is a strong need to challenge this inequality as an important human rights issue. Improved health is likely to lead to improved quality of life for both individuals with ID and their families. Yet, part of the reason why the health outcomes of this group are poor is due to the fact that people with ID are reliant on both informal and formal carers to promote healthy lifestyles and to make healthy choices on their behalf. However, ID professionals and family carers may not be fully cognizant of the particular needs of this population or fully aware of the importance of health promotion activities.

Globally, it is estimated that over 12 million people are diagnosed with cancer every year. The global cancer burden has doubled in the last thirty years of the 20th century, and it is estimated that this will double again by 2020 and nearly triple by 2030 (Boyle & Levin 2008). Although cancer is the third main cause of death in people with ID, the incidence of cancer among this population has been reported to be lower than that of the general popu-

lation (11.7–17.5% vs. 26%). Hollins *et al.* (1998) reported that cancer accounted for 8–13% of deaths in their study population. Likewise *et al.* (2002) in Sydney found that 17.5% of deaths among people with ID were caused by cancer. Patja *et al.* (2001) found that half of all cancers in people with ID were digestive, followed by urogenital cancers and testicular cancer.

However, given that cancer is 'an older person's disease' this figure is set to rise partly because of the improved life expectancy of those with ID (Duff *et al.* 2001). More recent studies have shown that many people with ID will be affected by cancer during their lifetime; either through getting cancer themselves or through having a relative or friend who develops cancer (Tuffrey-Wijne *et al.* 2006). Despite the evidence that cancer is a leading cause of death for people with ID, there has been concern that cancer health screening services may be less than optimal. Davies & Duff (2001) have found that the reported incidence of cervical and breast cancer among women with ID was lower than women without ID. The authors stated that this could be as a result of poor detection rates because of a low level of screening and diagnosis among this group as they noted that only one-third of the women with ID had received invitations for mammograph screening. Reynolds *et al.* (2008) found that women with ID were 'significantly more likely to be ceased from screening raising concerns about equity of access to screening programmes'. Similarly, Peate & Maloret (2007) have also noted that little is done with regard to informing men with ID about the benefits of testicular self-examination. Consequently, it may be the case that ID professional carers, primary healthcare professionals and specialist breast screening nurses may be missing important opportunities to engage in health promotion activities with this vulnerable group (McIlpatrick *et al.* 2010).

Hogg & Tuffrey-Wijne (2008) in a review of the literature concerning cancer and people with ID found that in women with ID there was a reduced risk of cervical and breast cancer. However, they also raised concerns that cancer screening for women with ID was lower compared with the general population. Additionally, this population had an increased risk of ovarian and corpus uteri cancers, as well as an increased risk of colorectal

cancer over their male counterparts. On the other hand, cancer mortality was reported to be higher for men with ID compared with women with ID in all age bands (Durvasula *et al.* 2002). Men with ID had a considerably higher rate of stomach cancer than men without ID. The incidence of prostate and testicular cancer in men with ID was found to be lower than in men without ID (Patja *et al.* 2001), although the incidence of testicular cancer in men with Down syndrome is 'unusually' high (Yang *et al.* 2002). Given these striking findings, Hogg & Tuffrey-Wijne (2008) also highlighted the lack of attention given to screening for male specific cancers

Taggart *et al.* (2010) reported that there was growing evidence to suggest that women with ID are more likely to experience a greater number of risk-factors for breast cancer, thus placing them at an advanced threat of developing breast cancer compared with women without ID. These risk-factors include: leading a more sedentary lifestyle (McGuire *et al.* 2007); low levels of exercise (Temple & Walkley 2003); and consuming high-fat diets (Ewing *et al.* 2004) all of which can contribute towards obesity: a significant risk factor for breast cancer (Magnusson *et al.* 1998). In addition, Patja *et al.* (2001) reported that women with ID were also more likely to develop cancer as a result of sexual inactivity, nulliparity, loss of menstruation with low oestrogen levels and a shorter menstrual life.

Another important risk factor associated with increased stomach cancer, gastric ulcers and lymphoma is the class I carcinogen *Helicobacter pylori* (Duff *et al.* 2001; Wallace *et al.* 2004; Hogg & Tuffrey-Wijne 2008). A review of the risk factors of *H. pylori* among people with ID revealed a number of independent factors including a 'history of institutionalization, lower ability, higher levels of behaviour problems and living with flatmates with oral hyper salivation and faecal incontinence' (Wallace *et al.* 2004). The review calls for further information for carers in order to enable them to comply with eradication protocols, similar to those for the general population (Wallace *et al.* 2004).

O'Regan & Drummond (2008) highlighted that having access to cancer information should be considered a crucial part of providing optimum holistic care for this client group. However, Taggart *et al.* (2010) in Northern Ireland found ID nurses and

residential support staff rarely utilised user-friendly cancer health educational material and also infrequently engaged in health promotional activities regarding cancer breast awareness, up-take of breast screening and engaging in healthier lifestyles.

Tuffrey-Wijne *et al.* (2006) reported that a lack of user-friendly cancer information materials targeted at people with ID can lead to numerous barriers to good quality cancer health promotion cancer care. Such information would provide greater opportunities for people with ID to make informed decisions about their health choices and actions (Taggart *et al.* 2010).

Hogg & Tuffrey-Wijne (2008) also looked at carer health knowledge and revealed that 'both paid staff and family carers have a key role to play in ensuring that people with ID who indicate distress or pain receive appropriate medical attention'. However, they acknowledged the importance of further refinement of the association 'between specific syndromes and cancer in people with ID' (p. 514). A key issue to be addressed is the role that both family carers and front-line staff play in the early recognition of the signs and symptoms of ill-health including cancer and in promoting healthier lifestyles for people with ID. Evenhuis *et al.* (2000) reported that people with ID have had few opportunities to actively engage in health education, health promotion activities and health screening. The Disability Rights Commission (2006) stated that in interviews they conducted with people with ID only a minority reported ever receiving advice on health promotion. Moreover, MENCAP (2004) stated that paid staff do not receive the training they require to allow them to educate people with ID about different cancers and supporting them to reduce their risk of developing specific cancers (i.e. gall-bladder, gastrointestinal, breast, cervical, testicular).

Little is known about ID staff's knowledge of the signs and symptoms of cancer, their understanding of the risk factors of specific cancers as well as their training needs, and how they engage in cancer preventative behaviours on behalf of this vulnerable population. The aim of this study was to examine how staff engaged in cancer prevention and health promotion activities and behaviours on behalf of people with ID. To fulfil this aim, there were three objectives. The first objective was to examine staff's knowledge of the signs and symptoms of cancer as

well as the protective factors. The second objective was to investigate the physical health, family histories of cancers and lifestyle choices of people with ID regarding their risk of developing cancer. The third objective was to examine whether front-line staff promoted and engaged in cancer health promotion activities among people with ID.

Method

Design

This was an exploratory descriptive study using a postal survey design employing an anonymised questionnaire.

Settings and participants

The study was carried out in Northern Ireland, a region situated in the north eastern corner of Ireland but governed as an administrative division of the United Kingdom, with its own form of devolved government. The Northern Ireland Disability Discrimination Order (HMSO 2006) places duties on the public sector not to discriminate on grounds of disability equivalent to the UK Disability Discrimination Act (HMSO 1995, 2005) and authorities are required to make reasonable adjustments to meet the needs of people with disabilities. The region has a population of approximately 1.72 million people and operates an integrated health and social services system administered by one government Department for Health Social Services and Public Safety. Health and social services are delivered by five Health and Social Care Trusts (H&SCTs). This study was undertaken in one of these H&SCTs with an estimated residential population of 350 people with ID residing over 25 residential facilities catering for their needs. These facilities included nursing homes (24 people plus), residential homes (12–16 people) and supported living schemes (4–10 people).

Introductory letters were sent to care facility managers, informing them about the study and asking for their permission as 'gatekeepers' to distribute questionnaires and an information sheet explaining the purpose of the study to their staff. Completion and return of the anonymised questionnaire by care staff was taken as implied consent.

The respondents who completed the questionnaires on behalf of the person with ID were either ID nurses or residential workers, acting as their key workers, who knew the person and had experience of working with them for at least a year.

In total, 40 staff returned completed questionnaires on themselves and on behalf of 90 adults with ID. The authors acknowledge overall that the response rate (25.7%) was low but difficulties because of sick leave, work commitments and annual leave reduced the final response rate. This was disappointing; however, the results collected were still sufficient given the exploratory nature of the study (Parahoo, 2006; Polit & Beck 2010).

Instrument

Initial meetings took place with professionals working in the area of cancer and health promotion to discuss some of the issues pertaining to cancer health promotion activities. On the basis of this and a detailed search of the literature (Hermon *et al.* 2001; Sullivan *et al.* 2004; Tuffrey-Wijne *et al.* 2006), an anonymised self-completion questionnaire was developed so that information regarding health promotion and cancer prevention activities with people with ID could be obtained from a large sample of residential care staff. The questionnaire was divided into three parts.

Part one collected information on care staff regarding gender, age, job title, personal experience of cancer and training history. Part two of the questionnaire explored staff knowledge of the recognised signs of cancer and cancer risk factors according to Cancer Research UK (2009), the National Cancer Institute (2009) and the American Cancer Society (2009) (see Tables 1,2). This part of the questionnaire involved staff correctly identifying signs and symptoms of four particular cancers from a generated list.

The third part of the questionnaire asked each staff member for information regarding an individual person with ID whom they were caring for. If a staff member was caring for more than one person with ID, then a separate section was filled in for each person cared for. This third section of the questionnaire included closed questions and multiple choice questions relating to demographic information about each person with ID such as

Table 1 Cancer risk factors and protective measures

Cancer early warning signs	Changes to lower risk of developing cancer
An unusual lump or swelling anywhere on the body	Limiting amount of animal fat in the diet
A mole change (change in size, shape or colour of a mole)	Controlling your weight
A sore that will not heal after several weeks	Eating five portions of fruit and vegetables daily
A mouth or tongue ulcer that lasts longer than 3 weeks	Limiting sun exposure
A cough or croaky voice that lasts longer than 3 weeks	Getting some brisk physical activity daily
Persistent difficulty swallowing or indigestion	Moderate alcohol intake
Problems passing urine	Going for regular preventative cancer screening
Blood in your urine	Stop smoking
Blood in your bowel motions	
Change to more frequent bowel motions that lasts longer than 6 weeks	
Unexplained weight loss or heavy night sweats	
An unexplained pain or ache that lasts longer than 4 weeks	

Taken from Cancer Research UK, 2009 and the National Cancer Institute, 2009.

Table 2 Risk factors associated with certain cancers

Stomach cancer risk factors	Breast cancer risk factors	Cervical cancer risk factors	Prostate cancer risk factors
Having the infection <i>Helicobacter pylori</i> (<i>H. pylori</i>)	Being >55 years	Having human papilloma virus	Being >40 years
Being male	Family history	Smoking	Being black
Being >50 years	Being white	Being HIV-positive	A diet rich in red meat
Eating large amounts of smoked/salted foods	Having denser breast tissue	Having chlamydia	Family history
Smoking	Being diagnosed with benign breast conditions	Women use oral contraceptives	A diet rich in high-fat dairy products
Being obese	Working night shifts	Women who have had multiple pregnancies	
Having prior stomach surgeries, i.e. ulcers	Starting menstruation early <12 years	Women of low socio-economic status	
Having type A blood	Menopause starting later >55 years	Family history	
Suffering from pernicious anaemia	Women who have had no children		
Working in the coal, metal or rubber industry	Women use oral contraceptives		
	Excessive alcohol intake		
	Being overweight		

Taken from the American Cancer Society, 2009.

gender, age, level of ID, physical health, height, weight and body mass index (BMI), lifestyle choices (i.e. smoking, alcohol consumption, dietary intake), *H. pylori* testing and additional information about each person's family history of cancer. In addition,

the questionnaire collected data on whether staff promoted and engaged in cancer health promotion activities with each person with ID in their care (e.g. emphasising the importance of screening, smear testing, breast and testicular examinations,

etc.). This section of the questionnaire gave a detailed list of health promoting activities and behaviours, and staff were asked to rate how often they carried out each behaviour with the person with ID in their care.

Data analysis

The data collected from the questionnaires were coded and input into the Statistical Package for Social Sciences (SPSS version 11.5) for analysis. Ranges of descriptive statistics were employed to explore the data from the questionnaires. BMI was calculated using the standard metric formula. Independent *t*-tests and Mann–Whitney *U*-tests were employed to test for gender differences as well as staff knowledge throughout the questionnaire.

Ethics

Ethical approval was obtained from the University of Ulster's Ethics Committee. Confidentiality was assured throughout the study as anonymised questionnaires were used and the names of staff and the residential facilities were not sought. No personal identifiable information about the people with ID was obtained and the respondents were informed that the questionnaires would be destroyed at the completion of the study.

Results

Staff demographics

A total of 40 care staff completed the questionnaire, 30 (75%) worked in supported living schemes or residential homes and the remaining 10 worked within nursing homes. Thirty-two staff (80%) were female and eight staff were male (20%). Twenty staff (50%) stated that they were over 36 years old; with five staff (12%) aged between 16 and 25 years old. Non-qualified staff accounted for three-quarters of the respondents (75%) and included titles such as support assistant, support worker and residential worker. A quarter of the staff (25%) was qualified as ID nurses.

Staff knowledge of cancer

The respondents were asked to identify the early warning signs of cancer. In total, there were 12

recognised signs (see Table 1). The median number of signs identified by the participants was 9 (min = 3, max = 12). No significant differences were found between the unqualified and qualified staff, or whether participants had personal experience of cancer.

In terms of staff's knowledge of the risk factors for stomach cancer of the 10 recognised factors (see Table 2), the median number identified was 4 (min = 0, max = 10). Regarding staff's knowledge of the risk factors of breast cancer of the 12 recognised factors, the median was 4 (min = 1, max = 10). With regard to staff's knowledge of the risk factors of cervical cancer, of the eight accepted factors, the median was 3 (min = 1, max = 8). Similarly, staff's knowledge of the risk factors of prostate cancer, of the five known factors, the median was 3 (min = 1, max = 10). With regard to staff's knowledge of the preventative factors protecting people from developing cancer *per se*, of the eight documented factors (see Table 1), the mean was 7 (min = 4, max = 8). Using a series of non-parametric Mann–Whitney *U*-tests, no significant differences were found between the unqualified and qualified staff, or whether participants had personal experience of cancer, in terms of their knowledge of the risk factors of stomach, breast, cervical and testicular cancer.

Staff training

Of the 40 staff who completed the questionnaire, only three (7.5%) reported that they had received any form of training in cancer awareness and cancer health promoting activities targeted for people with ID. In addition, further probing revealed that this training was minimal and sometimes only consisted of written information being passed on to staff.

People with intellectual disability demographics

The 40 participants completed 90 questionnaires on behalf of adults with ID. Fifty-five adults with ID were female (61%) and 45 were male (39%). Over three-quarters (76.4%) were aged 45 years or over. The majority of adults (39.8%) had a severe ID, 33 adults (37.5%) had a moderate ID, 13 adults (14.8%) had a mild ID and seven adults (8%) had a profound ID.

Table 3 Average BMI calculations

	Weight (kg)	Height (metres)	BMI
Female	72.15	1.53	30.8
Male	66.31	1.65	24.4
Total	69.88	1.59	27.7

BMI, body mass index.

Weight, height and body mass index

Table 3 shows the average weight, height and BMI for the male and female adults with ID. The women were found to weigh heavier than the men (mean = 72.15 kg vs. 66.31 kg). The women with ID had an average BMI of 30.8 (min = 16.2, max = 47.6) which would be classified as obese according to NHS (2007) guidelines compared with men with ID who had an average BMI of 24.4 (min = 13.1, max = 42), which is within the normal classification. Of the 45 women whose BMI was calculated, only 12 women (26.7%) fell within the normal range (18.5–24.9). Four women (7.2%) had a BMI of 40+ and were therefore classified as morbidly obese. An independent *t*-test was conducted to examine whether there was a significant difference between the women and men in the sample regarding their BMI scores. A significant difference was found with the women scoring higher compared with the men ($t = 3.782$, d.f. = 74, $P < 0.001$) indicating that the women with ID were more likely to be overweight than the men.

Lifestyle behaviours

Staff reported that the majority of people with ID (90%) did not smoke, and of those who did only four people (4.4%) smoked 60 plus cigarettes per week. Likewise, the majority of people with ID did not drink alcohol (92.2%). However, staff reported that four individuals drank 1–2 units per week, one person drank 5–6 units per week and one person drank 10+ units per week. Just over half of the women with ID (52%) were reported as being either very active or regularly active compared with 48% of the women who were described as either a little active or not active at all. This contrasts with

the staff reporting that two-thirds of the men with ID were very active or regularly active and a third of the men being described as less active or undertaking no activity.

Less than a third of the people with ID (32%) consumed the recommended five portions of fruit and vegetables per day as indicated by the persons' key worker. Even less of the adults with ID consumed the required two portions of oily fish per week (26.7%).

Helicobacter pylori

Of the 90 completed questionnaires on adults with ID, staff reported that only two people (2.2%) had ever been tested for the *H. pylori* infection. In fact, a number of staff indicated on the questionnaire that they did not know what the *H. pylori* infection was.

Family histories of cancer

Part of the questionnaire sought information on staff knowledge with regard to the person with ID's family history of cancer (i.e. mother, father, siblings who may have had the disease). Questionnaires were completed for 90 adults with ID and while none of the staff reported that they knew of any family histories of stomach, colorectal or ovarian cancers, family histories of breast cancer were reported for three of the women with ID and a family history of prostate cancer was reported for two of the men.

Cancer health promotion activities

Just over half of the people with ID (57.8%) were offered advice from staff about the importance of a healthy diet either weekly or monthly. Similarly, just over half of the adults with ID (53.3%) were offered advice with regard to the importance of regular physical activity. Just less than half of the adults with ID (45%) were offered advice from staff about the importance of limiting the amount of animal fat in their diet at least every month.

With regard to more sensitive health promotion topics for preventing specific cancers; topics like regular bowel movements, ovarian screening and testicular screening were the least likely to be discussed. Only six of the women with ID (10.9%) were offered advice about the importance of regular

breast screening at least once a month; 18 women with ID (33.7%) were never offered advice on the importance of regular breast screening. Likewise, 21 men (46.7%) were never offered advice regarding testicular screening.

Discussion

This study was designed as a descriptive and exploratory study and data were collected from a small sample in a single geographical location; thus, care should be taken with regard to the generalisability of its findings. Nevertheless, there is a sense of 'fit' between this study's findings and those of previous studies (MENCAP 2004; Peate & Maloret 2007; Taggart *et al.* 2010). Significant gaps were found in residential care staff's knowledge of the signs and symptoms of cancer, as well as the risk factors for certain cancers such as stomach, breast, cervical and prostate. The majority of respondents had not received training in health promotion for people with ID and were unaware of the signs and symptoms of cancer, as well as the risk and protective factors for the disease.

Family history is now widely accepted as a risk factor for certain cancers (Offit & Brown 1994; Eberl *et al.* 2005; Gao *et al.* 2009). However, this study clearly illustrated that residential care staff had little knowledge of the family histories of cancer of people with ID within their care. Eberl *et al.* (2005) stated that persons who are identified as being at an 'increased risk of various cancers based on their family history' should be involved in an appropriate 'surveillance plan' and should also be well informed of the importance of maintaining a healthy lifestyle (i.e. diet, exercise) and undertaking regular screening (i.e. breast, cervical, testicular). Consequently, front-line staff looking after people with ID should be aware of and continuously carrying out these obligations on behalf of the people in their care: this appears to be absent within this study.

Eberl *et al.* (2005) also acknowledged that it is essential to identify people at 'increased risk' of cancer. Another risk factor found more specifically in women with ID is nulliparity (not giving birth) which can result in a fourfold increase in risk of developing breast cancer (Judkins & Akins 2001): however, less than a quarter of staff within this

study recognised nulliparity as a risk factor for developing breast cancer.

This study found that women with ID had higher BMIs compared with the men with ID, placing them in the obese category. These findings are not exclusive, as there is growing evidence to suggest that adults with ID, particularly women, are a high risk group with regard to developing obesity and its associated health risks (i.e. diabetes mellitus type 2, respiratory problems, cardiovascular problems (i.e. stroke and myocardial infarction), thereby leading to premature death (Martin *et al.* 1997; Marshall *et al.* 2003; van Schrojenstein Lantman-de Valk & Noonan Walsh 2008; NHS 2009; Sohler *et al.* 2009). This is of some concern as there is a link between high BMI, obesity and increased risk of cancer mortality (Hu *et al.* 2005; Melville *et al.* 2008). Hu *et al.* (2005) conducted a prospective follow-up study among middle-aged Finnish men and women in the general population to examine the association of physical activity, BMI and cancer mortality. The authors found that obese women had a 'significantly increased risk of death from breast, stomach, ovary and pancreas cancers' in comparison with those who were not obese (p. 899).

The staff in this study reported that only two people with ID had received the *H. pylori* test. This figure is concerning, especially when we take into account that the majority of people with ID in this study had been residing in these residential facilities for over 5 years plus. This must be observed with the growing evidence that links the *H. pylori* infection with gastrointestinal cancers (Duff *et al.* 2001; Hogg 2001). Moreover, there is mounting evidence to suggest that people with ID are more likely to suffer from the *H. pylori* infection (Hogg 2001; Clarke *et al.* 2008; Kitchens *et al.* 2008); yet, ID staff involved in this current study showed a limited knowledge of this infection, *H. pylori* testing or subsequent consequences if left undetected. According to Stone & Mayberry (2002), knowledge of the *H. pylori* infection is not widespread in the general population, as their study revealed that only 4% of the public knew what this infection was. However, although a lack of knowledge might be expected in the general population, front-line staff working with an 'at-risk' population, such as people with ID in residential care, should have a more in-depth knowledge of this infection, its treatment and

how treatment can diminish the persons' risk of developing gastrointestinal cancers.

The findings from this study support those published by Lindsey (2002), who stated that one of the barriers to the access of people with ID to appropriate health care may be a 'lack of family carer and professional awareness of the cancer health needs of people with ID'. She states that paid carers may not be aware of the importance of a healthy lifestyle and may misinterpret behavioural and physical changes that point to underlying health problems. Additionally, Young *et al.* (2007) argued that 'proactive methods of supporting staff learning and development are urgently required' among staff working with people with ID who may develop cancer. Likewise, Tuffrey-Wijne *et al.* (2005) also argued that there is a lack of information and training materials around cancer and palliative care for ID staff, and that more work is needed to develop appropriate training in this area. O'Regan & Drummond (2008) also note that further development of a wide range of accessible information materials on cancer and ID is necessary.

In a recent initiative to address these issues, a user-friendly information booklet on breast awareness has been developed in order to help carers and women with ID to understand the importance of breast awareness and breast care (Taggart & McKendry 2010). Additionally, little information currently exists on the effects of health-related behaviours and the application of preventive health programmes among persons with ID and there is a pressing need for additional research to explore these areas (Yamaki 2005).

The staff response rate to this study was lower than the authors would have wished and although this may have been due both to the sensitive nature of the questionnaire and the pressures of work in busy facilities, this may also indicate a lack of interest or awareness of cancer health promotion activities. The study explored staff knowledge of cancer risk factors for the people with ID in their care but did not examine staff's knowledge regarding their own risk of cancer. Likewise, it did not examine staff lifestyle with regard to their own cancer risk factors (exercise, diet, weight management, etc.). It would seem plausible that if ID staff do not understand, or are not aware of their own risk of developing cancer, then this will ultimately affect their

ability to provide appropriately informed health promotion activities to those in their care. If a similar pattern of unhealthy lifestyle choices was found in ID staff as in those with ID, it may be that ID staff members also need to have a raised awareness of their own lifestyle choices and the implications of these for cancer risk. ID staff would then be in a much better position to help and assist the people with ID in their care to make healthier lifestyle choices on their own behalf. Health promotion and cancer prevention initiatives targeted at care facilities as holistic units, involving both staff and people with ID may prove more effective than those aimed at people with ID alone.

Conclusion

As the life expectancy of people with an ID increases, therefore, the prevalence rates of cancer within this population group can also be expected to rise. However, many cancers are preventable and people with ID have equal right to cancer prevention and health promotion services as other members of the population. This study highlights a need for better staff education and training in health promoting activities that raise awareness of the signs and symptoms of cancer and the risk and protective factors for developing the disease. As many people with ID will have difficulty in understanding health literature about cancer awareness and the importance of a healthy lifestyle, then both ID and cancer professionals are challenged with the important task of developing appropriate health promotion strategies to encourage and empower this client group to embrace health behaviours which decrease their cancer risk and enable them to live healthier lives.

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