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Understanding the use of breast cancer screening services by women with intellectual disabilities

Summary

Objectives: The uptake of mammography for breast cancer screening is considerably lower among women with intellectual disability than for women in the general population. The purpose of the present study was to investigate carer perceptions of barriers and enablers to mammography use by these women.

Methods: To determine the reasons why women with intellectual disability are not utilising screening services, a series of focus groups were held with social trainers working in accommodation provided for people with intellectual disability.

Results: The major themes identified included the need for a medical referral or invitation from the mammography service to motivate people to attend; the belief that many women with intellectual disability would not understand the procedure or why it needs to be done and therefore would experience fear and anxiety to a greater extent than women in the general population; and that physical disabilities comorbid in many of the women would limit their ability to be adequately accommodated by the machines used to take a mammogram.

Conclusions: The social trainers agreed that many of the barriers to screening would be difficult to overcome and supported alternative strategies to mammography, such as clinical breast examination.

Keywords: Intellectual disability – Mammography – Australia – Preventive medicine.

Mammography screening programs have been established in many countries to reduce mortality from breast cancer (Ballard-Barbash et al. 1999). Despite the benefits of breast cancer screening, a significant proportion of the eligible population choose not to use these services, most of which are free or subsidised. Reasons not to attend screening include lack of encouragement by physicians (Grady et al. 1992; Nosek & Howland 1997; Miller et al. 1998; George 2000), lack of perceived risk (Orton et al. 1991; George 2000; Speedy & Hase 2000), fear (Thompson et al. 1997), embarrassment (Orton et al. 1991; Nosek & Howland 1997), inconvenience (Speedy & Hase 2000), insensitivity of health care workers (Nosek & Howland 1997; Thompson et al. 1997; Williams et al. 1997), pain or discomfort (Keemers-Gels et al. 2000; Andrews 2001; Sapir et al. 2003), physical disability (Nosek & Howland 1997), residence in a nursing home and dementia (Marwill et al. 1996).

Women with intellectual disabilities are among the least frequent users of screening mammography (Cowie & Fletcher 1998; Piachaud & Rohde 1998; Davies & Duff 2001), perhaps because the standard recruitment strategies are not suitable. Active recruitment into mammography programs is generally undertaken based on a mailing list derived from various sources such as general medical practitioner (GP) records or the electoral roll (Ballard-Barbash et al. 1999), and for many women with intellectual disability these sources may be inappropriate. For example, in the UK mailing lists are developed from GP records at the discretion of the GP, and women with disabilities may not be included if they are considered unsuitable for mammography (Piachaud & Rohde 1998; Davies & Duff 2001). In Australia, mammography services are coordinated by a federal agency, BreastScreen, with screening programs separately organised by individual states. The Western Australian (WA) branch, BreastScreen WA, has been operating since 1989. The mailing lists used are derived from information contained on the electoral roll and are stored in a state-based Mammography Screening Registry. This is an effective means of reaching the bulk of the population because voting is compulsory for the majority of Australian citizens. However, some exceptions exist, including women with intellectual disability who are exempt from voting.

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Recruitment to BreastScreen is supplemented through public health campaigns encouraging self-referral, however this is improbable for women with intellectual disability unless encouraged and organised by an advocate, such as a health worker, carer or a family member (Lennox et al. 2000). Furthermore, even when women do intend to undergo screening, other factors may inhibit their ability to complete the screening process. For example, they may not have adequate access to transport, and may find it difficult to cooperate with the screening staff because they have limited understanding of the procedure, or comorbid physical conditions limit their ability to use the machines comfortably (National Health Service Cancer Screening Program 2000; Walsh et al. 2001). An investigation of several measurable factors associated with reduced utilisation of mammography services indicated that the use of screening services was positively associated with milder intellectual disability, residence in a rural area and marriage, and was negatively associated with severe intellectual disability, institutional care and physical disability due to cerebral palsy (Sullivan et al. 2003). While these findings are predictable, the service uptake was not in fact consistently associated with these quantifiable factors, which indicates the need to better understand the dynamics that underpin mammography screening especially for women with moderate to severe intellectual disability. The aim of the present study was to explore the role of potential barriers and enablers for mammography screening among women with intellectual disability and to determine the interplay between these factors.

Subjects and methods

The study setting was hostels maintained by the Disability Services Commission (DSC), the state-based government body responsible for the provision of health and social services for people with intellectual disability in Western Australia. Eligibility for DSC services is based on a measure of intellectual disability status, which is determined by IQ and adaptive behaviour assessment, where a score of less than 70 on both tests is accepted as indicative of intellectual disability. DSC provides hostel accommodation for clients who cannot care for themselves and whose families are unable to provide care. The accommodation provided by DSC is classified according to the support requirements of the residents, and ranges from medium to high, and high-medical. These grades are based on the number of clients with behavioural problems and physical disabilities and on the severity of these conditions. High-medical support hostels cater for clients with severe comorbid medical conditions. The DSC hostels typically provide a greater degree of support than private facilities, and hence include fewer clients with low support needs.

In the present study, four focus groups were held with social trainers working in three DSC hostels located in the Perth metropolitan area. Initially the possibility of interviewing clients with intellectual disability was explored but this idea was not supported by clinicians working with DSC, who felt that direct information would only be obtainable from mildly affected clients. For those with moderate or severe intellectual disability, an interview would likely be conducted with the help of their social trainer who would often answer on their client's behalf, in effect giving their own opinion, not the client's. Given the significant influence social trainers have over a client's ability to access primary health care (Lennox & Kerr 1997), it was decided to determine the barriers and enablers to services as perceived by them. Social trainers provide general training, support and counselling to ensure emotional, social and physical well-being of clients with intellectual disability, and their duties include organising social activities, coordinating training programs, administering medication and arranging health care services when needed. Thus they play an important role in the daily lives of their clients and they are likely to exert significant influence over decisions affecting the utilisation of preventive health services, including mammography screening. For this reason, we considered that the social trainers were in a position to provide information about factors that influenced the use of mammography screening for women with intellectual disability, particularly those who were moderately or severely affected.

Given the exploratory nature of the study, focus groups were considered to be an appropriate research design to elicit information (Black 1994). Importantly, focus groups have been used to identify barriers to mammography among subpopulations that are traditionally low users of mammography, such as African American women and minority groups (Danigelis et al. 1995; Williams et al. 1997; Bobo et al. 1999; Ahmed et al. 2001).

To recruit a broader cross-section of social trainers working at different hostels, three DSC hostels were initially approached to participate in the study; one each catering for clients with medium, high and high-medical needs. The senior social trainer-cum-manager at each of these hostels was asked to identify trainers interested in participating in the study. There were 20 female clients with intellectual disability at the medium support hostel, nine at the high support hostel and 17 at the high-medical support hostel. The median age of women with intellectual disability at each of the hostels was 46, 60 and 39 years at the medium, high and high-medical facilities respectively.

Four focus groups were held, one each at the high and high-medical-support facility and two groups at the medium support facility. Two group discussions were held at the medium support facility because of the larger number of social trainers employed there (42 compared to nine in high support and 24 in high-medical support hostels). Each group discussion began with an explanation of the research project and the format of the focus group. Participants were provided with an information sheet, given the opportunity to ask questions and then invited to sign a consent form and complete a brief demographic questionnaire. Questions were asked by a moderator and the responses were recorded by audio tape and a non-participant note-taker. An open-ended interview guide was developed for the group discussions and the interviewing style was largely passive to allow participants to describe issues in greater detail (Frey & Fontana 1991; Kreuger & Casey 2000). Every possible effort was made by the investigators not to introduce bias into the discussions or influence the group in any way that would bias the outcome. At the end of each session, the moderator gave a short summary to provide feedback to participants and to allow them to raise any other issues of importance they felt had not been adequately addressed.

The four focus groups included a total of 30 participants, with groups ranging in size from four to 11 people. Demographic questionnaires were completed by 27 of the 30 participants. The majority of social trainers were women, most of whom were aged over 40 years and had a personal experience of mammography. All respondents spoke English as their primary language, the majority being born in English speaking countries. 60 % had a technical qualification, while with one exception all others had completed secondary education.

The data from the focus groups were transcribed from audiotapes and notes. These transcripts were read carefully and recurrent themes emerging from the data were outlined. Following this preliminary step a detailed index of the data was developed, with numerical codes assigned to themes for ease of analysis. Themes were charted and categorised in greater detail to define concepts, map the range and nature of the responses, and describe some of the key issues (Pope et al. 2000).

Ethical considerations

Ethical approval to undertake the study was granted by the Ethics Committees of the University of Western Australia and the Disability Services Commission (DSC) of Western Australia.

Results

Knowledge about breast cancer

The main causative risk factors reported by the participants to be associated with breast cancer were related to lifestyle; such as smoking, diet, lack of exercise and obesity, and genetic predisposition. There was a strong sense that breast cancer was an inherited condition. Only one participant mentioned the risk associated with nulliparity across the four group discussions. It was generally felt that the level of knowledge about breast cancer among clients (i.e., women with intellectual disability) was "extremely limited to nil". When asked whether they thought clients would have heard about breast cancer from the public awareness campaigns aired on television, the common feeling was that while clients may have seen advertisements they would not necessarily associate themselves as being at risk.

> "They would see things [on TV] and for many of them…they would see it as something out there as opposed to something that might happen to them."

Only one social trainer had any experience in dealing with breast cancer in a client with intellectual disability, and in this case the lump was found by accident. Other participants in this group expressed surprise that there had been any clients with breast cancer, as they were under the impression that their clients generally were less likely to develop cancer than people without intellectual disability. During the debriefing session at the end of the group discussion, the risk factors associated with breast cancer were listed for participants. The participants considered the high risk associated with nulliparity to be very important for women with intellectual disability as none of their female clients had given birth.

Access to preventive health services

In general, social trainers agreed that the contact with health services for their female clients with intellectual disability was satisfactory and most services were available when needed. They reported that all clients were expected to undergo an annual medical review, during which a GP would administer a health checklist. Some social trainers had reservations about whether the GPs went through this list thoroughly or, given their time constraints, tried to complete it as quickly as possible. The list includes a breast check, which involves a clinical breast examination. However, many of the participants could not recall having seen a routine clinical breast examination conducted during medical reviews.

Invitations or GP referrals were cited as reasons for utilising screening services. There was a strong indication that for many of those who had used screening services this had been the main motivation, rather than the client or carer instigating the appointment, because it demonstrated their duty of care. It was important for social trainers to be seen to be trying to fulfil their duty of care, particularly at the medium support facility, even though at times the desired outcome could not be achieved.

"The doctor actually signed to say that I took her down there but it was too traumatic an experience for her to go through. He signed that I had shown my duty of care but it couldn't be done."

Perceived barriers to screening

While breast cancer screening was perceived as important, it was also recognised that it does not get the attention it needs, largely because of the competing nature of other medical conditions that many of the clients with intellectual disability experienced on an ongoing basis:

"Quite often our clients have existing severe medical problems – you know in-your-face problems that have to be dealt with right away – so preventative medicine comes second. You are in crisis all the time… We tend to over-use the doctor and medical system, because of legalities and that. Client has a scratch, send them off for stitches, where you would probably go 'oh, stick a bandaid on it and stop your whinging.' We need to be educated."

Among the perceived barriers to mammography screening, the largest concern and the most frequently stated reason was that the clients would have trouble understanding what was happening during mammography. This lack of understanding was closely related to fear of the procedure, and many social trainers felt that this fear could in part be related to how medical services had handled people with intellectual disability in the past.

"Maybe historically when they went and had procedures done and because of their [limited] understanding some procedures aren't that OK and you just do them because it's part of your general health regimen. Sometimes it's not worth it, and because they don't understand the reasons why things have to happen sometimes, they look at this machinery and people in white coats and vicious looking buildings and they paint them all with the same brush… I don't know for sure whether it is because it reminds them of a past experience but I would suspect it had something to do with it for some people."

The lack of understanding was associated with increased stress and reluctance to cooperate with the radiographer. It was also a problem for those who found the mammogram painful because they could not understand why they should have to go through such a painful procedure. Several clients had refused to go back because their first experience had been painful.

"It's not pleasant when you know why you are doing it, so you can imagine how unpleasant it could be for someone who doesn't understand the implications and benefits. Milder clients are less frightened and more in tune with their own bodies. We have one lady who has the understanding but just refuses, so it doesn't always work and it depends on the individual. Next time she goes to a doctor it is more traumatic because she remembers the previous [visit]."

When asked about the possibility of attending as a group to ease the fears of some clients, participants thought this was not a feasible option, especially if a problem should arise. A further problem in this instance was that the client not being X-rayed could not be left unattended and would also be present in the room, which would compromise the dignity and privacy of the client being examined.

Many of the participants (i.e., the female social trainers) had experienced mammography themselves and some of these participants had a relatively negative view of the procedure, with words like "horrible," "bloody uncomfortable" and "physical squishing – in a fridge door" used to describe the experience. The social trainers who had a negative opinion of mammography were also those who were less optimistic about a client's ability to cope during breast screening. Another consideration that arose in relation to this question was that some clients were "just inappropriate for screening." On the other hand, those social trainers who had not experienced difficulties with mammography were more dismissive that pain or discomfort alone would be a major barrier.

A second major theme was physical disability. Clients were variously cited as being unable to stand up, to stand still or to stand straight enough and for long enough. Wheelchairs were also felt to be something that would prevent adequate mammography, particularly for those in reclined chairs. There was little knowledge, even among participants who themselves had undergone mammography, about the degree to which the mammography machine could be moved to accommodate physical impairments. Another concern was whether the mammography would be more painful for those with restricted mobility or movement, because of the need to stand straight.

Other barriers that were discussed included problems associated with short stature in several clients. In one case a client with extremely short stature had been precariously balanced on a box to be X-rayed. Also, there were clients who did not like to be touched; clients who misunderstood the concept of screening and feared that something would be found and they would become ill; and clients who understood what they were being asked but who refused to cooperate, "probably to assert their right of choice".

Perceived enablers for screening

There was a strong feeling that if a carer, or someone the woman knew, was allowed to go in the room with the client or even stand with her during the X-ray, the process would be made easier. In one case, a male social trainer told how a client had "screamed the place down" when he had taken her for a mammogram. On a separate occasion a female staff member had accompanied the same client and was present in the X-ray room during the mammogram and reported that the client was very cooperative.

The attitude of health workers was also perceived as having a strong influence over client cooperation during a visit and for ensuring re-attendance. While this question was asked with specific reference to mammography, some of the responses focussed on problems encountered with primary health workers in general. Most participants felt that staff had usually been helpful and kind but problems were encountered when radiographers had not treated the client like a person and had become very frustrated when the client was unable to cooperate.

> "I remember taking one client to get a chest X-ray and she had to hold her breath and there was just no way she could do that. And the radiographer was an angry man (and that's all I'll say about him) and I mentioned that she had a developmental delay and that might be why she wasn't cooperating. In the end he got it… No one told him she was disabled… In terms of how good people are at doing their job that counts and [his attitude] made a difference for her to understand."

The participants felt that health providers needed to develop some understanding of people with intellectual disability as it was important for improving client cooperation.

> "People don't know how to approach our guys – they look at us as if to say 'Help!' "

When this was explored further, participants agreed that some health providers were very helpful while others were less accommodating. Staff who were perceived as being abrupt or impatient were seen to negatively influence client perceptions.

> "If they were treating our guys that way it would be very difficult for them to build up any kind of rapport with them. Attitude of the staff goes a long way… Staff need to be more patient and aware."

Proximity to the clinic was another important factor. For social trainers, nearby clinics were attractive because they have to spend less time away from the hostel, where they may have had to leave some clients unattended.

One of the main themes that emerged from the discussions was the possibility of having a nurse, GP or other trained staff member to visit the hostels to perform monthly breast examinations. Staff felt that it should not be their responsibility and that a trained person, such as a GP or nurse, should do breast examinations. There were several reasons behind this apparent reluctance to undertake breast examination, including not knowing what is normal for the person being examined, not wanting the responsibility of missing any lumps and that male staff should not be performing such an examination. Through the course of the discussion, it became clear that many of the female social trainers who had conducted self-examinations were not following the recommended guidelines for performing examinations on themselves. They were aware of this and questioned their ability to examine their female clients.

> "[I] believe that breast examination needs to be their [DSC] focus but they don't have a procedure in place. In the morning staff are asked to look for anything that may be out of the ordinary, e.g., a rash, but you don't know their breasts and you're not doing a proper examination. You get to know your own body and there are so many people here and you wouldn't know what was right for them and what wasn't."

Staff were aware that DSC was currently restructuring its delivery of medical services and saw this as an opportune time for the issue to be formally addressed. Many of the participants felt that in addition to general practitioners undertaking or overseeing clinical breast examination, they should also have the responsibility to refer clients for breast screening. There was a suggestion that the medical review checklist should have an additional check box for mammography to remind physicians about the need to refer these women. However, some of the social trainers were concerned about whether clients would be able to cope with the treatments given should a lump be detected, and whether it would therefore be efficacious to check.

At the conclusion of the focus groups, questions were answered regarding how the Mammography Screening Registry was developed and maintained. After an explanation of how the Registry uses the electoral roll and the consequent limitations, it was also suggested by participants that BreastScreen liaise with DSC to add the names of eligible DSC clients to the Mammography Screening Registry.

Discussion

The qualitative techniques used in this study identified a number of important factors that impact on the use of screening services by women with intellectual disability. Many of the major themes that have been identified in other studies were also considered important for women with intellectual disability. However the importance of issues such as embarrassment and lack of perceived risk were overshadowed by more pervasive barriers such as physical disability and limited understanding (Nosek & Howland 1997). The most important factor seemed to be the need for a motivator, such as an invitation from BreastScreen or a GP referral. GP encouragement to attend mammography has been previously cited as a motivating factor (Grady et al. 1992; Nosek & Howland 1997; Miller et al. 1998; George 2000). This is especially important in countries where screening is not organised through a mailing register (Ballard-Barbash et al. 1999), but it is also important in this instance where women with intellectual disability are often precluded from the Mammography Screening Registry. The suggestion proffered by some participants that the names of women with intellectual disability be added to this Registry is currently being explored. However, increasing the role of the GP as an advocate for mammography would also be beneficial, especially as the hostels tend to prefer a single general practice.

The participants generally had a positive attitude towards mammography, however they realised that it would be difficult to overcome the barriers of physical disability and lack of cooperation. To a certain extent cooperation can be achieved by gentle coaxing of patients by understanding staff. However, it would be unethical to force a client to participate, and clients who move during the X-ray would be exposed to radiation without the benefit of having an informative mammogram. Social trainers were enthusiastic about introducing an organised system of clinical breast examination (CBE) as an alternative to mammography. CBE is generally thought to be less sensitive than mammography and is highly dependant on the skill of the examiner (Barton et al. 1999), but is still effective at detecting lesions, especially in younger women (Baines & Miller 1997; Kane et al. 2000). The employment of care staff to perform CBE may be hindered by financial and human resource constraints. From their comments social trainers are unlikely to take it upon themselves to examine clients. Even if they did, there are few educational materials available about CBE or breast awareness that specifically address the needs of women with intellectual disability (Beange et al. 1999). Indeed, materials for general health promotion and education among people with intellectual disability are minimal (Anderson & Fox 1988; Turner & Moss 1996; Lennox et al. 2000). Identification of the need for specialised health promotion by DSC has prompted the development of a booklet and training program to encourage screening (both CBE and mammography) among its clients. Health promotion for other age-associated diseases is needed for people with intellectual disability, and this need will only increase as this population ages. Carers need appropriate training and support in the conduct of preventive services, and the services themselves must be planned and administered with consideration to the special needs of women with intellectual disability.

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Zusammenfassung

Die Nutzung von Brustkrebsvorsorgeuntersuchungen von Frauen mit geistiger Behinderung

Fragestellung: Frauen mit geistiger Behinderung nehmen eine Mammographie als eine Vorsorgeuntersuchung von Brustkrebs erheblich weniger in Anspruch als der generelle Durchschnitt von Frauen in der Gesamtbevölkerung. Die Absicht dieser Studie bestand darin, die von Sozialbetreuern wahrgenommenen Hinderungs- und Erleichterungsgründe im Zusammenhang von Frauen mit geistiger Behinderung und deren Nutzung von Mammographien zu untersuchen.

Methode: Um die Gründe genauer zu bestimmen, warum Frauen mit geistiger Behinderung die Vorsorgeuntersuchungen nicht in Anspruch nehmen, wurde dieses Thema in einer Reihe von Arbeitsgruppen mit Sozialbetreuern, die in betreuten Wohneinrichtungen für geistig Behinderte arbeiten, diskutiert.

Ergebnisse: Wesentliche Gründe, die herausgearbeitet wurden umfassen: Die Notwendigkeit von ärztlichen Überweisungen oder Einladungen von Mammographie-Einrichtungen, um die Frauen zu motivieren, sich untersuchen zu lassen; die Annahme, dass viele Frauen mit geistiger Behinderung das Verfahren selbst und die Gründe für eine Mammographie nicht verstehen können und daher wesentlich grössere Unsicherheit und Ängste durchleben als Frauen ohne geistige Behinderung; und dass körperliche Behinderungen, die bei vielen Frauen mit einer geistigen Behinderung einhergehen, weitere einschränkende Folgen haben, da Apparate, die für eine Mammographie benutzt werden, körperlich behinderten Frauen nicht immer adäquat Platz bieten können.

Schlussfolgerung: Die Sozialbetreuer stimmten zu, dass viele der Hürden für eine generelle Mammographie bei geistig behinderten Frauen schwierig zu überwinden wären und unterstützten Alternativprogramme, wie z.B. klinische Brustuntersuchungen.

Résumé

Dépistage du cancer du sein chez les femmes souffrant d'un handicap mental

Objectif: L'usage de la mammographie pour dépister le cancer du sein est beaucoup moins fréquent chez les femmes souffrant d'un handicap mental que dans la population féminine en général. Le but de l'étude actuelle était d'examiner les perceptions d'aide familiale de barrières et enablers à l'utilisation de mammographie par ces femmes.

Méthode: Une série de dicussions de groupe ont été organisées afin de déterminer les raisons pour lequelles les femmes souffrant d'un handicap mental n'utilisent pas les services de dépistage. Ces discussions ont été dirigées par des formatrices attachées aux logements pour personnes handicappées.

Résultats: Les discussions de groupe ont révélé l'importance pour ces femmes d'être conseillées par leur médecin ou d'être sollicitées par le service de mammographie, un élément important étant la difficulté pour les femmes handicappées de comprendre la procédure et son importance et donc une tendance à éprouver plus d'anxiété que la population féminine en général. Il est aussi apparu que des handicaps physiques dont souffrent aussi beaucoup de ces femmes rendent difficile l'utilisation des appareils de dépistage.

Conclusions: Les formatrices confirment que beaucoup d'obstacles au dépistage du cancer par la mammographie sont virtuellement insurmontables et favorise d'autres stratégies telles qu'un examen médical des seins.

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