

Hidden Voices: A Qualitative Study of Cervical and Breast Screening Experiences for Women with Mild Intellectual Disability Living in the Community

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Abstract

This paper reports on the issue of gynaecological screening for women with intellectual disability living in the Australian community. A qualitative study using grounded theory was conducted with data collected through semi-structured interviews and focus groups. The participants were 31 women with mild intellectual disability and four of their carers, with some additional information contributed by health professionals. Themes emerging from the data identified barriers to cervical and breast screening services, as well as factors that appeared to facilitate the participants' access to screening. The study found three sets of linked factors influencing screening impetus. These were participant attributes such as knowledge level and ability to assess own risk, the relationships of the clients with significant others such as paid and unpaid carers, and health service provider behaviours that promoted respectful individualised consultations with adequate time for communication, explanation and education.

Conclusions from this study were that gynaecological screening of disadvantaged groups is likely to be increased by health education programs for consumers, as well as their carers and health service providers which focus on the specific issues for this group. The study also confirms what is already known from disease prevention campaigns aiming to improve screening and immunization rates: That proactive strategies such as health professionals offering gynaecological procedures in a sensitive manner to clients and registers that send out consumer reminder letters can substantially improve screening rates and support this consumer group's right to quality of life.

Introduction

Women with intellectual disability (ID) number approximately 203,700 in Australia (Australian Institute of Health and Welfare 2003:24) and have a longer life expectancy, with an average life span of 71 years (Sullivan et al 2003:507). The prevalence of those with mild intellectual disability is significantly greater than those with moderate to severely impairments (Wen 1997:27). Mild intellectual disability has been classified by the Australian Department of Social Security (Wen 1997:14) as a cognitive impairment manifested before 18 years of age with an intelligence quotient (IQ) level of 50-70 concurrently existing with related limitations in adaptive functioning. Whilst these limitations may affect the independence of this group of women, many are increasingly living within the community environment with more opportunity to establish sexual and marital relationships. These factors contribute to their comparable health risk for gynaecological cancers such as breast and cervical cancer. Although this consumer group is small within the general population, access to healthcare is an important indicator of their quality of life (Walsh et al 2001:198). This qualitative study explored issues surrounding gynaecologic screening access for 31 women with mild intellectual disability living in the Australian community.

In Australia breast cancer is the most common invasive cancer in women and, although the disease is not currently thought to be preventable, early detection has been shown to improve health outcomes and survival rates (Tracey et al 2006:50). In

2006 there were approximately 13,000 new cases of women's breast cancer in Australia and over 2000 deaths, with an age-standardised mortality rate of 18.4 per 100,000 population (Australian Institute of Health and Welfare [AIHW] & National Breast Cancer Centre [NBCC] 2006:xv-xvii). In 2004 cervical cancer was the fourteenth most common cancer and the eighteenth most common cause of cancer death in Australian women (AIHW 2007:29; Tracey et al. 2006:38;). The National Cervical Screening Program detects almost 15,000 high-grade cervical abnormalities annually in women aged 20-69 years. In 2004, 212 deaths attributable to cervical cancer occurred with an estimated age-standardised mortality rate of 1.9 per 100,000 (AIHW 2007a, 2007b). Most cervical cancer deaths are potentially preventable and an estimated seventy per cent are associated with underprovision of screening (NSW Health 2000:5). The nationally recommended screening guidelines include two-yearly mammographic screening of all women aged 50-69 years (AIHW & NBCC 2006:44) and a similar time schedule for cervical screening of sexually active women aged 20-69 years (National Health and Medical Research Council [NHMRC] 2006:6).

The majority of women with intellectual disability are nulliparous, which increases their breast cancer risk (Davies & Duff 2001:255; Sullivan et al. 2003:508). Although many of these women are sexually active of their own volition, there are a large number who are at risk of cervical cancer because of a high prevalence of sexual abuse (Cuskelly & Bryde 2004; Giulio 2003; Murphy & Elias 2006; Szollas & McCabe 1995). However, international studies from developed countries indicate that cervical cancer screening uptake by eligible and contactable women with intellectual disability is well below the national average rates with approximately 13 to 40% of these women accessing cervical screening (Biswas et al 2005; Broughton & Thomson 2000; McRae 1997; Stein & Allen 1999; Shaughnessy 1994). Reported breast screening rates are higher with 34.7 % (Sullivan et al 2003) to 58% (Pearson, Davis, Ruoff & Dyer 1998) attending screening. Numerous recommendations have been made to rectify this situation (Biswas et al. 2005; Broughton & Thomson 2000; Coultas & Capper 1996; Lunsky, Straiko & Armstrong 2003; McRae 1997; Pearson et al. 1998; Stein & Allen 1999; Sullivan et al. 2003). No studies were found in Australia that examined the issue from the perspective of the women themselves. Therefore, the present research aims to fill this gap in current knowledge by posing the following research questions: 1. What have been the experiences of Australian women with mild intellectual disability living in the community accessing cervical and breast cancer screening services; 2. What factors appear to facilitate or inhibit their use of screening services?

Theoretical Framework

Sociological literature over the past century indicates that social policy and praxis are informed by various health and disability theories. These affect people's ability to make choices and their access to resources for improving their health. Functional limitation is theoretically positioned within various social contexts. The positivist model (Oliver 1998; Waxman 1994) constructs disability as intrinsic impairment that prevents adequate social participation. The medical model has operated within a positivist paradigm to define who may be considered "normal", for example, the numerical scoring of an IQ test which normalizes cognitive ability. Social theory constructs disability as arising not from personal limitation but from disabling social environments (Barnes 1996). A problem with this model is that it ignores issues of gender or race, attempting to speak for all people of disability as a homogenous group when clearly individual situations and experiences vary considerably. Some theorists (Chenoweth 2006; Meekosha 2001; Samuels 2002) have called for the establishment of a disability

identity similar to feminism or the Black Civil Rights movement to advocate for justice for people with a disability.

Two health belief models that have attempted to explain the varied rates of health service uptake by individuals and groups are relevant to the present study. The Theory of Reasoned Action (Ajzen & Fishbein 1980) and its later modification the Theory of Planned Behaviour (Ajzen 1998) propose that people are more likely to engage in health promoting behaviours if they believe there will be a personal benefit or susceptibility, and that a particular health activity is positively regarded by a significant other. These authors also theorise that health promoting behaviours will increase where an individual has the capability and resources to undertake particular actions. For individuals with cognitive impairment choice is likely to be linked to how well health information and options are explained.

A qualitative design involving face-to-face interviews and focus groups was selected to explore the lived experiences, feelings, concerns and beliefs of informants. Qualitative methods facilitate exploration of complex social interactions and are particularly salient where participants have communication difficulties. Grounded Theory, a research method originally formulated for behavioral science by sociologists Glaser and Strauss (1967) and further developed by Strauss and Corbin (1990), was employed to categorise empirically collected data and generate theory to fit the data.

The decision to recruit women with mild intellectual disability as informants was an ethical consideration of participants' capacity to understand the research process and provide informed consent. Initial contact was made through the New South Wales Council for Intellectual Disability (NSWCID) which provided a list of relevant educational, employment and carer organisations. Letters requesting assistance were sent to seven of these groups, two of which responded quickly with offers to convey written invitations to clients. The response was adequate and further follow-up of additional sources was deemed unnecessary.

Prospective participants attended an information session in an organisational location familiar to them and in which staff and family members were also present. The author explained the nature of the research and discussed questions arising from prospective participants. Subsequently consent forms were signed and an interview schedule set up. Participants elected to be interviewed in either their workplace or home and chose whether or not to bring a support person to the interview session with them. Because discussion of sexual activity can trigger distressing memories in abused women, referral to local community health counselors was made available, but was not required by this group.

The interviews were semi-structured, with a focus on putting participants at ease and prompting disclosures about their knowledge and experiences of gynaecological screening. The following basic Interview Guide was used:

- Have you heard of a Pap test, breast screen or breast check?
- Do you know if you need one or not?
- What are they for?
- What do you know about these checks?
- What happens when you have a Pap test or breast check?
- Have you had one of these checks?
- Can you tell me what it was like for you when you had it?

Data collection and analysis

Thirty-one participants were interviewed before data saturation was reached, a process constituting theoretical sampling (Strauss & Corbin 1990:180). Analysis began from the first interview which was transcribed and scrutinised for key words and phrases to develop categories. This enabled more focused probing of subsequent interviews for emerging themes that were notated in an Analytic File (Minichiello et al 1995:218). After each interview personal observations made by the researcher were recorded, as well as reflections and account of issues arising during the interview in a Personal File which served as a memory aid. Comparative analysis (Strauss & Corbin 1990:62) of incoming data continued, either affirming or contradicting emerging categories, until a core category was developed with subcategories and contextual linking between them. Interviewing was ceased when new categories ceased to emerge. To promote rigour and reliability of the study each participant reviewed their transcript and made changes where information was not consistent with their views (Richards 2005:140). Additionally, two focus groups with participants were held after the individual interviews at the relevant organisations. The focus groups were attended by 8 women at one organisation, and 9 at the second, with each attended by a carer. During the focus groups the researcher discussed the emergent categories and themes with the participants and carers. The data collection took place over a period of six months from the first information session to the final focus group.

Research participants

The 31 primary participants were aged 19 to 68 years. Their assessed levels of intellectual disability as 'mild' or 'mild-moderate' were provided by the facilitating organisations and carers. Six participants also had co-existing physical disabilities which affected their walking or posture and most of the group displayed some degree of communication difficulty. All resided in the community: ten in group houses with a house manager or carer; eight in hostels; seven with family or a friend and six lived alone. Most were single, but three had been married and two had children.

Four professional carers also contributed data during the process of assisting the participants with their interviews by clarifying their answers or rewording questions in simpler language. These carers' contributions were also recorded, transcribed and included in the analysis. Additionally, a House Manager and carer informally provided pertinent information after several women in her house had been interviewed.

Findings of the Study

The findings of the present study suggest that gynaecologic screening rates in this consumer group may be influenced by three main interconnected factors: the women's own knowledge and understanding of their screening needs; their carers' attitudes and perceptions about the necessity for screening of women with a disability; and the attitudes of health providers towards this group resulting in a consultation environment that either encourages, discourages or ignores screening.

The core category that became evident from the data was that particular factors appeared to encourage and facilitate participants' screening access while other factors seemed to act as barriers and deterrents. Three major sub-categories emerged as key influences in screening uptake. These were the attributes of the participants, the relationships between participants and their significant others, and the behaviours of health service providers. Although each is discussed separately here, the three interact dynamically to either encourage or deter screening of this consumer group.

Findings concerning participant attributes

The participants' knowledge of breast and cervical cancer, their ability to assess their own risk, and their understanding of gynaecological screening programs were compellingly relevant to screening uptake. Farnum (1995) found that an understanding of personal risk was an important motivator for cervical screening. How information was presented and its source were important to the participants in the present study. Written health promotion materials require a reasonable knowledge of English literacy and few of these participants had good literacy skills. Most, however, were able to understand simple information with images. For example, one carer stated:

I think Rachel [the participant] and I agree that this is the one that we thought was a little bit better than the others ... we found the same with the mammogram ones. There were some that were all just writing but she actually tried to relate to the ones that had the pictures and she would say 'oh yes I know what that is' by the picture of the breast. But for Rachel, her reading skills are particularly good apart from her eyesight, and so she knows what they're about but she doesn't understand any of the brochure at all herself without somebody explaining it.

The participants reported obtaining health information from family, friends, workplace managers and health professionals because these were the trusted people with whom the participants felt comfortable. Paid carers in particular played an important role in informing their clients. Research by Rawlings, Dowse and Shaddock (1995:142) found that women with mild intellectual disability who lived alone were educationally disadvantaged by minimal contact with health professionals and home management staff. The present study confirmed this, finding that participants who lived in group homes or with carers appeared to have a better knowledge base than those who lived alone, regardless of level of intellectual disability. Consequently, the knowledge base of significant others is critical and there is clearly a burden on carers, colleagues and supervisors to provide accurate, current information in accessible language.

This group of participants revealed greater understanding of breast screening than cervical screening. Some described television shows with breast cancer storylines and these appeared influential in interviewees' knowledge and recall of breast screening issues. At the final focus group there was participant consensus that television was a useful means of health information acquisition, but also that affirmation from a trusted contact person was needed.

The group's beliefs mirrored those in the general community (Williams & Paterick 1998:10) that post-menopausal women are exempt from cervical screening. However, more than half the participants were unaware that two-yearly cervical screening was necessary for all sexually active women. Some participants struggled with the term 'sexually active', stating their belief it meant kissing and cuddling without sexual intercourse. Some could describe the cervical screening procedure even if they had not experienced it, while others could not. For example:

My Mum said it's when you lie down, and the doctor takes something from your vagina, and uh, puts it on a piece of paper and sends it back to see if there's any cancer around it.

Another participant was clearly able to clearly describe the importance of breast screening:

The first time I had it done, it was a bit painful, but you've got to have it done to check. I think everyone should have it. They take a picture

of your breast and put something under your breast and take a picture of it. Then take a picture of the other one. You've got to take all your clothes off and you're only in your pants or something and that's all. You've got to stand like this, like that, a different position for each one and "just wait, I'll take another one, just wait I'll take another one, you can go now" so I went and got dressed. They send you a letter saying you've got no cancer.

Apart from knowledge and comprehension, other crucial factors in screening impetus were the participants' self-confidence, self-image and self-reliance, as well as fear associated with the procedures. Screening involves quite a complex set of social and physical actions such as communicating, self-assertion, making and remembering appointments, transportation, undressing, overcoming emotional and physical impediments to examination, and so on. The participant's self-image was relevant to their ability to initiate seeking out and asking for information. Some who seemed capable of understanding screening requirements reported feeling constrained by the limitations of their disability and consequently were unable to ask for information. Self-confidence and self-reliance also appeared to affect participants' ability to access screening unaided. One participant felt sufficiently confident to organise attending screening herself as she had experience in making her own dental appointments by telephone and negotiated the necessary public transport to the provider's office unaided.

Fear of pain during screening was a serious issue for some participants. Pain and discomfort are a well known deterrent for women in general following negative experiences, particularly with cervical screening (Hill, Gardner & Rassaby 1985; Peters, Bear & Thomas 1989). In the present study one sexually active participant commented:

I get frightened with everything. Cause, what happened before when I've had the pap smear with Dr L. He really hurt me, he pushed it in and opened me up and that was it. So I thought: After this I'm not going to have any more.

Some participants disclosed that they found cervical checks so uncomfortable they would prefer it under general anaesthetic. The supine position used for the test can be difficult for women with co-existing physical disabilities, and interviewees were unaware that alternative positions may be assumed. Most said they appreciated the support of a carer during these tests but desired that the health provider speak courteously and directly to their patient during the consultation.

In the general population experience of cancer in family members has been shown to diminish screening motivation in other members (Burnett, Steakley & Tefft 1995:1555). Participants in the present study who had close family support stated that talking to family members had helped them overcome their fear of screening and of pain during screening, while participants living on their own had found it more difficult and were less likely to attend for screening.

In summary, the participants in this study who had received adequate explanations of screening were found to be able to speak knowledgeably about these procedures and the reasons for accessing them. Pictorial health education materials with simple text were informative for them, but their first preference was verbal information from trusted acquaintances. The participants reported a general willingness to undergo screening tests if conducted sensitively and with consideration for their communication and physical limitations. Most appreciated the support of a carer both in making screening

appointments and during the tests. Relevant screening uptake factors were knowledge and understanding, self-confidence, self-image and self-reliance, fear, pain and previous experiences of gynaecological cancers and screening.

Findings concerning relationships with significant others

The data indicated that carers, both paid professionals and unpaid family members, played a pivotal role in determining whether or not these participants were screened. Carers provided health information and clarification, answered questions, listened to participants' fears, negotiated with families and health care providers, made appointments, arranged transportation, provided both physical and psychological support for their clients during screening procedures and followed-up results and treatments. However, the relationship that developed while providing these services appeared to be more than the sum of its parts. As one participant put it:

The thing is, the lady who used to work here, she was like a second mother to me and she and I could talk about anything. When you talk about Pap smears and taking people to the doctor that's who took me.

Despite the intimate nature of sexual health, for some of these participants their carers's sex seemed unimportant, while others preferred to discuss these matters with their own sex. A more influential factor was the duration of the relationship, which appeared to correlate with participants' feelings of ease, trust and confidence in their carer. Phrases such as 'they know me' and 'I felt really comfortable with [name]' in the transcripts were frequently used in reference to longer term relationships. The carers, too, identified duration as important. For example, one experienced carer, when discussing a mentoring program for new group house carers, described the process of carer-client relationship development in temporal terms:

It's a time, a process, you know? And you learn together with them [the clients]. I've known them for four-and-a-half years but only got to know them really intensely the last fifteen months. And that's what I've got to try to explain to the other staff.

The professional carers interviewed appeared to take their advocacy role seriously, several stating they attended NSW Family Planning workshops in Sexuality and Disability education to update their own knowledge and passing new information on to their clients. These carers tended to regard some family carers as 'gatekeepers' who controlled information, were not always well informed themselves and did not always act in clients' best interests. For example, one carer described how a family member withheld consent for cervical screening of a client residing in a group house because of a conviction that the client was not sexually active, despite contradictory advice from staff. Differences between paid and unpaid carers have been recognised in the literature (Langan, Whitfield & Russell 1994).

In the present study the personal beliefs and attitudes of carers towards gynaecological screening also appeared to be relevant. Carers who encouraged and assisted their clients to attend screening spoke positively about the tests, while those expressing less positive attitudes were less inclined to encourage and facilitate it. Similar findings were reported by Sullivan, Slack-Smith and Hussain (2004:402) who observed that carers' attitudes to breast screening influenced their promotion of breast screening services. Carers' knowledge of health issues constitute an important link between women with intellectual disability and gynaecological screening. However, maximum effectiveness is most likely dependent upon the strength of the relationship and carer preparedness to advocate for the well being of this consumer group.

Findings concerning health provider factors affecting screening

The main health provider factors that appeared to affect screening uptake were the sex of the provider, their knowledge and attitude, their ability to negotiate participants' communication difficulties and to explain complex health concepts, their provision for co-existing physical disabilities and the development of therapeutic relationships. Consultation time was an issue in some, but not all, of these factors.

While the majority of participants expressed a preference for female screening providers, the development of trusting relationships between providers and patients seemed equally important, outweighing the gender issue in some cases. More problematic was that some providers appeared reluctant to screen, particularly cervical screen, these participants. As one carer explained:

He wasn't too impressed that I wanted, like, a head to toe check up of everything, you know? And the mammogram, that was just kind of pushed to the side and, it was change the subject. But after a few visits he said that he couldn't kind of forgive himself or "I wouldn't be able to forgive myself [sic] if there was something wrong with you, if there was a lump or anything because that is something that, that I should be able to detect, um, whereas you don't know what's going on on the inside". So he kind of say, you know, be all right if they got cervical cancer 'cause that's something you can't see that was there, you know?

Participants and carers both also reported health providers' tendency to speak to the carer rather than the patient during consultations, a practice which effectively rendered those participants non-persons and adversely affected their self-image. Larson, Anderson and Doljanac (2005:174) linked this problem to inadequate education of General Practitioners (GPs) about intellectual disability and insufficient training in communication skills.

A recurring theme in the interviews was the participants' desire for more time to discuss health issues. One participant, who was fearful because of her experience of cancer with a close family member, was able to undergo screening after the provider encouragement and clear explanations. Some also asserted that their doctors seemed to attribute most concerns to the patient's intellectual disability or physical disability, a phenomenon called 'diagnostic overshadowing' which has been reported in other studies (Bridge-Wright 2004; Howe & Salthouse 2004). Smeltzer and colleagues (2007:167) concluded that substandard healthcare for women with disability can become a cyclical process in which inadequate provider skills produce a negative consultation experience, which deters women from returning, which reduces provider opportunity to develop their skills. This increases the risk of poor screening uptake. The present study indicated that uptake of screening increased when providers suggested it and allowed adequate time to manage participants' communication difficulties and physical disabilities. This sometimes required a double consultation appointment.

The participants' desire for more time to discuss issues during consultations is a well known health care problem which has given rise to the practice of double appointments. It is arguable that education about and discussion of screening tests could be undertaken outside of medical consultation times by professionals other than doctors. In the same way that a substantial number of dentists now employ hygienists, doctors could dual consult with health educators, nurse practitioners and counselors prior to or concurrent with screening appointments. This does not discharge the requirement in medical curricula for improved education about the needs of people with

disability or the development of therapeutic relationships, but it might increase screening uptake by reducing consultation time pressure on both providers and patients.

Conclusion

Women with intellectual disability are a consumer group with at least the same risk of breast and cervical cancer as the general female population. Like other women, this group requires a regular program of screening to detect health problems in the early stages and, where possible, prevent minor abnormalities from developing into major disease. These basic health promoting measures are designed not only to preserve quality of life but also to reduce the burden of disease on the community.

Motivation to undergo screening is more likely if people are knowledgeable about the purposes of these procedures and about their own risk of disease. This was true for the participants in the present study who could become well informed by studying pictorial rather than textual health education materials, including audio-visual programs, and by discussing health issues with well informed people they trust. It is arguable that women with mild to moderate intellectual disability who are post-pubescent and potentially sexually active should not only be offered screening but should also have free access to health education programs without requiring the consent of their family. Indeed, not to do so is a human rights issue.

It was clear that screening uptake in this consumer group could be increased by the advocacy of carers to support clients' education, assist with appointment-making and transportation, and pressure health providers to supply screening services. While some of these functions can be automated, for example, reminder letters from a centralized register, others involve interpersonal skills and generosity of spirit that were clearly evident in both professional and family carers, as well as some of the health providers the participants described.

Carers and health providers also require appropriate education programs to enhance their understanding of women with intellectual disability. Community attitudes towards disability can construct or dismantle barriers to health screening. Therefore, greater awareness of screening prerequisites and the difficulties this consumer group face may help promote respectful, sensitive interpersonal relationships between parties and increase screening uptake. Programs such as 'Best Buddies' (2007 online) that link school students with and without disabilities already assist in changing attitudes at an early age and in fostering community acceptance of diversity. Theoretical implications from this study support the need to move away from a positivist medical model of disability to one that encompasses different abilities for all people.

This study also confirms what is already known from disease prevention campaigns aiming to improve screening rates: that proactive strategies such as health professionals offering procedures to clients and centralized reminder letters can assist in achieving health promotion goals. Strategies that facilitate optimal use of consultation time, such as pre-screening patient education and the support of allied health professionals, may also make the screening experience easier for patients and health providers. Alternative models of service provision such as mobile and workplace clinics could also be considered. Further research is needed to test the efficacy of these measures in clinical practice.

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