

Screened Out: Women with Disabilities and Preventive Health

KELLEY JOHNSON^{*}, RIA STRONG^{**}, LYNNE HILLIER^{**} & MARIAN PITTS^{**}

^{*}Royal Melbourne Institute on Technology University, Melbourne, Australia, ^{**} Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia

ABSTRACT *This paper explores the lived experience of women with disabilities in relation to preventative health. It is based on qualitative research in Australia involving 25 individual interviews and 4 focus groups with women with disabilities about their experience of cervical screening (Pap tests), 16 interviews and 2 focus groups with service providers and advocacy organizations and an audit of 4 Pap Test Services by a researcher with a disability. The research identified three kinds of barrier that prevented some women from accessing cervical screening: societal barriers, individual living circumstances, and the way the women and those around them constituted their subjectivity. This paper outlines briefly the key findings from the study, focussing particularly on barriers relating to subjectivity.*

“Disability,” I write, “it’s a social problem.
A problem of access and acceptance.
People can enable or disable.
They can include or exclude.”

Disability is that and more.
Disabled people struggle
In a world not made for us, limited
By bad design, bureaucracy.
Attitudes and assumptions
And (yes) by our own bodies and minds
(*Ria Strong*)

These lines, written by a disabled woman poet, encapsulate the findings of the research described in this paper. Access to preventative health, in this case cervical screening, was found to be problematic for women with disabilities because of the nature of the world in which they lived and because of the way in which their subjectivity was constituted both by themselves and by others.

Cervical cancer is the 14th most common form of cancer in Australia (The Cancer Council Australia 2001) and consequently cervical screening is seen

by health authorities as an important preventative health measure for all women aged between 18 and 70 years who have ever had sex with men. Campaigns to educate women about the importance of cervical screening have been very successful, with overseas and Australian research revealing that approximately 80% of women have a Pap test over a 3 year period (Centre for Research on Women with Disabilities 1999, The Cancer Council Australia 2001). Some groups of women, however, still have difficulty in accessing regular Pap tests (Centre for Behavioural Research in Cancer 2001) and often these are women who are marginalized in other ways in the community. In particular, research has shown that women with disabilities are less likely than other women to have regular Pap tests. For example, a study of women with an intellectual disability in one health district in the UK found that only 13% had had a Pap test in the previous 5 years (Stein & Allen 1999). Similar research by Mencap revealed that only 8% of women with intellectual disabilities underwent Pap tests in comparison with 85% of women who did not have disabilities. This finding is not restricted to women with intellectual disabilities.

Women with physical disabilities (Nosek & Howland 1997, Shabas & Weinreb 2000, McConnell 2001) are less likely than women without physical disabilities to have regular access to cervical screening or breast examinations. Little research has been done on the experience of women with psychiatric disabilities in relation to cervical screening (Family Planning Victoria 1998, 2000, are exceptions) and there is no research at all relating to the experiences of women with sensory disabilities. None of the published research has described how women with disabilities themselves viewed the experience of cervical screening. Rather it has focused on the incidence of non-testing and on the identification of barriers through surveys of service providers and in some instances women with disabilities. The voices of women with disabilities have not been heard directly in research to date.

Previous research has shown that many of the barriers that women generally experience in accessing cervical screening are social ones and that these are exacerbated for women with disabilities. These barriers include the attitudes of general practitioners, (Cockburn, White, Hirst & Hill 1991), lack of information about cervical screening, (Campbell, McDonald & McKiernan 1996), lack of access to women medical practitioners (Fernbach 2000, Hirst 1988, Moore, Gridley & Johnson 2000) and cost (Hirst 1988). Research which has focussed particularly on the obstacles confronted by women with intellectual and physical disabilities also found that social barriers were of primary importance. These included: the attitudes of health professionals who did not offer the test to women with disabilities (Stein & Allen 1998, Seymour 1998, Scullion 1999), access to buildings and to the equipment needed to undertake the test (Nosek et al. 1997, Stein et al. 1998) and, in the case of women with intellectual disabilities, difficulties in obtaining informed consent (Witmeyer 2001). Most of these identified barriers are ones which are social and structural in nature and form part of a larger system of discrimination and exclusion of people with disabilities (Finkelstein 1993, Oliver 1996).

The identification of social and structural barriers in relation to preventative health is important, but a focus on these may lead to the exclusion of other factors that women might find difficult to articulate through questionnaires and surveys. While some of the previous research named issues such as pain, discomfort, poverty, bad experiences with doctors, embarrassment and shyness as barriers for women with disabilities, researchers have not explored them in any depth (Broughton & Thompson 2000, Nosek et al. 1997). There were no attempts to link women's views about Pap tests with the way their subjectivity was constituted by themselves or those around them.

This paper reports on the link between subjectivity of women with disabilities and their views of cervical screening as an example of preventative health. In this paper subjectivity is defined as "the conscious and unconscious thoughts and emotions of the individual, her sense of herself and her ways of understanding her relation to the world." (Weedon 1987:32).

This definition focuses on a woman's inner experience of self: how she sees herself as a unique person and her awareness of that self. It also indicates that subjectivity is not fixed self regard but is partially dependent on how the woman is perceived and known by those around her and how they behave towards her (Henriques, Hollway, Urwin & Walkerdine 1984). The importance of subjectivity for women with disability has been explored by some feminist writers who have stressed the denial of gender issues which can occur when a woman has a disability, the effects of the current social emphasis on the nature of the body as an important issue in subjectivity and the denial of the existence of an inner life for some people with disabilities (Deegan & Brooks 1985, Asch & Fine 1992, Johnson 1998, Traustadóttir & Johnson 2000, Atkinson et al. 2001). However, these writers have not explored the ways in which a woman's subjectivity may influence life decisions about health.

The Study

Our study, *Screened Out*, sought to address practice concerns identified by the Cancer Council in Australia about the difficulties which some women with disabilities had experienced in accessing cervical screening (Pap tests). The study used qualitative methods as it focused on understanding the nature of the experience of Pap tests for women with disabilities and providing an opportunity for their voices to be heard. Semi-structured interview questions were designed to develop discussions with women with disabilities, organisations representing them and service providers.

A reference group was established to guide the project. It comprised women with disabilities, advocates and service providers. Because of the sensitive nature of the issue the role of the reference group was particularly important. Advocates and women with disabilities assisted in finding women who were willing to talk about their experiences by using their networks and media. The reference group collaborated with the researchers in the design of questions used with women, advocates and service providers, assisted in the analysis of findings and in the drafting of the final report.

In order for their stories to be included in the study, women had to be aged between 20 and 60 years, have been sexually active at some point in their lives and to self identify as having a psychiatric, physical, sensory or intellectual disability. Approximately 60 women with disabilities participated in the study. Twenty five individual interviews were held and the remaining women were included through focus group discussions. The women who were individually interviewed ranged in age from 26 to 59 years. Fourteen of the women were unemployed, only two worked full-time. The majority received some form of pension. Five lived in country areas and the rest lived in a capital city. Three came from culturally and linguistically diverse backgrounds. Eleven women in the group had physical disabilities. Four of these women had been disabled since birth, the rest had acquired a disability in adulthood. Six women with psychiatric disabilities, four with intellectual disabilities and five with sensory disabilities participated in the study. Two women had multiple disabilities. All of the women lived in the community with their families, alone or in supported accommodation.

Twenty five individual interviews were undertaken with women with disabilities. The interviews lasted for approximately 1 hour. Counselling support was available for women who wished to debrief in more detail about their experience. Four focus group interviews were also carried out with two groups of women with intellectual disabilities, one group of deaf women and one group of women with psychiatric disabilities. In all cases the women concerned chose to discuss the issue in a group.

Individual interviews and focus groups were also undertaken with 16 organizations with worked with or represented people with disabilities. Discussions or interviews were held with 20 people who provided cervical screening services. An audit of four cervical screening services was designed and undertaken by one of the researchers who has a disability. Permission was obtained from each service before undertaking the audit and the service received a report back from the researcher. Audits involved a checklist of which began with a telephone call to make an appointment and proceeded to a visit and discussions with staff.

The Findings

This paper focuses on the findings from interviews with women with disabilities. To protect each woman's confidentiality, they have been given pseudonyms. Three key themes relating to subjectivity emerged from an analysis of the interviews with the women: perceptions about self as a woman, privacy and control, the lived experience of sexuality and sexual abuse. These need to be explored in the context of how the women perceived cervical screening.

Women's Perceptions of Cervical Screening

Given the invasive nature of cervical screening it is hardly surprising that none of the women who participated in the study saw it as a positive

experience, although some commented that it was reassuring to get a result which showed no abnormalities.

However there was considerable variation among the women in the way they viewed the test. For some it was a minor intrusion in their lives. Sarah, a woman with a physical disability commented that: “cervical screening doesn’t really phase me. It’s not something I find particularly invasive.” In spite of physical access barriers Sarah had regular cervical screening. For others, going for a Pap test was a very difficult experience. Marie, a woman with physical disabilities found that the experience was always extremely painful. She commented:

I just had to bear it. It’s like the catheter change, you just have to bear it because there was nothing they could do because my legs were in so much spasm they couldn’t . . . the muscles wouldn’t relax enough to let the legs flop.

A Pap test was something she had to prepare for over time and it left her physically and psychologically exhausted for days afterwards, disrupting her work and social life. With medical friends and supporters she had sought many ways of relieving the physical stress but with only limited success. She continued to have intermittent cervical screening.

Some women saw Pap tests as something so unpleasant or disturbing that they would not have them under any circumstances. Several women did not seem to understand the reasons for having cervical screening. Georgia, a woman with an intellectual disability refused to consider the possibility of having a test saying: “Yuck I’ll never have one of them.” Georgia did not have a clear view of what the tests were for and her refusal to undergo one was based on reports about it from other women.

Other women knew the risks of not having cervical screening, but were willing to accept them rather than have the test. Margaret, a woman with a psychiatric disability had considered the issue carefully before reaching a negative decision:

I don’t do it . . . And . . . fear of dying from it if you don’t, if you don’t do the steps . . . to make sure it doesn’t happen to you . . . The hating of it [cervical screening] must outweigh the fear, otherwise I would be able to do it.

When we began this research we expected that women would talk about barriers to cervical screening in social and structural terms. And they did. All of them raised issues about access, information and the attitudes of medical practitioners (see Johnson, Strong, Hillier & Pitts 2003 for a detailed account of these findings). However we did not expect to hear so many stories from women which were so passionate and angry. An analysis of the interviews revealed that the social and life circumstance barriers that we thought would be central were not the ones that evoked these responses. The interviews revealed three key themes which were central to women’s views about cervical screening and which were extremely important in shaping their decision making. All of these themes related to the ways women’s subjectivity was constructed by either those around them or by themselves. These themes

were: the women's perceptions of themselves as women, privacy and control, sexuality and experiences of sexual abuse.

Perceptions About Self as a Woman

Only a few women with disabilities in the study saw themselves as leading full lives as women. They were workers, lovers, partners and parents or independent lone women.

Sarah, for example, commented: "I live on my own. When I'm not working I spend quite a lot of time climbing . . . surfing, body boarding, the odd bit of partying here and there", while Fiona, a strong self-advocate for people with intellectual disabilities spoke of a long and lasting relationship: "We've been married 14 years."

Other women struggled to achieve their desires and dreams as a woman. For example during her interview Marie spoke of abandoned dreams and hopes:

I've had to make all me own dreams and find a way to achieve them. You know when I was a kid it was . . . I'd rattle on about when I grew up and have kids . . . and it was kind of like . . . yeah, yeah, isn't that sweet darling, you've got your dreams. Or it was like, just be realistic and realise that you're never going to achieve that . . . I've been self made basically.

For other women the experience of disability led to a denial of themselves as women. For example Martina who had experienced a sudden illness which left her quadriplegic said:

I just didn't feel like a woman. I never ever, I didn't look at my face, at my face in the mirror for seven years . . . After my illness, yeah, I never looked at myself. I felt ugly. I felt all sorts of things relating to not being a woman.

This response had implications for her views about cervical screening. It evoked for her painful memories of a time before the onset of her illness and she did not even consider the possibility of going for cervical screening. She was not alone in this response. Cervical screening for some women was a powerful and negative reminder of what they saw as a "loss of self" as a woman. Marie's painful experiences of cervical screening discussed earlier, gained increased power because she came to see that she would not be able to have children. For Jean screening evoked memories of a marriage that ended after she acquired a disability.

Cervical screening could also become attached to a strongly negative view of oneself as a woman at a very physical level. Margaret, in talking about her psychiatric illness commented:

. . . that part of the epicentre of my evil is my vagina. So it's like there's a contaminant in me and in that part of my body. And I'm not comfortable about people . . . exploring that part of my body in any sort of way 'cause of this lingering feeling that they'll be contaminated by me. It's a really horrible feeling. It's not very nice.

Given the strength of Margaret's feelings it is not surprising that she refused to countenance the possibility of cervical screening under any circumstances.

In the study we found that women who had more positive views about themselves as women, who had been able to find meaningful lives tended to be less negative towards cervical screening. However, for many of the women in this study a negative construction of themselves as women with disabilities effectively prevented them from undertaking this form of preventative healthcare.

Privacy and Control

Some of the women we interviewed lived their lives in the public gaze. They needed attendants to assist them with intimate care, or they were living in supported accommodation with staff constantly present. In these kinds of circumstances they felt that the only privacy and control remaining to them was within their own bodies. Any intrusion in this area was seen as a gross violation. In at least one instance intervention by a nurse was experienced as abusive and added to Martina's refusal to undergo any other invasive approaches. She said:

I did menstruate irregularly and there was this one nurse that insisted that I use tampons but I couldn't insert them myself so she did it for me. I felt so invaded . . . it's kind of like the last, your last bastion of privacy and dignity was totally gone . . .

Many women spoke of the invasiveness of the test which for some was heightened by the nature of their disability. Marie commented with wry humour: "I mean there's nothing worse than somebody standing over you sort of with a vice like grip holding your legs apart with somebody else putting one of those do-dahs up you to have a look."

All of the women participating in this study emphasized the importance of retaining a sense of dignity and self-respect. Cervical screening, which involved an intimate examination of very private parts of their bodies with sometimes what felt like physical force to achieve it, was experienced as an attack on the identity of the woman and her sense of control over her own body.

Lived Experience of Sexuality

There was a close link between a woman's constitution of her sexuality and her attitudes to cervical screening. Three expressed anxiety that they may not be eligible for inclusion in the study because it had been a long time since they had had sex. Two were uncertain about their inclusion because their current sexual orientation was lesbian, although they had experienced heterosexual sex in the past. In many of the interviews the discussion moved quickly from cervical screening to issues of sexuality and relationships. The perceived relationship between cervical screening and sexuality was complex.

It was common practice among medical practitioners to ask women prior to having cervical screening if they had been sexually active. A negative answer led the doctor or nurse to inform the woman that she did not need the test. Some women saw this as a negation of them as women and a reinforcement of their lack of sexual lives. Others who had experienced a negative reaction while having the test were told by their doctors they did not need the test in future. Leonie, a woman with an intellectual disability stated: "I had a turn on the bed when I was having the Pap test. The doctor said 'don't worry, you don't have to have it any more.' I felt awful. Not like a woman." It was only after some years and with the support of other women with disabilities, that Leonie felt able to go for another test.

Some women had not experienced sexual expression or relationships as a positive part of their lives. The link made by medical practitioners between sexuality and cervical screening could reactivate negative memories. For Martina, this link was one of a number of reasons she had decided not to have cervical screening. She said:

I've never been great about sex – heterosexual or even lesbian sex. I mean I've enjoyed lesbian sex more than heterosexual sex but I mean I hated heterosexual sex. I hated it. So it all just reminds me of that in a way, the invasion of your body.

Furthermore, the link between sexuality and cervical screening was fraught with anxiety for some women because it meant they had to admit publicly to having a sexual life. Previous research has revealed that many women with intellectual disabilities lead secret sexual lives (McCarthy 1999, Johnson, Hillier, Harrison & Frawley 2001) in part because of strong prohibitions about their sexuality which are held by staff and families. Consequently, some of these women had difficulties in asking for cervical screening since it is tantamount to a statement that they do have, or have had, a sexual life. This dilemma was raised by some women with intellectual disabilities in focus groups and was explored by both service providers and Marie, an activist with a physical disability who commented:

The medical profession have this control thing, you know and they see us as being unable to make decisions for ourselves and they talk about things like this with our parents and carers and partners . . . the whole issue about parents and what say they've got in it, you know, that should not even be an issue. You know we don't need doctors going to our parents and saying do I have permission to tell your daughter about Pap smears you know.

Women could thus be caught in a paradoxical situation in relation to sexuality and cervical screening. For some, acknowledging a loss or absence of a sexual life to a medical practitioner as part of the cervical screening process, was a further denial of their position as women. For others, acknowledging that they had a sexual life to a medical practitioner threatened them with sanctions and criticism from those who believed that they should not be involved in sexual relationships. Both of these positions led women to refuse to undergo the examination.

Sexual Abuse

Previous research has shown that up to 86% of women with intellectual disability will have experienced some form of sexual assault or abuse in their lives (McCarthy 1999). For women who had previously experienced sexual assault or abuse, cervical screening was a painful reminder of it. This led some women to refuse to have the tests or to be extremely hesitant about them. Fiona, a self-advocate with an intellectual disability stated bluntly: “The scariness of the tests is because I was raped”, while Lorraine (a woman with an intellectual disability) described a Pap test in the following terms “They get these four or five guys . . . look like body guards and hold you down and it’s horrible.”

This experience of sexual abuse was not restricted to women with intellectual disability. It was also raised by women with physical and psychiatric disabilities. Margaret commented: “It’s this feeling of powerlessness and I suppose for me it reminds me of sexual abuse in a way because that was a powerless feeling and you feel as though you have no control over the situation. It’s not very nice.” There is little doubt that such negative experiences make it much more difficult for women to subject themselves to an intrusive medical test which resonates with previous negative experiences.

Conclusion

The women involved in this study identified a wide range of barriers that they saw as preventing their access to regular Pap tests. Some of these were the easily identifiable (though often difficult to change) social barriers identified in other research. However, many of the stories they told had much more to do with how they saw themselves as women and their experiences of sexuality. Such issues are not easily discussed in public forums. However, a failure to take them into account may lead to a superficial view of the concerns that women have about their access to preventative health. A focus on the external barriers may lead to a continued denial by those around them of the importance of the internal life of women with disabilities: their fears, desires and perception of themselves.

The discourse around subjectivity revealed in this study cannot be divorced from the wider social discourse about what it means to be a woman in our society. For example “modern consumer society invites us to celebrate the possibilities of pleasure derived from a cultivated and enhanced embodiment” (Seymour 1998:vi). If one is no longer able to meet these requirements then there are implications for how the person views themselves as well as for how they are viewed by others. This study demonstrates that issues of subjectivity related to “being a woman” are not restricted to one area of a woman’s life, but permeate all of it and may be strong factors in making decisions about whether to undertake possibly life-saving health measures. A failure to understand this discourse may lead to the removal of superficial barriers to healthcare but leave untouched women’s more fundamental and passionately held concerns.

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