

Barriers to Cervical Screening Experienced by Victim/Survivors of Sexual Assault - Pilot Study

Karen Carlson
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CASA House



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Research team

Principal Investigator Jill Astbury, Associate Professor, Key Centre for Women's Health in Society, University of Melbourne

Associate Investigators Heather Gridley, Marg D'Arcy, Janet Joss, Rosemary Burrell, Keran Howe, Jill Duncan.

Researcher Karen Carlson

◆ **Introduction**

About CASA House

The Centre Against Sexual Assault attached to the Royal Women's Hospital (CASA House), commenced service delivery in May 1987. It is presently one of 15 Centres throughout Victoria, funded primarily by the State Government to provide support services to both recent and past victim/survivors of sexual assault. Over the past 15 years, the Centre has provided services to over 15,000 victim/survivors of sexual assault through the provision of crisis care, counselling and group work. CASA House is also involved in public advocacy, community and professional development and research. Issues and experiences raised by victim/survivors of sexual assault form the basis of public advocacy undertaken by CASA House. (See Appendix 1)

Research background

The impact of violence against women is an important public health issue, particularly given that up to one-third of women experience pervasive distress after the violence (Kilpatrick, Edmonds and Seymour, 1992). There has been much focus on the emergency care needs of victims of violence but little consideration of women's experience of, and access to, healthcare in the longer term (Koss, Koss & Woodruff, 1991). Disclosures received by those working with victim/survivors regarding their reluctance to access cervical screening are typified by the following case example. A woman in her early thirties rang CASA House to request counselling at the suggestion of her doctor. She had expressed reluctance to participate in cervical screening and, on inquiry, had disclosed her experience of sexual violence to her doctor who informed her of the services offered by CASA House. Anecdotally, avoidance of Pap tests among victim/survivors of sexual assault seems to be prevalent, and it is these types of disclosures which lead to the question of whether victim/survivors may be underscreened and therefore at greater risk of cervical cancer.

Reports from women accessing our service and their supporting professionals have made us aware that those victim/survivors of sexual assault who do participate in screening and other forms of gynaecological care find it unpleasant or traumatic and may have specific needs. On examination of the barriers to cervical screening documented by the Anti-Cancer Council of Victoria (Fernbach, 1999) it was suggested that the reasons offered by women for underscreening could be masking a common cause for their reluctance. Traumatic past experience was cited as a possible underlying reason for women's reluctance and it would appear that it is being informally expressed by women in the context of counselling. In March 2001 a submission for a Community Grant was made to the ACCV and \$5,000 was granted to support preliminary research into the barriers to cervical screening experienced by victim/survivors of sexual assault. It was agreed that a

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questionnaire would be developed and piloted with 20 women using a semi-structured interview format.

The research has been developed with the support of a reference group comprising academics and women's health professionals experienced in designing and conducting research into violence against women and aware of the issues specific to such research. The researcher who designed and implemented the pilot study is an experienced counsellor/advocate in the field of sexual assault, ensuring an informed approach to the research design and implementation in order to create the least possible level of discomfort to participants. A research proposal describing the pilot study was submitted to the Royal Women's Hospital Research and Ethics Committees and received approval following minor adjustments

The pilot study has been conducted by CASA House and will be followed by a prevalence study in all CASAs across Victoria to determine the extent of underscreening in women who seek counselling following their experience of sexual assault and to identify strategies to promote and support their access to cervical screening.

Aims of the pilot study

The aim of this initial stage of the research was to pilot and refine a semi-structured interview schedule which will assist in:

- a) examining the factors that influence participation in cervical screening procedures by victim/survivors of sexual assault
- b) documenting victim/survivors' experience of cervical screening procedures
- c) documenting victim/survivors' attitudes towards Pap tests
- d) documenting women's suggestions for healthcare providers regarding the sensitive provision of cervical screening to victim/survivors of sexual assault.

◆ **A review of the literature**

Overview

Screening for cervical cancer has been available for over 35 years, having been introduced with the expectation that it would eradicate this slow developing, initially curable disease (Orbell & Sheeran, 1993). Reduction in the incidence, morbidity and mortality of cervical cancer requires high rates of participation in cervical screening. Detection relies on women's participation to enable such identification and treatment however, over 30 per cent of women in Victoria do not regularly screen for cervical cancer (Jones & Clarke, 1997). In Victoria alone, 76 women died of cervical cancer in 1995 (Fernbach, 1999), indicating that despite the presence of screening programs women continue to be at risk of developing cervical cancer. The lack of success in eradicating cervical cancer is demonstrated worldwide, cervical cancer being the third most common malignancy among women (Eaker, Adami & Sparen, 2001).

It has been reported that up to 50 per cent of women who develop cervical cancer have never been screened (Eaker et al, 2001; Jones & Clarke, 1997), hence cervical cancer will remain a serious global health issue until women who do not participate in screening programs are identified and barriers to screening are eliminated.

Research into cervical screening

Information, knowledge and attitude towards cervical screening have all been studied internationally in relation to non-participation in cervical screening programs (Orbell & Sheeran, 1993; Fylan, 1998). Findings indicate that where women have increased knowledge of the need for screening, awareness of their eligibility, and suggestion from their doctor, they are more likely to participate (Baillie & Petrie, 1990). Most commonly women have reported that it was on the advice of their doctor that they started or continued their involvement in screening for cervical cancer (Baillie & Petrie, 1990; Brenna et al, 2001). It has recently been confirmed that regular care by their family physician predicts higher rates of preventive healthcare, including Pap testing, among women (McIsaac, Fuller-Thompson & Talbot, 2001). This demonstrates the importance of healthcare providers suggesting that women engage in cervical screening and providing options that reduce the barriers to cervical screening. A concerted effort by doctors to encourage cervical screening has been shown to reduce the death toll from cervical cancer (Schwartz, 1989).

Many other studies have looked at women's cervical screening participation in relation to gender of practitioner, intention to repeat screening, age, marital status, education, and exposure to screening campaigns (Orbell & Sheeran, 1993; Fylan, 1998). Studies investigating variables influencing screening uptake are of a piecemeal nature and efforts to compare groups are frequently

confounded by differing methodologies employed in the research (Orbell & Sheeran, 1993).

Who underscreens?

Those found to underscreen include older women, single women, women from lower socio-economic backgrounds, non-English speaking women, less educated women, rural women and lesbians (Orbell & Sheeran, 1993; Springs & Friedrich, 1992; Fylan, 1998; Marrazzo et al, 2000; Riain et al, 2001). This can be partly attributed to the lack of opportunistic screening in women who do not attend for pre-natal, gynaecological or contraceptive care (Maxwell et al, 2001).

Much research examining non-participation in screening programs has avoided questions of a particularly sensitive or sexual nature in order to avoid discouraging participants (Hesselius et al, 1975; Orbell et al, 1995). Reasons for non-attendance have been couched in non-specific terms and almost certainly conceal emotional barriers or avoidance (Fernbach, 1999; Orbell & Sheeran, 1993; Hesselius et al, 1975). For example, responses regarding preoccupation such as 'didn't get around to it' or 'forgot' could indicate avoidance of Pap tests.

It is well documented that women find Pap tests embarrassing, painful, degrading and uncomfortable (Barling & Moore, 1996; Holroyd, Twinn & Shia, 2001; Orbell & Sheeran, 1993; Schwartz, Savage, George & Emohare, 1989). These responses have also been found to be associated with underscreening. Unpleasantness has also been associated with Pap testing in underscreened women (Larsen & Oleson, 1993; Hesselius et al, 1975). Larsen & Oleson (1998) reported that emotional discomfort was more significant to women than the physical discomfort of Pap tests and more of a predictor of non-attendance at screening programs. Women's reported reactions of anxiety and embarrassment have not yet been further explored to reveal more detailed reasons for these feelings (Orbell & Sheeran, 1993; Orbell et al, 1995; Fernbach, 1999; Crombie et al, 1995). It has therefore been suggested that more research take place examining women's negative attitudes towards cervical screening procedures (Orbell & Sheeran, 1993; Orbell et al, 1995; Barling & Moore, 1996; Hesselius et al, 1975).

Particular attention needs to be paid to identifying those women who do not participate in screening programs in order to ascertain the nature of barriers to their screening and to improve their experiences of Pap tests (Cullum & Savory, 1983; Larsen & Oleson, 1998; Jones & Clarke, 1997).

Impact of violence against women on healthcare utilisation

The impact of violence against women is an important public health issue, particularly given that up to 30 per cent of women have experienced either adult or childhood sexual assault (Astbury & Cabral 2000; Mazza, Dennerstein

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& Ryan, 1996), and up to one-third of these women experience pervasive distress after the violence (Kilpatrick, Edmonds & Seymour, 1992). Post-traumatic stress is particularly common amongst victim/survivors of sexual violence. According to one American study, up to 31 per cent of victims of rape develop post traumatic stress disorder, compared to five per cent of non-victims (Kilpatrick et al, 1992). In addition, violence related alterations in health behaviours can increase susceptibility to disease many years later (Koss, 1993). Victim/survivors of sexual violence experience increased general health and gynaecological problems (Springs & Friedrich, 1992) and engage in lower levels of preventative healthcare. Victim/survivors have been shown to exhibit an increased incidence of risk behaviours, and experience higher rates of sexually transmitted infections and cervical cancer (Astbury & Cabral, 2000; Resnick, Acierno & Kilpatrick, 1997).

Recent evidence has linked intimate partner violence with an increased incidence of cervical cancer in women. It is not yet clear whether the increased incidence of cervical cancer is due directly to the sexual assault and transmission of the human papilloma virus, or indirectly through the negative impact on women's health behaviours, such as participation in cervical screening procedures (Coker et al, 2000). It is imperative that regular screening be made accessible to women who have experienced sexual violence to acknowledge and redress their increased risk of cervical cancer.

Victim/survivors experiences of gynaecological care

Although victim/survivors of sexual assault have a higher rate of contact with health services than non-assaulted women, their violence related health issues are frequently overlooked, particularly in relation to voluntary procedures (Robohm & Buttenheim, 1996; Koss et al, 1991; Mazza et al, 1996; Resnick et al, 1997). In particular, there is little international research into gynaecological care experiences of victim/survivors of sexual assault although it is consistently raised as an area requiring further exploration (Robohm & Buttenheim, 1996; Courtois, 1997).

There is evidence in the research that victim/survivors find gynaecological procedures particularly uncomfortable and may be more likely than the general population to avoid them (Kitzinger, 1990). Reasons for avoidance of such procedures may seem obvious but little research is available to give voice to women's experiences or preferences in relation to gynaecological care (Robohm & Buttenheim, 1996).

Robohm & Buttenheim (1996) found that gynaecological procedures are associated with feelings of helplessness, vulnerability, shame, and reminders of the abuse for victim/survivors of sexual assault. Their study showed that over 40 per cent of victim/survivors are reminded of the assault by gynaecological procedures and that victim/survivors also experience more pain, discomfort and anxiety than their non-assaulted counterparts. Some

women have reported re-traumatisation by gynaecological procedures including intrusive thoughts, memories or flashbacks after the examination (Courtois, 1997; Kitzinger, 1990; Robohm & Buttenheim, 1996; Burian, 1995). Other women report that dissociation occurs during such procedures (Robohm & Buttenheim, 1996; Burian, 1995). It is evident that many women continue to undergo screening despite finding it traumatic.

For these reasons, and due to the reminders of the assault experiences of many women inherent in gynaecological procedures, (Kitzinger, 1990; Burian, 1995) it is important that the treating practitioner be aware of the prevalence and long term impact of sexual assault and adopt an informed and sensitive approach.

Healthcare providers and screening for violence

On many occasions healthcare providers may not be aware they are treating a victim/survivor of sexual assault and, importantly, the choice not to disclose remains the woman's right. Therefore it is necessary for healthcare providers to employ a degree of sensitivity with all patients that would incorporate victim/survivors who do not choose to disclose their experience of sexual assault. It would seem from the research, however, that women, particularly victim/survivors of violence, would prefer that their doctor was aware of their situation but that 82 per cent had never been asked (Robohm & Buttenheim, 1996). It is rare, however, that woman spontaneously volunteer this information and many have never viewed their history of sexual assault as an issue with medical relevance (Mezey, King & MacClintock, 1998; Mazza et al, 1996). Springs and Friedrich (1992) reported that two per cent of women had discussed their experience of sexual assault with their doctor. Although the majority of victim/survivors of sexual assault feel their doctor would be in a position to assist them (Friedman et al, 1992), in one study, 92 per cent of women who disclosed their experience of violence to a doctor did not receive referrals or further information about sexual assault (Warshaw, cited in Acierno, Resnick et al, 1997).

Victim/survivors have reported that encouragement to disclose their history of sexual assault assists in building trust and open communication with their doctor (Bachmann, Moeller & Benett, 1988; Holz, 1994). Disclosure has been shown to have positive effects on health (Bachmann et al, 1988; Koss, 1993; Resnick et al, 1997) and may represent an initial help-seeking step. It has been suggested that a positive response to disclosure may moderate the long-term impact of violence on health (Gibbons, 1996).

Doctors also believe they could assist but few ask women about their experiences of violence despite recommendations from researchers and trainers (Astbury & Cabral, 2000; Medical Council on Scientific Affairs, 1992; Aceirno et al, 1997). Time shortages, fear of legal involvement and a sense of powerlessness to effectively intervene have all been cited by doctors as barriers to asking women about their experiences of violence (Acierno et al, 1997). This could be seen to reflect society's reluctance to acknowledge the

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prevalence and impact of sexual assault (Gibbons, 1996). The importance of permission to disclose, or discuss issues of violence is paramount in demonstrating a divergence from the lack of awareness in the larger community (Burge, 1989; Koss et al, 1991).

Due to women's reluctance to disclose and doctors' failure to inquire, many doctors report a lower incidence of sexual assault among the women they see than is likely to be accurate when incidence statistics are examined (Medical Council on Scientific Affairs, 1992). Acierno et al (1997) reported that two-thirds of doctors said they had not treated a victim/survivor in the past year.

In contrast, it has been suggested that as many as 38 per cent of female patients will have experienced sexual assault (Lechky, 1991). All healthcare providers who work with women will be in contact with issues of violence against women even though they may not recognise it (Lechky, 1991; Friedman et al, 1992; Kitzinger, 1990). Doctors are also a major contact point for the community and are listed among the persons to whom victim/survivors are most likely to disclose their experiences of violence (Burge, 1989) despite the fact that these disclosures are not common.

Barriers to disclosure

The views of healthcare providers parallel those in the wider community and there is little training to assist them to cope with the magnitude of issues raised by the impact of physical and sexual violence against women. Women have reported the barriers to disclosure of violence to be those stemming from myths perpetuating stigma and blame and their previous negative experiences of disclosure.

In one American study, screening for violence was introduced into a healthcare setting and disclosures of sexual violence tripled (Saunders et al cited in Acierno et al, 1997). Until doctors inquire about women's experiences of violence the health impact of sexual assault will go unacknowledged. Training for healthcare providers has been recommended in identifying and managing the impact of violence on women's health (Kilpatrick, Resnick & Acierno, 1997; Koss, 1993).

Removing the barriers to cervical screening for victim/survivors of sexual assault.

Fylan (1998) reported that satisfaction with healthcare is a predictor of compliance, and many suggestions for improving women's experience of gynaecological care, and therefore their uptake of screening procedures have been made in the research. A common element throughout is the need for control on the part of the woman (Larsen, Oldeide & Malterud, 1997; Holz, 1994) and the necessity for doctors to spend time and offer choices regarding women's care (Courtois, 1997; Burian, 1995). It has been recommended that healthcare providers acknowledge women's need to choose their own course

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of action and provide a response that is antithetical to the assault situation (Burge, 1989; Kitzinger, 1990; Fylan, 1998).

Providing the choice of a female practitioner has been shown to increase the uptake rate of cervical cancer screening programs (Majeed et al, 1994; Fylan, 1998). Some studies have not indicated a strong preference for a female practitioner (Orbell and Sheeran, 1993; Crombie et al, 1995), however, underscreened women appear to have a preference that a woman performs the examination (Cullum & Savory, 1983). Studies have shown that where a woman was available to carry out the procedure, this factor was more important to women than whether the healthcare provider was a doctor or a nurse (Schwartz et al, 1989).

It is becoming increasingly necessary to recognise the impact of sexual assault as a major influence on women's utilisation of health services and to acknowledge victim/survivors' experience of medical care (Koss et al, 1991; Koss, 1993; Astbury & Cabral, 2000). The impact of violence on women's health is increased when victimisation remains undetected in the healthcare system (Resnick et al, 1997). The failure of victim/survivors to participate in screening programs may be as costly as their reported over-use of the healthcare system generally (Kilpatrick et al, 1997).

There is compelling evidence of the need for further research into the experiences, perceptions and needs of victim/survivors of sexual assault to assess the barriers they may face in relation to cervical screening. This is particularly pertinent in light of the evidence of increased risk factors for cervical cancer experienced by victims/survivors and requires an urgent response.

◆ **Methodology**

Stages of the pilot study

The following stages were implemented in the pilot study:

1. Literature review of relevant international research.
2. Semi-structured interview schedule regarding barriers to cervical screening piloted with 15 victim/survivors of sexual assault although 20 was the initial target. A reduced number of interviews were conducted in light of unforeseen difficulties in recruiting participants to the study. Fifteen interviews were considered by the reference group to adequately represent the range of women's experiences in order to refine the interview schedule for use in broader research.
3. Data entry and transcription of interviews.
4. Examination of interview responses and utilisation of participant feedback in revision of the interview schedule.
5. Production of a report documenting results of the pilot study and revised interview schedule.

Development of the semi-structured interview schedule

The interview schedule for the pilot study (*Appendix 2*) was designed using open-ended questions in order to elicit qualitative information and to allow the responses of the women to guide further refinement of the schedule to be utilised in later stages of the research. Initially non-identifying demographic data was collected including information regarding the nature of the sexual assault, cultural identity, age, age at assault, and the nature of the relationship to the offender (*Appendix 3*). Women who chose to take part in the pilot study were asked about their participation in cervical screening programs and their experience of Pap tests. Women were also asked how healthcare providers could assist in encouraging participation in screening programs. Questions regarding disclosure to healthcare professionals and future alternative options have also been included. The *Impact of Events Scale* (Horowitz, Wilner & Alvarez, 1979), which comprises 15 items measuring current subjective distress in relation to the traumatic event, is included at the end of the interview schedule. It is widely used in assessing the psychological consequences of exposure to traumatic events. The scale allows standardised collection of data regarding some of the impacts of sexual assault commonly reported by victim/survivors. Women were asked about their experience of the interview and the scale, and invited to provide feedback that has guided revision of the interview schedule for use in broader research.

Participants

Women who attend CASA House include those who have been assaulted in childhood as well as women assaulted as adults. All women over the age of 22 years who attended CASA House for regular counselling during the research period and who were sexually assaulted two years previously or more were invited to participate in the pilot study. Women currently in crisis were not asked to participate. Selection of the age of 22 years was in accordance with the recommendation by the Anti-Cancer Council that women commence cervical screening at the age of 20, or two years post their first sexual experience. Prior to this there is likely to be no indication of how their cervical screening behaviours and experiences have been influenced by sexual assault.

Process of recruiting participants

Women were informed about the pilot study by their counsellor/advocate. Those who expressed interest were provided with further information and contact details to make their own confidential arrangements for an interview. Counsellor/advocates were only aware of any woman's participation in the research if the woman chose to discuss it with them. Counsellor/advocates at CASA House were briefed regarding participant information and possible support requirements, and specifically resourced regarding follow-up counselling and advocacy options for participants of the pilot study.

Tally sheets were distributed to counsellor/advocates in order to estimate the response rate and invite feedback regarding the process.

Participant information

A participant information statement (*Appendix 4*) was developed and given to all women expressing interest in participation. The research processes and any potential risks or discomforts were fully outlined in this document and women were encouraged to ask further questions. Information about the sensitive nature of the research was included in the participant information statement and discussed with participants at the commencement of the interview. Participants were advised of their right to withdraw at any stage of the study. The option of debriefing with the duty worker and information regarding follow-up support options was made available to all participants. Information regarding complaints procedures in place at CASA House and contact details for the Royal Women's Hospital Patient Representative were included in recognition of the difficulty that may be experienced by some women in making complaints directly to the agency. Participants signed a consent form (*Appendix 5*) stating that they had read and understood the participant information statement and were willing to participate in the interview.

With the permission participants, the interviews were taped and the researcher took notes. Participants were also offered a copy of the report

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documenting the process and outcomes of the pilot study on its completion. Participants are not individually recognisable and no identifying information has been included in the report.

The possibility that a participant may disclose inappropriate treatment by a healthcare provider in the course of responding to questions asked by the researcher was anticipated. If this situation arose, the researcher was to provide the woman with contact information for the Health Services Commissioner where a formal complaint could be lodged if the woman chose to do so. Counselling and advocacy would also be offered in order to ensure that the woman had the opportunity to address her negative experience.

Interview process

Women contacted CASA House to make appointments for an interview. The interviews were conducted in counselling rooms at CASA House by three members of the research team. Some women chose to make an appointment to see their counsellor/advocate following the interview. It was planned that if a woman became distressed at any stage of the process, the option of ceasing the interview would be discussed and the woman would be offered immediate support at CASA House (*Appendix 6*). Referrals for further counselling at CASA House or other services following participation were offered where requested. The researchers did not provide counselling services at CASA House during the research period.

Handling the data

On completion of the interviews, demographics and questionnaire responses were entered into an SPSS data file and tapes of interviews transcribed.

Responses to quantitative interview questions were coded and others collated from the transcriptions under question headings and topics to enable identification of themes and selection of quotes.

Interview notes were coded with a study number to avoid identification. The privacy of participants has been further protected by the storage of data separately to the signed consent forms. Two women chose not to have their interview taped and results were collated from the interview notes. The interview schedule has been adjusted to improve the clarity of the questions for use in further research. Women's suggestions regarding alterations and additions to the semi-structured interview schedule have been examined and incorporated where applicable (*Appendix 7*).

In future stages of the research, data will be gathered with a view to establishing a body of knowledge regarding women's cervical screening participation and experiences, however, the small sample included in the pilot study only permitted identification of possible themes. Trends in question responses have been examined and women's experiences documented,

giving voice to the issue and identifying a need for further research in the area.

Ethical considerations

The pilot study was designed according to Royal Women's Hospital research guidelines. The research team, made up of a combination of social workers, nurses and psychologists has supervised the pilot study, guided by the *Australian Association of Social Work Code of Ethics and Principles of Practice* (1999) and the *Australian Psychological Society Code of Ethics* (1997). Design of the current study has also drawn on and adheres to *World Health Organisation Ethical and Safety Recommendations for Research on Domestic Violence Against Women* (Watt, Heiss, Ellsberg and Moreno, 1999). In addition, staff of CASA House practice according to *National Standards of Practice for Services Against Sexual Violence* (1998), *Standards of Practice for Victorian Centres Against Sexual Assault* (1996) and an in-house code of ethics for the provision of services and general conduct, that have also guided the implementation of the pilot study. The main ethical considerations were to guard against possible re-traumatisation of participants, and to protect their privacy and the confidentiality of their interview material.

◆ **Results**

Sample

Fifteen women who were victim/survivors of sexual assault and attending CASA House for counselling participated in the interviews for the pilot phase of this study. All women participating in the study were aged over 20 years of age. Eight were aged between 20 and 34 years, four between 35 and 49 years and three more than 50 years. All women spoke English and 14 had been born in Australia.

Childhood sexual assault was the main issue that had prompted eight women to attend CASA House, while the other seven women were attending because they had experienced rape in adulthood. In all but two cases, the offender was known to the woman and all offenders were male. Of the three participants who reported having a disability, two reported a psychiatric disability.

Screening behaviour

Twelve women reported that they had been invited to have a Pap smear in the past two years. Of these six were invited by a doctor or other healthcare provider, four by the Cervical Screening Registry and two reported 'other'. Of the total sample, 10 of the 15 women reported having had a Pap smear in the previous two years. Three women in the sample reported that they had never had a Pap smear. Almost all women (14) reported that being a victim/survivor of sexual assault had affected their regular participation in, and attitude towards Pap tests.

Women were asked to specify the main reason they had not had a Pap test in the past two years if they had not. The following include themes expressed throughout women's responses to the questions and some quotes.

Themes

- ◆ Pain, embarrassment and fear,
- ◆ Physical and emotional discomfort.

Quotes

I do not have regular pap tests, I might be due for one, they are awful. They are painful, uncomfortable and embarrassing. I think they just make me feel awful, I actually do not choose to have it, there is no choice there.

Fear of exposing my body to a stranger and someone poking metal things inside and the pain of it. The feeling the Pap smear brings back to me. I feel abused once again with a stranger touching me.

The main reason I do not like having them is I do not like the part when they go inside you and cut this bit off. I found it very traumatic. The most recent Pap smear, I had a

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female doctor. I specifically went to a female doctor, where I usually go to a male doctor.

All women were asked to specify which reason or reasons they would have chosen for not having a Pap test, when the list of possible reasons did not include past sexual assault.

The wording of this question was as follows:

‘In the past, women were not asked about sexual assault as a possible reason for not having Pap tests. Which of these options would you have ticked if asked the following question: “Can you tell me why you haven’t had a Pap test recently?” ‘ Results are presented in Table 1 below.

Table 1

	Number endorsing	(%)
No female doctor or nurse available	12	(80.0%)
Can’t be bothered	3	(20.0%)
Embarrassment	14	(93.3%)
Fear	14	(93.3%)
Dislike	14	(93.3%)
Not enough money	3	(20.0%)
Not a priority	2	(13.3%)
I didn’t have enough time	6	(40.0%)
Doctor/nurse didn’t have enough time	0	
Forgot	5	(33.3%)
Pain/Discomfort	14	(93.3%)
Other reasons	15	(100.0%)

Abnormal test result

Of the 12 women who had ever had a Pap test, four reported that they had been informed of an abnormal test result and all four reported that they had participated in the suggested follow up investigations of this abnormal result.

Women’s experiences of Pap tests

Women were asked to describe a negative as well as a positive experience of having a Pap test in order to ascertain ways in which the experience could be improved.

Negative experiences

Women reported a number of negative experiences when having a Pap test.

Themes

The following elements of negative experiences were expressed throughout women's responses:

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- ◆ Pain, fear, discomfort.
- ◆ Humiliation, disempowerment, feeling exposed, loss of control.
- ◆ Anger, sense of injustice.
- ◆ Reminders of the sexual assault, flashbacks.
- ◆ Insensitivity of healthcare providers - roughness, and poor responses to disclosure of sexual assault.

Quotes

Cold speculum, being pinched, rough handling. Just that ignorant approach. They do not care who you are or if you are in pain. This 'don't care' attitude makes the whole experience difficult and uncomfortable.

She commented on what going on up there, and that was pretty awful. She commented on it quite a lot, like she was shocked or something, really strange, It made me feel really abnormal, and then somebody walked into the room.

I felt trapped and powerless, could not get away. Very angry and resentful. I felt very humiliated. I felt she was rough, and it took too long. I could not wait to get out of there.

The nurse held me down and the doctor did the examination and I was between 24 and 26 years.

And I was left there with the speculum inside me with my legs open and facing door ...she went out and left the door open.

I did not feel comfortable to say I have been assaulted and I managed to squeeze it out. She basically did not listen and then did this incredibly clinical type of teaching Pap smear where she was explaining to this woman what she was seeing and I just was not there.

The woman who did it was fairly rough, and the woman doctor who came in for clarification, she grabbed me and yanked me and said this is not it this just something, whatever. And she walked out and did not even speak to me, yet she was touching my vagina really roughly and it was very painful. I never had a Pap smear that bad for 12 years. I have not gone back yet. I am building courage to go back. - Really disempowering and you can't move and it brings on a whole lot of memories, because that's what sexual assault is. You're stuck, trapped while someone does something to you.

She did not wear gloves. I just felt really freaked after that. I never went there again. She said 'you have good muscle'. She was saying it about sex, but she did not say it. I thought 'this is crazy'. She was smelling her hands. She did not wear gloves. After that I just never go anywhere but my GP.

As I am in this position with him wheeling in between my thighs and asking 'so where did you do your degree?' I appreciate him making an effort to make me more comfortable. However, the effect on me was humiliating and I remember saying to friends afterwards 'I would have liked to suggest to him that he remove his clothing from the waist down, and we will chat about where he did his degree'.

It just felt like another episode of sexual assault.

12 women said that having a negative experience had deterred them from having a subsequent test.

Positive experiences

Women reported the following positive experiences of having a Pap test.

Themes

- ◆ Explanation of procedure
- ◆ Rapport with healthcare provider/trust
- ◆ Understanding and supportive healthcare provider

Quotes

I think possibly the second last one that I had that came back abnormal. I actually talked to the doctor for about 20 minutes before the test so I would be able to build a rapport with her.

A Thai doctor and he also had a nurse there and he was just right, there was no way he was going to cross any boundaries. He was very efficient without being hard. And he was gentle and highly professional. It is important that it is done really quickly. I had a urinary tract infection and he was talking to me about that while he did it and so it was quickly over.

I like my GP, I know her and I trust her.

One woman doctor warmed the instruments, and she explained everything she was doing as she did it like 'just now I will do this and now I will do this', so I know what she will do to me, so it was less uncomfortable.

It is a personal thing, this woman doctor was a caring person who cared for women's health, she did not put herself above me, and she talked me through it all. She made me feel comfortable and respected, this is the main element it is an undignified test. I like to be respected and have my body respected.

Physical and Emotional discomfort

Women were also asked to rate their last remembered Pap test in terms of its physical and emotional discomfort. A 1-10 scale was used and women were asked to rate their experience with 1 indicating no discomfort at all and 10 representing extreme discomfort.

Only three women rated their last Pap test as involving no physical discomfort, while the rest (nine) reported varying degrees of discomfort and of these five women reported extreme discomfort.

In rating emotional discomfort, only 1 woman reported no discomfort with her last remembered Pap test. The remainder reported varying degrees of discomfort and four reporting extreme discomfort.

Healthcare providers - disclosures and preferences

All women who described having a negative experience of having a Pap test, believed that being a victim/survivor of sexual assault had contributed to this experience being negative. Despite the perceived significance to a negative Pap test experience that women attributed to sexual assault, it is of interest that only two of the 15 women reported that a healthcare provider had ever asked about the experience of sexual assault in the context of talking about having a Pap test. However, 12 women reported that they had disclosed being sexually assaulted to a healthcare provider at some point in their lives.

The victim/survivors in this sample were unanimous in preferring to go to a woman to have a Pap test but not when it came to the type of healthcare provider preferred. Two preferred a doctor, four preferred a women's health nurse and the remainder had no clear preference.

Making Pap tests easier

When asked to select the factors that would make having a Pap test easier, there was a high level of agreement amongst the women. All endorsed the importance of a female provider, privacy, trust, having a sense of control, permission to stop at any time and being given a blanket. Fourteen women also specified the importance of explanation and a warm room and warmed instruments, while 13 nominated being able to have hands and arms free during the test rather than used to support their buttocks during the examination. Twelve women specified that physical positioning was important, nine nominated having a pillow to hold and eight suggested having a friend or support person with them would be helpful. All women could think of additional factors that would make the test easier. The following suggestions were made by women participating in the study for improving their experience of Pap tests.

- ◆ 'It's important to build rapport.'
- ◆ Taking time to talk through the procedure.
- ◆ A friendly, caring approach.
- ◆ Experience with victim/survivors.
- ◆ Less chitchat, especially whilst the woman is undressed.
- ◆ Doctor initiating discussion about sexual assault.
- ◆ A less sterile, confronting environment.
- ◆ 'It is important to have control and be asked what works for you.'
- ◆ 'A caring person who is skilled and competent that you feel comfortable with.'

- ♦ 'I wish there was a procedure where women could somehow do it to themselves.'

Quote

There needs to be an information card actually placed in the waiting room, and also inform the patient when they come in, that if you find the Pap smear painful or hate it for any reason, for example, being raped or sexually assaulted, then feel free to talk about this to the doctor. Then when you go in, the doctor does not have to say too much verbally he could just say 'I just was wondering if you saw the card out there, is there anything you would like to raise with me or anything you want me to be aware of?' So they do not have to ask you if you have been raped, but they can just provide the space to talk about that, a point before you start getting into the procedure and you are on the table because it is too late sometimes.

Self-testing

Women were asked about their opinions of the possibility of taking their own cell samples. 13 of the 15 women said they would want more information about this, would consider using this method and that it would be likely to improve their experience of Pap testing. Nine women said that it would be likely to encourage them to perform Pap tests more regularly.

Many women made additional comments about this possible future option.

I could do it at my own place and time and have control and not have someone looking at my fanny. And I am sure I would not hurt myself.

I would have more privacy and more control if it was me and I know what I can tolerate. I would not feel that there are other people around. I would not be so embarrassed with myself, and it would be done in my own environment where I would feel more safe.

It's about control and about me not having to endure something somebody else has to impose on me.

Impact of Events Scale

The impact of events scale (IES) (Horowitz et al, 1979) is a widely used and well validated measure of the level of current subjective distress related to the impact of a past traumatic event. The IES measures the two most commonly reported experiences in response to stressful events: intrusion and avoidance. Intrusion refers to thoughts, images, feelings, dreams and repetitive behaviours which intrude upon an individual's awareness and are distressing (7 items) together with or oscillating with periods of avoidance. Avoidance refers to psychic numbing, conscious denial of the impact of the stressful event, blocking of thoughts and images, behavioural inhibitions and counterphobic activities (8 items). The 15 items are rated on a four point scale of frequency of occurrence (not at all, rarely, sometimes, often) scored as 0, 1, 3 and 5 respectively.

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A sample of adults seeking psychotherapy as a result of reactions to a serious life event was utilised in the original study by Horowitz et al (1979). Their total mean score on the IES was 39.5 (SD=17.2, range 0-69), their mean intrusion score was 21.4 (SD=9.6, range 0-35) and their mean avoidance score was 18.2 (SD=10.8, range 0-38). In the current study, 10 of the sample of 15, had total IES scores of 46 or above suggesting a high level of symptoms of traumatic stress was being experienced by participants at the time of the study. The mean intrusion score was 23.6 (SD=10.19) and the mean avoidance score, 20.5 (SD=10.47). The intrusion scores particularly are higher than those reported in a number of other studies on women in a variety of conditions for example pre and post abortion (Cohen & Roth, 1984), three weeks and three months after being caught up in a bank raid (Hodgkinson & Joseph, 1995) and with sexual assault victims pre and post counselling (Resick & Schnicke, 1992).

◆ **Discussion**

Research into violence against women

Sexual assault is a traumatic event with immediate and long-term consequences for health and wellbeing. Women report that they frequently experience poor responses to their disclosures, which exacerbate the impact of the assault. Due to the sensitive and traumatic nature of sexual assault, any study in this area requires a careful and informed approach.

Feminist research seeks to enhance women's situation and commonly employs qualitative research practices and in-depth interviews in order to allow women's experiences to be more fully understood (Lee & Renzetti, 1993). The current research draws on literature relating to sensitive research practices and has adopted methodology specifically to protect participants whilst gathering information about this particularly personal issue. Distressing memories and emotions occasionally result from participation in research of a sensitive nature. The current research was designed with an awareness of such outcomes and provisions were made to minimise distress to participants and appropriately manage any adverse outcomes. Draucker (1999) suggests that where traumatic effects result from participation in research it is predominantly due to insensitive, overly intrusive or exploitative research practices and maintains that under confidential and trustworthy conditions the benefits of such research outweigh the immediate distress of participation. Many women have reported the benefits they experienced from participation in research of a sensitive nature (Lee & Renzetti, 1993; Draucker, 1999; Watts et al, 1999).

In the pilot study some women commented that although their experiences were difficult or painful to discuss, that this was outweighed by the importance of the issue.

You obviously visualise and live it to some extent. I realised that would be a possibility before I participated in this interview, and I think this is a necessary experience to go through to build a better knowledge and understanding of this issue. It has not been as uncomfortable as having a Pap smear test.

I realise once again that I was a victim of child abuse when I was trying to push it to the back of mind. I feel exhausted and drained, but I think it's really good and I have no regrets because I want my contribution to help myself and other women.

Issues arising from the findings

Many of the findings in the current pilot study are consistent with previous research. Some common experiences are clearly articulated by the women in the study. Although it is not possible to draw firm conclusions from the data obtained, there is strong, suggestive evidence that being a victim/survivor, affects women's regular participation in and attitudes towards Pap testing. The results are unclear in relation to whether the women interviewed participate in

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cervical screening less regularly than the general population but verbal reports indicate that women delay their Pap tests longer than suggested intervals or force themselves to comply.

All women reported that being a victim/survivor affected their Pap test experience and some reported that they had felt reminded of the assault and re-traumatised by having Pap tests. Many women reported feeling obliged to participate in cervical screening despite negative feelings towards having Pap tests.

When examining women's reasons for not screening, it was not usual for women to forget or not get around to having a Pap test but more commonly their experience of, or feelings about the process of having a Pap test were reported as the main reasons. In the current study embarrassment, fear, dislike and pain/discomfort were all endorsed, over other reasons. When the ACCV (Anti-Cancer Council Victoria) asked the same question of under screened women without providing the option of past sexual assault as a possible reason for under screening, 38 per cent of women reported that the experience of the Pap test itself was their main reason. In addition, 51 per cent of participants responded that they could not be bothered, forgot or that it wasn't a priority. It is not possible to assess which of these reasons may mask discomfort with Pap testing due to sexual assault, but it is clear that many women find the experience of Pap testing the most stringent deterrent.

In comparison with Victorian Cervical Cytology Registry (VCCR) statistics, it is apparent that this group of women was at higher risk of being recalled following their pap tests than the general population. Four of the 12 participants (33.3%) had been required to have post Pap test follow up compared to 8.2% of the general population being recalled for some reason annually. The ACCV figure includes those recalled because of unsatisfactory smears (1.5%). Despite the small sample in the pilot study, their high rate of recall warrants further exploration as it may be a significant indication of increased incidence of abnormal Pap test results in the victim/survivor population. It is also disturbing that this group of women find Pap tests particularly distressing and are required to repeat their experience when they receive a recall notification or abnormal result.

Most commonly women in the pilot study reported that they were inclined to comply with Pap testing because of their fear of cancer. They have reported that this places them in a position where they feel they have no choice but to comply with participation in an experience that may be traumatic physically and emotionally.

I am committed to it and I force myself to do it, although my experiences have been really mixed. I do not like them. I have regular tests for health reasons.

Factors which made women feel less inclined to comply with recommended Pap testing were their experiences of sexual assault and their negative experience of Pap tests.

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Healthcare providers have a role to play in improving women's experience of Pap tests and feature highly in women's reports of both their positive and negative experiences of having Pap tests. Providers are in a position to improve the cervical screening rates and experiences of victim/survivors if appropriately educated about the incidence and impact of sexual assault and willing and able to modify their clinical practice and history taking in response to these issues. In particular, it is important that having a Pap test is suggested by the healthcare provider. Women in this study expressed a preference for the healthcare provider to initiate a discussion about sexual assault. Currently, this does not appear to be the case.

Consistent with international research, women in the study reported that they had not been asked about their experiences of sexual assault by their healthcare provider. Despite this, they did report making disclosures to healthcare providers in the hope that their experience may be taken into account in the context of their health care provision. Women reported varied experiences of disclosing to their healthcare provider. Many were said to have responded in a way that was supportive and to have adopted strategies, which acknowledged the woman's past experience and improved her current experience. Other responses to disclosures to healthcare providers were reported to have resulted in insensitive or inappropriate responses. Women have indicated an expectation of positive responses from healthcare providers to their disclosures of violence, in their willingness to disclose spontaneously. Nevertheless they expressed a clear preference for the doctor to initiate discussion about sexual assault. This too, is consistent with international research and indicates an expectation that the healthcare providers will offer supportive, knowledgeable healthcare.

As reported, participants indicated a strong gender preference for a female provider throughout the interview responses. The importance of a female healthcare provider was mentioned often in positive experiences and ideas for making Pap tests easier. A woman provider was unanimously preferred and gender was more important than the provider being a doctor for the majority of participants.

Our results showed that women responded positively to questions about the possible future option of performing Pap tests on themselves. There has been little exploration into the possibility of self collection of cervical cells in the general population, but where it has been incorporated into STD check-ups it has been described by participants as preferable to gynaecological examinations. Not unlike the indications made by the participants in the current study, adolescents said it would encourage them to self-test regularly (Wiesenfeld et al, 2001). Another recent study (Gravitt et al, 2001) found self-testing effective in ascertaining the presence of HPV - a virus known to be a precursor to cervical cancer. It seems that if self-collection of cervical cells were to become an option many women would want to know more about it and may be encouraged to increase their participation in cervical screening.

Changes to the semi-structured interview schedule

The interview tool has been adjusted to elucidate clear information about women's experiences and participation in cervical screening. Alterations include the following:

- ◆ Inclusion of information about past assaults in addition to presenting issue.
- ◆ Impact of Events Scale will be introduced early in the revised interview schedule to obtain this information prior to women's participation in the interview. In the pilot study the IES was administered after the interview and it was possible that the experience of the interview could have coloured responses to the IES.
- ◆ Wording changes and questions re-ordered for clarity and simplification.
- ◆ Alteration of questions about frequency of screening to clarify screening intervals.
- ◆ Inclusion of questions about the incidence and follow-up of abnormal Pap test results.
- ◆ Inclusion of a question asking about the impact of Pap tests.
- ◆ Additional triggers added to the question asking what would make a Pap test easier selected from women's responses to this question in the pilot study.
- ◆ Inclusion of a question asking, 'Is there anything you would like to tell healthcare providers about doing Pap tests?'

Future of the research

From the results of the pilot study, it is clear that further research is required to explore the cervical screening rates and experiences of victim/survivors of sexual assault. Women have reported distressing examples of Pap tests and many suggestions for improving their experiences.

The current research gives voice to the experiences and needs of victim/survivors and has the potential to further influence the training and practices of healthcare professionals in the area of violence against women. Attention needs to be given to improving the experience of Pap testing in this potentially at-risk group of women who are reporting that they are deterred from Pap testing by negative experiences and fear. It would seem imperative that the negative Pap testing experiences of this group be addressed as a matter of urgency to avoid placing them at greater risk of both cervical cancer and re-traumatisation.

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A great deal of enthusiasm regarding the issue has been expressed by service providers, academics and women who have disclosed their experiences of both sexual assault and participation in cervical screening. Funding is being sought to continue the research beyond the pilot stage.

Copies of the report will be available from CASA House from September 2002.

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◆ Appendices

1. CASA House brochure
2. Semi-structured interview schedule
3. CASA House intake form
4. Participant information sheet
5. Consent form
6. Process for women who became distressed during the interview
7. Revised semi-structured interview schedule

**For copies of Appendices please contact
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