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A synthesis of qualitative research on cervical cancer screening behaviour: women's perceptions of the barriers and motivators to screen and the implications for policy and practice

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Abstract

Cervical cancer is one of the most preventable and treatable cancers. It has been estimated that up to 90% of the most common type of cervical cancer may be prevented if cell changes are detected and treated early. Early detection is undertaken using a Pap test. In most Western countries, including Australia, and in many less developed countries, screening for cervical cancer is provided to women in the form of an organised program. These programs typically provide Pap tests free or at low cost, at the point of delivery. However, as most cancers occur in women who have never or rarely screened, increasing the rate of screening remains an important issue.

Numerous studies have identified the variables associated with women rarely or never screening. Older, poorer women, women living in rural communities and those from non-European ethnic backgrounds (in Australia, especially those who do not speak English) are much less likely to screen than their younger, richer, urban-dwelling, English-speaking sisters. This type of information can be used to target women less likely to screen but does not address what women perceive to be the major barriers to their having a Pap test or what messages might be most effective in convincing them to have the test. A number of qualitative studies have examined these issues. In this project, the results of such studies have been synthesised in an attempt to answer two questions:

1. Why don't some women have Pap tests?
2. What would work to encourage women who currently do not screen to change their behaviour?

This synthesis adopted the meta-ethnographic approach as described in Campbell et al (2003). The results from 16 papers were appraised in terms of the quality of the research undertaken as well as results and conclusions.

The results indicate that the majority of women have heard of or know about the Pap test. However, many were misinformed about the details of the test and its implications. Women may not think a Pap test is relevant for them for a number of reasons: many believe that it detects cancer (rather than cervical abnormalities which may or may not be pre-cancerous lesions). This may lead to under-screening if a woman is afraid of cancer or believes that screening is only necessary if and when symptoms appear. Women may also not screen if their cultural and/or religious beliefs connect cervical cancer with sexually transmitted infections acquired as the result of pre-marital or extra-marital sexual contact (ie promiscuity). Common barriers to accessing Pap tests included the direct cost of the test and various opportunity costs in terms of time and availability of childcare. The lack of availability of female health care providers was also an important barrier.

The synthesis has indicated that there are some standard preferences and barriers which cross cultural, demographic and socio-economic lines that could be considered by practitioners and policy makers attempting to improve services and increase screening uptake. Practitioners can encourage women to screen by emphasising the curable nature of cervical lesions, being honest about the relationship between sexual activity and cervical cancer and explicitly recommending a Pap test. There is also a need for more individually tailored approaches to target specific ethnic groups. An understanding of community-specific beliefs is invaluable to health professionals if they are to provide cultural sensitive and appropriate services.

Background

Screening for cervical cancer

Cervical cancer is one of the most preventable and treatable cancers. It has been estimated that up to 90% of the most common type of cervical cancer (squamous cell carcinoma) may be prevented if cell changes are detected and treated early. Currently, such early detection is undertaken using a Pap test, a relatively straightforward exercise for an experienced and well-trained doctor or nurse. Having a Pap test involves the practitioner perform an internal examination during which cells from the cervix are collected, placed on a slide and sent to a laboratory where they are tested for changes in the cells of the cervix. It does not check for other problems in the reproductive system and it is not a check for sexually transmitted diseases (STDs) (Australian Department of Health and Ageing 2005). Most abnormalities detected by a Pap test are not cancer but some are regarded as pre-cancerous or potentially pre-cancerous. Guidelines for the treatment of screen-detected cervical abnormalities indicate the recommended management for particular abnormalities. In Australia, the original guidelines were issued in 1994 and after a process of review by the National Health and Medical Research Council (NHMRC), new guidelines have been issued. (National Health and Medical Research Council 1995);(National Health and Medical Research Council 2005).

In most Western countries, including Australia, and in many less developed countries, screening for cervical cancer is provided to women in the form of an organised program (Australian Department of Health and Ageing 2005; National Health Service 2005); (McLachlin C 2005); (Steinberger E 2004). These programs typically provide Pap tests free or at low cost, at the point of delivery. For example, in Australia, Pap tests are provided mainly by general practitioners (GPs) and the only potential cost to women for a standard Pap test is any out-of-pocket costs associated with the consultation (ie if the GP does not bulk bill). Additional activities undertaken by the Australian National Cervical Screening Program (NCSP) include advertising and marketing the program to both women and general practitioners, sending reminders to women about when their test is due and coordinating data collection and quality control for laboratories. Programs such as the NCSP have, on the whole, been successful in raising the population rate of screening as well as improving the quality of Pap test sampling and analysis (Australian Department of Health and Ageing 2005). Debate continues about such issues as the most effective and cost-effective age range for screening and what interval between Pap tests to recommend as well as the place of new technologies such as liquid-based Pap tests (designed to increase the accuracy of the test) and testing for human papilloma virus (HPV), now considered the probable cause of many cervical cancers. Such discussion is focussed on improving an existing program for women who already screen. However, as most cancers occur in women who have never or rarely screened (National Health Service 2005), increasing the rate of screening amongst these groups remains an important issue for policy makers.

Research about why some women rarely or never have a Pap test

Numerous studies have identified the variables associated with women rarely or never screening. Older, poorer women, women living in rural communities and those from non-European ethnic backgrounds (in Australia, especially those who do not speak English) are much less likely to screen than their younger, richer, urban-dwelling,

English-speaking sisters (Taylor 2001; Ngyuen TT 2002). This type of information can be used to target women less likely to screen but does not address what women perceive to be the major barriers to their having a Pap test or what messages might be most effective in convincing them to have the test.

In order to address these issues, it is necessary to i) reflect on the possible reasons for non-screening behaviour, ii) assess whether the results from qualitative studies confirm the existence of these mechanisms and iii) consider the extent to which such information can be used to design programs aimed at altering non-screening behaviour.

There are three major reasons why a woman might not screen for cervical cancer:

1. She does not know about Pap tests;
2. She knows about Pap tests but does not think having one is relevant for her circumstances (note: there may be many such circumstances; for example, being too young or too old, not being sexually active or only having one partner, not wanting to be seen as sexually active due to religious or cultural beliefs etc);
3. She faces barriers in accessing Pap tests (eg due to financial, geographical, cultural barriers etc).

A number of qualitative studies have examined these issues. In this project, the results of such studies have been synthesised in an attempt to answer two questions: Why don't some women have Pap tests? What would work to encourage women who currently don't screen to change their behaviour? The paper is organised in the following way: the next section deals with the synthesis of qualitative studies and the method adopted in this project. The findings of the study and an interpretation of the results precede a discussion and conclusion which draw out some lessons for practitioners and policy makers.

Method

Meta-analysis of qualitative research

Techniques such as meta-analysis are used for conducting quantitative systematic reviews and involve the application of criteria for assessing the quality of the research to form a separate study. There has been much discussion as to whether such techniques could be used for assessing qualitative research. Noblit and Hare's (Noblit and Hare 1988) meta-ethnographic approach enables a rigorous procedure for deriving substantive interpretations about sets of ethnographic or interpretive studies, like the quantitative counterpart of meta-analysis the process of putting together studies, comparing and analysing them to create new interpretations can be considered a complete study in itself. Campbell et al (Campbell, Pound et al. 2003) set out to evaluate the meta-ethnography approach and applied it to research on lay experiences of diabetes and diabetes. They also wanted to test whether the meta-ethnographic approach would work on a large number of varied studies. Noblitt and Hare (Noblit and Hare 1988) based their method on 2-6 papers and Campbell et al included 10 (Campbell, Pound et al. 2003). Their synthesis was undertaken as part of a formative evaluation of methods for appraising and synthesising qualitative research which was explicitly designed to explore whether it was possible to achieve a meaningful synthesis using method. Campbell et al (2003) concluded that meta-ethnography can

lead to a synthesis and extension of qualitative research in a defined field of study but that it required further testing and evaluation before it could be recommended for more widespread adoption. In this study, Campbell et al's method for reviewing qualitative research of diabetes is used to synthesise qualitative research which aimed to investigate the reasons women do not screen (Campbell, Pound et al. 2003).

The study methods

The initial literature search was restricted to the following keywords: cervical screening, cervical cancer screening, Pap test/s, qualitative, women's perspective/s. A search of the electronic databases (EMBASE and Ovid MEDLINE) was undertaken to identify relevant English language publications. A second round of articles was gleaned from references cited in the first batch of papers.

This synthesis adopted the meta-ethnographic approach as described in Campbell et al (2003), who in turn, adapted their comparative criteria from the Critical Appraisal Skills Programme (CASP, 1998) (Noblit and Hare 1988);(Campbell, Pound et al. 2003). Stage one involved asking two screening questions:

1. *Is this qualitative research?* and
2. *Does it address the issue we are interested in?*

All papers were read and assessed in this way by two researchers and their selections compared. If an affirmative response to both questions was made by both researchers, the paper was appraised in stage two of the process using criteria 3-9 (see Table 1).

Table 1: Critical appraisal questions

Stage 1	*1. Is this qualitative research?*
	2. Does it address the issue we are interested in?
Stage 2	*3. Is there a clear statement of the aims of the research*
	4. Is the theoretical perspective identified a. which theoretical perspective is identified
	5. Was a recruitment/sampling strategy outlined a. who was recruited b. where were they recruited c. how were they recruited d. how many were recruited e. how many refused f. why refused g. participant characteristics outlined
	6. Data collection addressed research question a. how were data collected b. were methods used described explicitly c. is data saturation discussed
	7. Data analysis a. was method described b. is role of researcher considered c. is it possible to summarise the findings of this study d. are findings explicit

	8. Key concepts a. sufficient data presented to support findings b. data selection explained c. links between data and interpretation d. negative cases/contradictory data
	9. Overall a. adequate discussion of the evidence for and against researcher's findings b. credibility of findings discussed c. findings discussed in relation to the aims of the research/research question d. Include in synthesis

Campbell et al highlight how Noblit and Hare (1988) describe three different types of synthesis which are distinguished by the way in which the papers to be synthesised relate to each other. The simplest form of synthesis is that achieved when the accounts contained in the papers are similar and synthesis can be achieved through reciprocal translation. Conversely, accounts may conflict in which case a refutational synthesis can be produced. The third type of synthesis is a line of argument syntheses which they characterise as 'essentially about inference: What can we say of the whole (organisation, culture, etc.) based on selective studies of the parts?' Campbell et al's synthesis of diabetes research included an initial translation of findings from one paper to another and then applied the 'line of argument' synthesis (Campbell, Pound et al. 2003). This study follows a similar format building a 'line of argument' synthesis. Following a description of the appraisal and the general synthesis of them, the evidence for and against the previously described causal mechanisms is detailed. A description of each study is provided in Appendix 1.

Findings

Appraisal

Eighteen papers from the first round were reviewed. Of these, five were rejected; two as they were not considered to be qualitative research and three as they did not address the reasons for 'not screening' adequately. From the second round (ie those papers identified from the reference lists of the original papers) a further eight papers were reviewed, with five of these being rejected as they were not deemed to be qualitative. The full synthesis was then carried out on the remaining 16 papers; the level of agreement between the two assessors was high despite a wide variation in the quality of the papers.

Quality of the papers

The overall quality of each paper can be judged by assessing the extent to which it met criteria 3-9 (see Table 1). Such as assessment reveals that the papers varied somewhat in meeting important indicators of quality. Ten papers included a clear statement of the aims of the research such as "investigation of the barriers and motivators to cervical screening", two included a general statement such as "assess factors associated with cervical screening" whilst four did not include a statement of aims.

Eleven of the papers explicitly discussed the theoretical perspective adopted. Of these, five used grounded theory or a similar ethnographic approach, three used the Health

Belief Model and three used another theory (relational model proposed by Rolland, framework of illness representations and stage models). Twelve papers described in detail their recruitment strategy. Of note is that three of the five papers which did not adopt a theoretical perspective also did not describe a recruitment strategy. It is also important to note that not describing a recruitment strategy is also associated with no details being available about who refused the offer to participate in the research and why. All papers were clear about the methods used to collect the data: four used focus groups, six used in-depth interviews, four used a combination of focus groups and interviews and two used other combinations (review of medical records plus interviews and focus groups plus questionnaires). All papers described the analytical techniques used but the detail varied between papers. Papers with a detailed description of the analytical methods also tended to include some explicit discussion about the role of the researcher. In six papers, there was no discussion of the role of the researcher.

Rigor is an important concept in qualitative research. It is enhanced by being explicit about the issues discussed above. However, there are two additional issues which are vital in ensuring the rigor of the research: providing information about negative cases and/or contradictory findings and explicit discussion of the credibility of the findings. Most papers performed well in relation to these indicators: six of the papers neither alluded to nor discussed negative cases or contradictory data; one paper did not discuss the credibility of the findings although four others included only a brief discussion of this issue.

The synthesis

In all 16 papers the groups of women studied were perceived to be at higher risk for cervical cancer and/or with reported lower screening uptake than the rest of the population. Initial formulation of the synthesis highlighted a division between those papers which focused on the screening behaviour of ethnic minority groups or immigrants and those which focused on mainstream population groups that were selected as potential under-screeners because of their age, level of income, education and/or geographic location. Ten studies used techniques based on established theoretical perspectives such as the Health Belief Model, Grounded Theory, The Theory of Planned Behaviour, Illness Representations, and the Relational Model or adopted an Ethnographic or Anthropological approach.

The papers can be divided into four sets: (1) a main group consisting of ten papers that concentrated solely on women's knowledge of cervical cancer and screening and the barriers and motivators to screening (Naish, Brown et al. 1994; Price 1997; Jameson, Sligo et al. 1999; Lazcano-Ponce, Castro et al. 1999; Strickland 1999; Carey Jackson, Taylor et al. 2000; Lee 2000; Boyer, Williams et al. 2001; Fernbach 2001; Jackson, Do et al. 2002); (2) two papers that used techniques that focused on illness representation and salient beliefs, referents and controls (Savage and Clarke 1998; Agurto, Bishop et al. 2004); (3) one paper that centred only on psychosocial and cultural influences (White 1995) ; and (4) a group of three papers that also included men's and/or health service workers perceptions (Abrahams, Wood et al. 1997; Jennings 1997; Arredondo 2003). However, apart from these relatively subtle variations in the focus of the papers, all of the studies revealed, to a greater or lesser

degree, women's perceptions of the Pap test and the major influences on their screening behaviour.

General information about the papers

In thirteen of the sixteen papers, the studies were undertaken in countries with highly developed health systems: USA (7, including 1 with groups in both the USA and Canada) (Jennings 1997; Price 1997; Carey Jackson, Taylor et al. 2000; Lee 2000; Boyer, Williams et al. 2001; Jackson, Do et al. 2002; Arredondo 2003), Canada (2 including 1 with groups in both the USA and Canada) (Strickland 1999), Australia (2) (Savage and Clarke 1998; Fernbach 2001), New Zealand (2) (White 1995; Jameson, Sligo et al. 1999) and the UK (1) (Naish, Brown et al. 1994). The remaining three studies were undertaken in Mexico (Lazcano-Ponce, Castro et al. 1999), in five Latin American countries (Agurto, Bishop et al. 2004) and in South Africa (Abrahams, Wood et al. 1997), countries which, whilst not having highly developed health systems, promote screening for cervical cancer and offer some incentives to encourage the uptake of screening.

Of the 13 studies conducted in countries with highly developed health systems, 10 were undertaken with groups of women whose ethnicity distinguished them as having low rates of screening: English women from East and South Asian and Middle Eastern backgrounds (Naish, Brown et al. 1994), Americans of African, Hispanic, Korean, Cambodian and Chinese background (Jennings 1997; Price 1997; Carey Jackson, Taylor et al. 2000; Lee 2000; Boyer, Williams et al. 2001; Jackson, Do et al. 2002; Arredondo 2003), Canadians of Pacific North West Indian background (Strickland 1999) and New Zealand women from a Pacific background (Jameson, Sligo et al. 1999). The Mexican study targeted women living in both rural and urban areas (Lazcano-Ponce, Castro et al. 1999), the Latin American study targeted low-income women (Agurto, Bishop et al. 2004) and the South African study targeted black women (Abrahams, Wood et al. 1997). One Australian and one New Zealand study targeted older women (White 1995; Savage and Clarke 1998) and the second Australian study focussed on young women (Fernbach 2001).

Factors that influence women's knowledge of cervical cancer and screening, perceptions of the Pap test and cervical cancer treatment, and the barriers and motivators to screening can be divided into two main themes: cultural/psychosocial and practical/structural influences; in other words, a division as to how screening behaviour is influenced by personal or community beliefs and attitudes, in addition to external factors, such as the level of information available, access to health services and the quality of care provided. In the interpretation of the results below, the synthesis has been organised around the proposed reasons for not screening which have been set out in the first section of this paper. Information about factors likely to encourage screening (as opposed to reasons for not screening) and cultural issues which impact on the probability of a women screening, has been used to suggest practice or policy interventions.

Interpretation of synthesis

1. Women do not know about Pap tests

Only one paper reported that some participants had no knowledge of Pap tests (Fernbach 2001). This study focussed on young women in Australia and only the two youngest participants had no knowledge of the test. In all other studies, all participants had heard of a Pap test and most had a general idea of its purpose. However, many women were misinformed about the details of the test and its implications.

2. Women know about Pap tests but do not think having one is relevant for their specific circumstances

A very common misconception is that Pap tests are used to detect cancer, rather than cervical abnormalities (many of which are not pre-cancerous and all of which can be successfully treated). This may seem a minor issue given the complexities of the system used to describe and classify the abnormalities. However, although there may be some benefits to this misunderstanding (eg if women believe that Pap tests detect cancer early and therefore mean earlier treatment and possible cure), there may also be some negative connotations (eg if women are fatalistic about cancer, believe that nothing can be done about it and would "rather not know"). A number of studies mentioned the importance of specific provider recommendations as a motivating factor in a decision to have a Pap test. This points to the need for women to be educated and informed about Pap tests as well as encouraging providers to recommend they have a test, when appropriate (Carey Jackson, Taylor et al. 2000; Lee 2000; Boyer, Williams et al. 2001).

A related issue is women's understanding of the implications of cervical abnormalities being largely symptomless. Screening involves testing healthy symptom-free populations and amongst some groups of women, accessing health services is regarded as something to be undertaken only when a person has symptoms; ie is "ill". Such findings illustrate the potential importance of opportunistic screening when a woman presents at a health service for another reason. Further, events associated with life-stages such as becoming pregnant, giving birth and menopause (which are often regarded as special women's business by particular ethnic groups) provide practitioners and policy makers with opportunities to inform women and encourage them to have a Pap test (Lee 2000; Jackson, Do et al. 2002; Arredondo 2003; Jennings 1997).

An important issue is the relationship between cervical cancer and sexually transmitted diseases (STDs). In a number of the studies, participants referred to promiscuity and lack of hygiene as factors in the development of cervical cancer (Sawyer, Earp et al. 1990; White 1995; Jameson, Sligo et al. 1999; Strickland 1999; Jackson, Do et al. 2002). Whilst there is no connection between general hygiene and cervical cancer, it is the case that unprotected sex with multiple partners places women at higher risk for cervical cancer and STDs in general. As knowledge of the causal relationship between HPV and cervical cancer increases, practitioners and policy makers will need to find ways to acknowledge the fact that many cervical cancers are, in fact, STDs, whilst avoiding being drawn into moral or religious arguments about sex and/or sex education. Here a great deal can be learnt from HIV and STD safe sex campaigns. Informing both women and men that safe sexual

practice reduces the risk of cervical cancer as well as HIV and other STDs may encourage and increase the use of such practices.

3. Women face barriers to accessing Pap tests

In many of the studies women detailed specific reasons for not being able to access the services providing Pap tests. In the USA-based studies, the cost of tests and lack of health insurance to cover the cost was always a factor mentioned by women as a barrier to accessing health services (Jennings 1997; Price 1997; Carey Jackson, Taylor et al. 2000; Lee 2000; Boyer, Williams et al. 2001; Arredondo 2003). Other financial barriers included lack of availability of child care and/or transport to enable women to access care (Naish, Brown et al. 1994; Carey Jackson, Taylor et al. 2000; Jackson, Do et al. 2002). More subtle barriers to the provision of health services included those of language and gender of the provider of care and the quality of care (Naish, Brown et al. 1994; Jennings 1997; Savage and Clarke 1998; Carey Jackson, Taylor et al. 2000; Boyer, Williams et al. 2001; Jackson, Do et al. 2002; Agurto, Bishop et al. 2004). It is likely that culturally appropriate care delivered by a female provider will increase the probability that women will attend for a Pap test. Many women mentioned embarrassment and pain as reasons for not having a test. High quality services (ie involving well-trained, skilled, experienced providers) are necessary to overcome such barriers as well as others mentioned such as the use of inappropriate venues with little privacy, the lack of appropriate health services information and the need for health workers to promote testing (Jennings 1997; Price 1997; Savage and Clarke 1998; Jameson, Sligo et al. 1999; Carey Jackson, Taylor et al. 2000; Fernbach 2001; Arredondo 2003).

More problematic barriers to overcome may be those associated with long or rigidly held beliefs concerning sexuality and sex. Women whose cultural or family beliefs include disapproval of pre-marital sex and the primacy of men in male/female relationships face specific barriers to accessing Pap tests which are not readily addressed by high-level policy initiatives (Jameson, Sligo et al. 1999; Lazcano-Ponce, Castro et al. 1999; Arredondo 2003; Agurto, Bishop et al. 2004). The most promising means of doing so are likely to involve trusted female providers offering women and men detailed information about cervical cancer and Pap tests and strongly recommending the test. In doing so, it is crucial that a balance be maintained between providers who are cultural sensitive and the need for confidentiality, particularly around issues of sexual practices and sex outside marriage. It is also important to be mindful that a number of studies highlighted groups of women who simply felt western techniques of prevention were inappropriate for them and both practitioners and policy makers need to consider the consequences of attempting to impose such actions on women from non-Western cultures (Carey Jackson, Taylor et al. 2000).

Discussion and conclusion

This synthesis has provided some useful insights into the influencing factors affecting women's cervical screening behaviour. Whilst the studies were of variable quality, all provided information about perceived barriers to screening from women's perspectives.

It is difficult to gauge the impact that the assessed quality of the research process had on the quality of the outcomes ie the breadth and depth of the discussion and the extent to which the results were translated into implications for policy. For example, whilst there were a number of papers that included very little or no detail about recruitment strategies or the role of the researcher, it is not possible to know whether this was because they really did not consider these issues or because space precluded their inclusion in the article. More important issues such as not using a theoretical perspective to inform the research and/or lack of discussion regarding negative cases or the credibility of the findings do not seem to have resulted in less trustworthy or useful results.

A number of studies focussed on minority ethnic groups living in countries with well-developed health care systems as these are groups often perceived as not accessing services such as screening for cervical cancer. Others conducted research in countries where the uptake of Pap tests has been low among many women (eg Mexico and South American countries). A few studies concentrated on young or old women who are also less likely to access screening services. Thus, a major area of interest for many studies was the influence of cultural beliefs and norms which may deter or motivate the uptake of screening.

Many cultural attitudes and beliefs were perceived as barriers. In particular, cultural attitudes which emphasized control over women by parents and/or husbands, frowned on pre-marital sex and stressed the relationship between sex outside marriage, promiscuity, sexually transmitted infections and cervical cancer were perceived by research participants as barriers to taking up screening.

Another set of culturally-defined issues which were seen to have an impact on the take-up of screening were non-Western views about the origins of disease, the impact of different life-stages on a women's vulnerability to disease and a generally fatalistic attitude to illness, and in some cases, cancer in particular. For example, many cultures believe that illness or disease is the result of an imbalance within the body: Chinese women refer to "yin and yang"; Latinas refer to "hot and cold". In addition, it is common to believe that women are more vulnerable to certain illnesses or diseases at the onset of menstruation, after childbirth or at menopause. Generally speaking, these attitudes and beliefs were not barriers to screening but may represent opportunities to increase the utilisation of screening services.

The synthesis has also highlighted that there are some standard preferences and barriers which cross cultural, demographic and socio-economic lines and that could be considered by practitioners and policy makers as ways to improve services and increase screening uptake. Emphasising the curable nature of cervical lesions, being honest about the relationship between sexual activity and cervical cancer and making a strong recommendation to have a Pap test are ways in which practitioners can encourage women to screen. Policy makers have a responsibility to design programs which reduce the systemic barriers as much as possible; ensure that there are sufficient numbers of well-trained, culturally attuned providers, increase the number of female providers and reduce financial barriers as far as possible.

In contrast, the wide range of cultural factors that were uncovered by research indicates the need for more individually tailored approaches to target specific ethnic groups. An understanding of community-specific beliefs is invaluable to health professionals if they are to provide cultural sensitive and appropriate services. A particularly good example of this is noted in the paper by Jameson and colleagues (Jameson, Sligo et al. 1999), whose study of Pacific Islander women in New Zealand showed that not only did the community resent being targeted by a screening promotion campaign as they were 'sick of being associated with bad news', it also highlighted the difficult balance often required in providing services – in this case the need for Pacific Islander health care providers to overcome a language barrier went hand in hand with women's preferences for a provider from outside the community to avoid any consequences associated with knowing which women were sexually active (the confidentiality barrier).

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Appendix 1

Title of paper	Target groups	Aims/research questions	Methods	Findings		
				Knowledge	Relevance	Barriers
Naish, Brown and Denton, 1994 Intercultural consultations: Investigation of factors that deter non-English speaking women from attending their general practitioners for cervical screening. BMJ 309(6962): 1126	Bengali, Kurdish, Turkish, Urdu, Punjabi and Chinese speaking women living in east London	To determine factors that deter ethnic minority women living in east London from attending their GP for cervical cytology screening. Study motivated by the attitude of local GPs that women from ethnic minorities are not interested in cervical screening.	Qualitative study using focus groups: Established community groups Specially convened groups			Administrative and language barriers, inadequate surgery premises and concerns about sterility preference for a female doctor and for childcare facilities
Lee, 2000. Knowledge, barriers and motivators related to cervical cancer screening among Korean-American women: a focus group approach. Cancer Nursing 23(3):168-175	Korean-American women	What is the degree and type of knowledge about cervical cancer, especially its cause, early detection and prevention? What are the barriers that prevent early screening for cervical cancer using the Pap test? What are the motivators for early screening for cervical cancer?	Eight focus groups (n-102) using 11 questions derived from the Health Belief Model (HBM).	Misinformation and knowledge about cervical cancer and therefore women were confused about the causative factors and preventive strategies related to cervical cancer.		Lack of health insurance, time and language problems.

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Boyer et al, 2001. Hispanic women's perceptions regarding cervical cancer screening. JOGNN 30(2): 240-245	Hispanic women in the USA	To examine factors affecting cervical cancer screening behaviours	Interviews with sample of 20 Hispanic women aged 18-65 recruited purposively	Lack of knowledge about Pap smears and available services	Lack of a health promotion/disease prevention perspective, in general, participants accessed health care services primarily during times of illness or in association with impending marriage, childbirth or for birth control	Lack of trust in physicians; a failure of health care providers to recommend Pap smears; financial barriers and inadequate access to care in particular to female Spanish-speaking health care providers.
Fernbach, 2001 Young women's issues associated with Pap tests: a qualitative study of Victorian women. Health Promotion Journal of Australia 12(3): 254-257	Younger and older women in Australia	To examine younger women's knowledge, attitudes and behaviour associated with Pap tests to inform the development of educational campaigns	Ten focus groups (n=57) with women aged 15-44.	Two youngest participants knew nothing at all about Pap tests, the younger group lacked knowledge about why women had Pap tests Focused on cancer as opposed to detecting abnormalities, some women thought it tested for thrush vaginal warts and HIV; most women of all ages had little idea of the causes of cervical cancer and HPV.		Test perceived as uncomfortable, embarrassing and unpleasant. The older group found it intrusive and inconvenient with some reporting pain or discomfort Those with children reported childcare problems
Jameson, Sligo and Comrie, 1999 Barriers to Pacific women's use of cervical screening	Pacific women in New Zealand	To explore barriers to the use of cervical screening, information and	Face to face interviews with 20 Pacific women recruited using snowball method.			Belief in the sacred nature of human sexuality; religion; embarrassment and language issues

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services. Australian and New Zealand Journal of Public Health		services.				
Price 1997 Generational influences on cervical cancer screening and the capacity of the public health system to assure responsive services. Unpublished MPH dissertation, University of North Carolina.	African-American women	What are the family beliefs systems about cervical cancer and Pap smears among rural older African American women? How do family belief systems mediate their understanding of past experiences with cervical cancer screening services? What are the health care system values that influence older African American women's current responses to cervical cancer screening? How do family belief systems affect the capacity of the public health district to assure cervical	Focus group interview of African-American women; in-depths interviews with health care professionals.		All women stated that they did not have access to adequate information about cervical cancer and cervical cancer screening services	Older women associated experience with pain and fear..

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		cancer screening in African American families?				
Strickland, 1999 The importance of qualitative research in addressing cultural relevance: experiences from research with Pacific Northwest Indian women. Health Care for Women International 20: 517-525	Yakama and Nooksack tribes, Pacific Northwest Indians	To determine conditions under which women would seek a Pap test	In-depth interviews and focus groups			Some women also said that they did not seek Pap test because they had some previous unpleasant experiences with health care provider (no detail given) and some are wary of going to a clinic as it highlights them as sexually active.
Lazcano-Ponce et al 1999 Barriers to early detection of cervical-uterine cancer in Mexico. Journal of Women's Health; 8(3): 399-408	Urban and rural Mexican women	To explore the principle barriers to use of the early detection program for cervical-uterine cancer	Four focus groups in urban and rural regions.	Lack of understanding of the aetiology of cervical-uterine cancer, not knowing what the Pap test is used for, most thought it tested for STDs as well		Non-consent from their male sexual partner especially if the test carried out by a male provider; dislike of the pelvic examination itself, feelings of discomfort, no privacy, and feeling invaded. Waiting time for testing and results, problems in the interaction between the medical institution and patient and the doctor-patient relationship,

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						perception of high costs for care despite the test being provided free of charge in the public sector.
Carey Jackson et al, 2000 Development of a cervical cancer control intervention program for Cambodian American women. Journal of Community Health; 25(5): 359-375	Cambodian American women in Seattle, USA	To obtain information about cervical cancer screening behaviour	42 unstructured interviews with Cambodian American women. Four focus groups. Participants were aged 19-75 years.	Paucity of appropriate educational material. Relatively poor knowledge about cervical cancer and Pap testing, many believed a hysterectomy is required if results are abnormal.	No familiarity with western early detection concepts. Many see it as an American disease and therefore not relevant not concern them, others believe they are only at risk if get an STD	Embarrassment, pain and fear of the test. Access to health care access, a lack of insurance, cost, problems with scheduling appointment as not fluent in English, transportation, childcare, and a lack of female providers.
Carey Jackson et al, 2002 Development of cervical cancer control interventions for Chinese immigrants. Journal of Immigrant Health; 4(3): 147-157	North American Chinese women in Seattle, U.S.A and Vancouver, Canada	To develop a culturally relevant video and pamphlet for use as a cervical cancer screening educational intervention.	87 qualitative interviews and nine focus groups with Chinese women.	Lack of culturally relevant information. Issue with translation and understanding as the cervix is not an anatomic part identified in lay Chinese.	Uterine problems are seen as related to poor hygiene and promiscuity (including their spouse) diet and environmental conditions.	language ability makes making appointment difficult, transportation, childcare, the lack of female providers and interpreters and. Location specific issues: in Vancouver the women felt they needed to see a specialist and were not happy with a GP carrying out the test In Seattle lack of health insurance and costs deterred women

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Agurto, 2004 Perceived barriers and benefits to cervical cancer screening in Latin America. Preventive Medicine 19:91-98	Women and men of low education and income status, and health providers in five Latin American countries	To describe the results of studies on the barriers and benefits of cervical cancer screening and compare them to findings from the literature	Five separate qualitative studies (focus groups and interviews) conducted in Venezuela. Ecuador, Mexico, El Salvador and Peru.			Lack of access to services and availability of health centres, transport and opening times, long waiting times in clinic, slow turnaround of results; misinformation such as lost of results, poor quality Pap smears rejected by lab, costs, time and cost of medicine, privacy, courtesy of providers found lacking, information and counselling inadequate, language issue for indigenous groups. Lack of symptoms means no action necessary, acceptability of pelvic examination feelings of modesty, discomfort and defencelessness, acceptability of exam by partners, anxiety over results and subsequent treatment (or lack of it)

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Savage S and Clarke V 1998. Older women's illness representations of cancer: a qualitative study. Health Education Research 13(4): 529-544	Screeners and non-screeners in Australia	To identify and describe older women's illness representations of cancer and cancer screening	Unstructured face-to-face interviews with 20 women aged 45-70.		No longer sexually active, no longer on the pill. Three under-screeners said that screening was more important for younger women.	No symptoms, difficulty finding a female doctor, fear of discovering a prolapse that would require surgery, sorting problems out for themselves and using alternative therapies; experience of Pap smears being uncomfortable, undignified, and embarrassing.
Eyres White, 1994 Older women's attitudes to cervical cancer: a New Zealand experience. Journal of Advanced Nursing 21: 659-666	Older women in New Zealand	To determine how older woman's perceptions of cervical cancer and cervical screening services might be affecting health seeking behaviour.	In-depth interviews with nine women aged 45-70	Too much information and too confusing. Most women presumed the smear was to detect cancer, most thought you would die from it	Not wanting to take up doctors time as not sick, no need to waste resources on old best to spend resources on young, put children above themselves	Pain, death In general only go for health checks if they are sick or worried, due to cost, and fear of what they might find out Loss of confidence in doctor who had made a misdiagnosis
Abraham, Wood and Jewkes, 1997 Cervical screening in Montagu District: women's experiences, coverage and barriers to uptake. Report to Medical Research Council, January 1996.	Black women in South Africa	To explore barriers to Pap smears as perceived by women and health workers	In-depth interviews with service users, women who had not used the service and health care wokers.			Lack of staff, seasonal movement of women, follow-up difficult, lack of transport both for the women and to get samples/results to and from laboratory. Influence of male partners.

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Arredondo, 2003 Evaluating a stage model in predicting Latina's cervical cancer screening practices: the role of psychological and cultural predictors. Unpublished dissertation for PhD, Duke University USA		To evaluate the role of psychosocial /cultural factors that influence screening behaviour	Structured interviews with 178 monolingual Spanish-speaking Latinas.	Many women thought the purpose of a Pap test was to have a look and to clean the area.	A common belief was that if a woman had no symptoms then there was no need for test.	Lower income levels and being less likely to have insurance, cost is too high, and screening creates many worries, embarrassment and physical pain.
Jennings, 1997 Getting a Pap smear: focus group responses of African American and Latina women. ONF 24(5): 827-835	African American and Latina women in the USA.	To identify barriers and facilitating factors associated with Pap smear use			Older African American and Latin women believed it was problem only for young, promiscuous, or those who were unhygienic	Lack of access to a doctor or only a male doctor, cost and fear of discomfort.