

Women's understanding of abnormal cervical smear test results: a qualitative interview study

Anne M Kavanagh, Dorothy H Broom

Cancer
Epidemiology
Centre, Anti-Cancer
Council of Victoria,
1 Rathdowne Street,
Carlton South
3053, Australia
Anne M Kavanagh,
research fellow

National Centre for
Epidemiology and
Population Health,
Australian National
University,
Canberra 0200,
Australia

Dorothy H Broom,
senior fellow

Correspondence to:
Dr Kavanagh.

BMJ 1997;314:1388-91

Abstract

Objective: To describe how women interpret their experiences of diagnosis and treatment of a cervical abnormality and how healthcare services for such women can be improved.

Design: Qualitative study using detailed individual interviews.

Setting: Australian gynaecology clinics.

Subjects: 29 Women who had a cervical cytological abnormality and who attended a gynaecologist.

Main outcome measures: Women's views on their diagnosis and their information needs.

Results: Most women wanted to participate in decisions about their care but found it difficult to get the information they required from doctors because they were confused by what their doctors told them and felt unable to ask questions in the consultation. Medical terms such as wart virus and precancer were difficult to understand. Not being able to see their cervix also made it hard for women to understand what their abnormality meant and what treatment entailed. Most women tried to make sense of their abnormality in the context of their everyday lives. For some women their gynaecological care was not consistent with the way they understood their abnormality.

Conclusions: The inherent power structure of medical practice combined with time pressures often make it difficult for doctors to give the detailed information and reassurance patients need when a diagnosis is distressing or when investigation and treatment are strange and upsetting.

Introduction

Dealing with cervical abnormalities may be comparatively routine for doctors, but for women who have such abnormalities the diagnosis can be alarming and confusing. Although abnormal cervical smear test results are quite common,¹ most women with abnormal results do not have symptoms. Unlike with most health problems, the women have no way to recognise and monitor their condition. In these circumstances, how well do healthcare services meet the needs of women with cervical cytological abnormalities?

Subjects and methods

Because women's feelings and perceptions are at the centre of this study we used a qualitative method.² We conducted individual interviews with 29 women who had abnormal smear test results between late 1990 and mid-1992. Those eligible for the study also had gynaecological assessment and treatment for the abnormality. Women with invasive disease were not included. Participants were recruited from three private outpatient gynaecological services (there are no public outpatient gynaecological services in Canberra) and a women's health service.

AMK conducted semistructured interviews with all the women, guided by a theme list.³ The schedule included the following topics: women's experiences with their healthcare providers; understandings and explanations of their abnormal smear result; perceptions of their cervix; perceptions of control; and feelings about how this experience had changed their lives. All interviews were tape recorded and transcribed.

Text from the interviews was entered into the computer program NUDIST (Non-numerical Unstructured Data Indexing, Searching and Theorising).⁴ A coding framework was constructed based on the aims of the research, the interview schedule, and recurring themes. Each interview was also coded for socio-demographic data (age, marital status, education) and clinical data (diagnosis, treatment, time since treatment).

We assessed the validity of our findings by feeding them back to the women and discussing the results with gynaecologists.^{2 5 6} Because the analysis is based on small numbers, the research findings are not presented numerically.² Instead, terms such as most or many (more than half), several, and a few (usually two to five women) are used to provide an indication of the frequency of a particular interpretation or theme.

Results

The cytological abnormalities leading to referral ranged from inflammatory or wart virus changes through to cervical intraepithelial neoplasia stage 3. The women ranged in age from 19 to 70 years. Table 1 shows details of the sample of women interviewed.

Although women already had some relevant information, having an abnormal cervical smear result

Table 1 Sociodemographic details of women interviewed

Variable	No of women
Age:	
15-24	5
25-34	10
35-44	6
45-54	6
≥55	2
Education:	
Some secondary school	6
Completed secondary school	10
Trades or apprenticeship	0
Certificate or diploma	3
Bachelors degree or higher	10
Place of birth:	
Australasia	25
Europe	3
Other	1

prompted them to seek further information from books, pamphlets, the media, clinical staff, and family and friends. Women were often concerned or confused by the information they got. The most helpful material addressed their fears about the malignant and deadly potential of the abnormality and dispelled concerns about its sexually transmitted nature. Individual women required various amounts of information at differing levels of detail. Some felt that they needed information to feel in control of decisions about their gynaecological care.

Women often found it difficult to understand what doctors told them because it was too technical or because they were distressed by their abnormality and could not take in material presented in the consultation. One woman remarked: "You're sitting in their office and they're telling you things but you're not absorbing them. It doesn't seem to make a lot of sense to you. You go out and you think, 'what did they say about that?' You can't even remember because you are feeling so nervous and wondering what is going to happen. The gynaecologist was good but he was talking on a technical level and you can't get basic information out of them."

Women wanted to understand the rationale for treatment and the precautions recommended after treatment. One commented: "They didn't give me much information at all. Even as to what they were going to do He told me he was also going to do a biopsy I didn't know what to expect ... they don't tell you you're going to bleed or have a discharge afterwards. They give you a little sheet of paper and it says do not swim, do not bathe, do not wear tampons, etc ... but they don't tell you why you can't do these things."

Information needs

Although most women experienced some bleeding or discharge after treatment some did not expect to have heavy bleeding or discharge so they were concerned that these symptoms signified a problem. Few women had any conceptual framework for interpreting symptoms after treatment. For example, although one woman was told by her gynaecologist to contact him or his staff should she have heavy bleeding or discharge, she couldn't judge whether her experience was what was meant by heavy.

The doctors described as honest were those who expressed uncertainty about their own lack of knowledge and the long term outcome of the condition. Perhaps surprisingly, such candour enabled women to trust their doctors. Women were upset if their condition recurred and their doctors had not mentioned the possibility. In addition, several women learnt of discrepancies between the cytological and histological results and interpreted them as signifying that their condition was worsening. Doctors rarely explained such discrepancies.

Relationships with doctors

Practitioners who spent time, answered questions, and enabled women to make their own decisions were commended. Nurses in the specialist clinics and a few general practitioners were mentioned in this regard. Gynaecologists were often criticised because they did not respond to questions even during the consultation. Many consultations with the gynaecologists were perceived as rushed and lacking opportunities to ask questions. One woman said: "He was talking to me while I was up [in the colposcopy chair], and it is not conducive to thinking of what you're meant to ask As you get out of the chair, he starts writing his notes, you get dressed, and he opens the door for you. There's really no discussion at all—you virtually just do as you're told." Most women were not satisfied by being told "not to worry," and women who were satisfied spoke of how they preferred not to know too much and talked about trusting their doctor.

Inclusion in the decisionmaking process was important for many women. One said: "I went to the health clinic to discuss the options of having laser treatment, and their response was I would take their advice. So again you're left high and dry, unsatisfied."

Several women used factory metaphors to describe their experience of gynaecological treatment. "I would like it not to be a production line, in a slot, and that's as much time as you're given. You're not allowed to deviate. I would have liked to discuss other things peripheral to it but that were important to me but you just feel this is your time and you shouldn't deviate."

Gauging severity

Women used subtle cues in their practitioners' behaviour to gauge the seriousness of their condition. Some women maintained that they were not told enough at the time of their initial diagnosis and they were critical of what they perceived to be information gatekeeping by their doctors. Because women thought they were not being told everything, they used the doctors' non-verbal behaviour to assess the severity of their abnormality.

Most women were notified by their general practitioner of their abnormal smear result by telephone or letter. This is different from their usual experience, where communication with general practitioners outside the consultation is rare. Women took such written or telephone communication to mean that their condition was serious. Seriousness often equated with cancer and imminent death.

Many said that they initially believed that cervical abnormalities were uncommon because they had not heard of anyone else who had had one. If it was rare they assumed it must be serious. After they received the

diagnosis they found other women who had experienced similar problems, which sometimes allayed their anxiety. Because health promotion material on cervical screening does not address how screening prevents cancer, many women had not heard of abnormalities picked up by screening and concluded that any abnormality must be cancer. One commented: "You either get an all clear or you have got cancer."

Interpreting medical terminology

Most women did not understand the specific meanings of technical terms such as wart virus or precancer. In the absence of adequate discussion and explanation they had to rely on lay understandings of warts (on the hands), and they were confused by the use of laser for viruses. Women had not heard the term precancer before they had their cervical abnormality. When they first heard precancer many thought it was the same as cancer: "I didn't know anything about precancer; soon as it was linked to cancer I thought I'd had it."

Given the associations between precancer and cancer, and between cancer and death, some women spoke about how the diagnosis caused them to reflect on their own mortality. One commented: "You realise how important life is to you, and you want to live, you don't want to die. You want X amount of years ahead of you and you are not going to waste them."

Perceptions of the cervix

For many women a cervix gone awry affected their sense of their femininity: "I think the fact that it is part of your anatomy, you feel your femininity is affected I'm not so much a woman any more." Most women associated their cervix with reproduction and considered their reproductive capacity a defining feature of womanhood. Hence a cervical abnormality undermined their femininity because a cervical abnormality was evidence of reproductive disorder. Because they had never seen their cervix some women felt that they did not know it the way they knew other parts of their body. "If you've got a skin cancer you can love it. It's like a baby or a child, if it falls over you rub it's knee and make it better. If it's [the cervical abnormality] getting worse you can't see it."

In contrast, two women had observed their own cervix during colposcopy. One described how this visual knowledge helped her come to know her cervix. "I've seen my cervix on photographs [taken at colposcopy], I've also seen my cervix in smear testing, and I've felt it lots of times now. It's a bit odd but I feel like I've made friends with it now because I realise, especially after seeing it in the mirror, that it is part of my body that needs to be cared for."

Another woman described how seeing her cervix facilitated her understanding of her cervical abnormality. "Having the monitor helped a lot, because you could see it all. It was just a mass of discoloured cells, you could see it wasn't green and gangrenous Before I visualised it as horror, absolute horror. I imagined it as a big black mass of growth."

Many women felt that seeing their cervix, or a video of the procedure, would enable a better understanding of their cervical abnormality.

Explaining the abnormality

Most women sought to make sense of the alarming, and often distressing, diagnosis of a cervical abnormality in ways that were personally meaningful. They struggled with the implicit questions, "why me?," "why now?," and "will I get this again?" Some experienced their clinicians' approaches as dissonant with the meanings the abnormality had for them. In other instances clinicians enabled women to understand their abnormality in more positive terms than they had initially.

Stress and sexual activity were two common explanations women used to make sense of their abnormality. "I think it is probably significant that I got this, at this time ... because I was married and it was a very, very bad marriage and it was just very, very stressful for me and I think that is why it happened then." For this woman, her stress narrative made sense of why she developed a cervical abnormality at this time in her life.

The stress idiom enabled women to feel in control of their own risk of cervical cancer in two ways: by changing exposure to stressful events and by modifying their response to those events so that they did not feel stressed. Some women who used the stress explanation experienced the treatment as inappropriate because it did not address what they felt was the underlying problem.

Although most women mentioned associations between cervical abnormalities and sexual transmission, few accepted sexual transmission as an explanation for their condition. Instead, they developed ways of understanding their abnormality that were consonant with their own circumstances and world view. Doctors facilitated this: "I know the doctor said that normally it was with promiscuity that you got this sort of thing, but then he said you know nuns have had it, little old ladies or whatever."

Doctors' explanations were not always accepted, however. For example, several women associated the oral contraceptive with their abnormality. Doctors tended to reject the pill as a cause of women's cervical abnormalities. Nevertheless, a couple of women stopped taking oral contraceptives. Similarly, several women thought they had a general tendency towards warts, illustrated by a history of warts on their hands which they believed to be related to cervical warts. This belief persisted despite their doctors' explanations to the contrary.

A few did not seek a specific explanation for their abnormality, rather they considered it to have occurred because of bad luck or fate. These women most often found their clinician's approach to their abnormality acceptable.

Discussion

Previous research has found that women who have abnormal cervical smear results may experience psychological consequences including fears about cancer, sexual difficulties, changes in body image, concerns about the loss of reproductive functions, and fears about the gynaecological investigations and treatments.⁷⁻¹¹ Our research shows how women's interaction with healthcare services contributes to the psychosocial difficulties they experience. We found that most women did not receive the information they required.

We also found that women's accounts of their abnormality often conflicted with their clinician's approach. The problems in doctor-patient communication and differences in the world views of patients and their doctors are well known. It is tempting to suggest that the problems we identified could be overcome by improving the communication style of doctors. Such interventions, however, fail to address the structural factors which maintain the power imbalance between doctors and their patient and constrain any possibility for real change.¹² They also add to the time pressure under which most doctors now practise.

A colposcopy clinic necessarily involves the doctor interviewing the woman and conducting a gynaecological examination. The consultation is directed by the doctor, limiting women's capacity to be active participants. Indeed, women spoke of how they felt unable to ask questions in this setting.

Building on the work of Silverman, who instituted preadmission clinics for parents of children attending paediatric cardiology clinics,¹² we propose that outpatient colposcopy services develop a similar service for women referred for colposcopy. Such precolposcopy clinics could be organised for groups of women and facilitated by a doctor and a nurse. The structural impediments to women asking questions and getting the information they require would be reduced because the discussion group would be organised around the needs of women rather than the needs of doctors to ask questions and examine women. The staff could explain the meaning of medical terms, details of the procedure, treatment options, and the after effects women might experience as well as encouraging questions to explore other issues the women thought important. Women could also discuss their explanations for their abnormality and how they might deal with it in their daily life.

The session could include a video of the procedure explaining what happens and what the doctor sees during colposcopy. The women could then decide whether they wanted to observe their own cervix when they had colposcopy. The women would be better informed by the time they saw their doctor, and the doctor could spend less time providing information to individual women. Precolposcopy clinics would need to be evaluated to assess whether women's experiences of their gynaecological care are different if they participate in a discussion group. Silverman found that a paediatric preadmission clinic resulted in greater parental involvement.¹² If discussion groups are effective, they would be a simple, low cost method of meeting

Key messages

- Women who have abnormalities detected on cervical smears are confused, afraid, and find it difficult to get the information they require
- In this study women often assumed that they had cancer because they did not know that smear tests detected precancerous lesions
- Women needed information about the seriousness of their abnormality, the rationale for treatment, and the precautions recommended after treatment
- Because the abnormality involved the cervix many women felt their femininity was undermined
- Women used explanations such as stress, the pill, or sexual activity to make sense of their condition and through these explanations identified things they could do to reduce their risk of cervical cancer

women's needs for more information and support without placing additional burdens on doctors.

We thank the gynaecologists and their staff for allowing us to recruit women for the study; Jo Healy-North for helpful editorial comments; David Legge and Sandra Gifford for guidance in developing the study; and, most importantly, the women interviewed.

Funding: Australian Capital Territory Health Promotion Fund. AMK is supported by Public Health Research and Development Committee fellowship from the National Health and Medical Research Council of Australia.

Conflict of interest: None.

- 1 Kavanagh AM, Santow G, Mitchell H. Consequences of current patterns of Pap smear and colposcopy use. *Journal of Medical Screening* 1996;3:29-34.
- 2 Schmerling A, Schnatter P, Piterman L. Qualitative research in medical practice. *Med J Aust* 1993;158:619-22.
- 3 Britten N. Qualitative interviews in medical research. *BMJ* 1995;311:251-3.
- 4 Richards T, Richards L, McGalliard J, Sharrock B. *Nudist 2.3*. Melbourne, Australia: Replee, 1992.
- 5 Mays N, Pope C. Rigour and qualitative research. *BMJ* 1995;311:109-12.
- 6 Lather P. *Getting smart: feminist research and pedagogy with/in the postmodern*. London: Routledge, 1991.
- 7 Campion MJ, Brown JR, McDance DJ, Atia W, Edwards R, Cuzick J, et al. Psychosexual trauma of an abnormal smear. *Br J Obstet Gynaecol* 1988;95:175-81.
- 8 Posner T, Vessey M. *Prevention of cervical cancer: the patient's view*. London: King's Fund, 1988.
- 9 McDonald TW, Neuten JJ, Fischer LM, Jessee D. Impact of cervical intraepithelial neoplasia diagnosis and treatment on self-esteem and body image. *Gynaecol Oncol* 1989;34:345-9.
- 10 Quilliam S. *Positive smear*. London: Penguin Books, 1989.
- 11 Lerman C, Miller SM, Scarborough R, Hanjani P, Nolte S, Smith D. Adverse psychologic consequences of positive cytologic cervical screening. *Am J Obstet Gynecol* 1991;165:658-62.
- 12 Silverman D. *Communication and medical practice: social relations and the clinic*. Bristol: Sage Publications, 1987.

(Accepted 11 March 1997)

One hundred years ago

Is cigarette smoking a cause of death?

At a recent inquest on the body of a boy of 16 at Felling, near Gateshead, the jury found that he died from syncope due to nicotine poisoning caused by the excessive smoking of cigarettes, on which the coroner is reported to have said that there seemed to be quite an epidemic of such cases. Though there can be no doubt that excessive cigarette smoking, especially in youths, acts injuriously on the digestive and nervous systems, and, through the cardiac ganglia, affects the heart, it would be interesting to learn what were the symptoms which in the case quoted preceded

death, and how it was inferred that they were due to cigarette smoking. The coroner urged that the attention of parents should be called to the danger of their children smoking at too early an age. We do not certainly desire to see established in England the Burmese habit of children learning to smoke as soon as they can walk, but we venture to think that the coroner overstated the case when he said there seemed to be an epidemic of deaths from cigarette smoking. It would be satisfactory to have more authentic facts on this subject. (*BMJ* 1897;iii:1444.)