

CIN 1

Study of the current
attitudes of gynaecologists
and consumers to the
management of women
with histologically
proven CIN 1

Study of the
Current Attitudes of
Gynaecologists and
Consumers
to the
Management of Women with
Histologically Proven
CIN1

Edith Weisberg
Jane Ussher
Les Irwig
(Gynaecologists Survey)

Final Report

*Funded by the
Commonwealth Department of Health and Aged Care*

*Managed by
NSW Cervical Screening Program*

Acknowledgments

We would like to thank Ellen Minehan RN, research assistant at the Sydney Centre for Reproductive Health Research, for her untiring efforts in recruiting women, conducting the focus groups and carrying out the preliminary analysis of themes, and Sue Stuart RN, research assistant at the Sydney Centre for Reproductive Health Research, who worked with Ellen in recruitment of gynaecologists.

We would also like to thank Christine Whiting, FPNSW, for transcribing the tapes from the focus groups, and Wyeth Ayerst for allowing us to use its list of Australian gynaecologists.

This document has been produced with the support of the Commonwealth Department of Health and Family Services.

National Library of Australia Cataloguing-in-Publication data:

Study of the current attitudes of gynaecologists and consumers to the management of women with histologically proven CIN1, New South Wales, March 2000.

ISBN 0-7313-9738-X

Key Words: *CIN1, Cervical Intraepithelial Neoplasia Grade 1, gynaecologist, women, attitudes, management, observational, surgical, low grade abnormalities.*

Suggested Citation: Weisberg E, Ussher JM, Irwig L.

Study of the current attitudes of gynaecologists and consumers to the management of women with histologically proven CIN1, New South Wales, March 19, 2000.

Sydney Centre for Reproductive Health Research
Research Division of FPA Health
Published by the NSW Cervical Screening Program 2000.

Further copies of this report can be obtained from:

NSW Cervical Screening Program

PO Box 533

Wentworthville NSW 2145

Telephone: (02) 9845 8045

Facsimile: (02) 9845 8047

Email: nswcsp@wsahs.nsw.gov.au

Web page: <http://www.csp.nsw.gov.au>

Objectives Of the Study

The objectives of the study were to investigate the current practices of gynaecologists in relation to active treatment or an observational approach in the management of histologically proven CIN 1; and to determine the management preferred by women with this diagnosis. These results are to be used to inform a review of the recommendations for best practice of the NH&MRC as outlined in its Guidelines on the Management of Women with Screen Detected Abnormalities.

Background

The NH&MRC guidelines recommend a policy of either active or observational approach to the management of women with histologically proven CIN1. However certain technological elements and a medico-legal environment have had major implications for current management practice. There appears to be a reluctance by gynaecologists to practice the observational approach based on their belief that this approach is not safe. This makes a randomised study between active and observational management difficult for practical and logistic reason at the present time.

However, an observational study of current gynaecological practice can generate data about each management option. As the development of invasive disease will be uncommon in either approach, this study has chosen to document significant differences in outcomes of approach such as consumer or provider satisfaction, rather than attempting to show differences in histologic progression or the development of invasive disease.

Terms of Reference

- To establish the feasibility of a prospective study of the differences between active and observational management of histological proven CIN 1.
- To explore and document provider and consumer preferences and attitudes in relation to both approaches.

Contents

Introduction	1
Executive Summary	3
Gynaecologists Survey	7
Results	11
Discussion	23
Women's Focus Group Study	29
Background to the research on women's preferences	30
Methodology	32
Recommendations	65
Appendices	66
Scenario	66
Information for gynaecologists from the women's focus groups.	66
Gynaecologists survey on management options for CIN1	68
Tables	71
Abbreviations	72
References	73

Introduction

This study incorporated two distinctly separate protocols to determine current attitudes to the management of biopsy proven CIN1 lesions of the cervix:

a quantitative study of gynaecologists attitudes ascertained by means of a randomised survey, and

a qualitative study of women's attitudes through a series of focus groups for women.

The results of these studies are reported individually but the executive summary incorporates findings from both studies to indicate the similarities and differences between the two groups, their perceptions of each other and areas where better understanding would improve the outcome for women and gynaecologists.

The recommendations for these protocols are presented together towards the end of this document.

Executive Summary

Gynaecologists Survey- a quantitative study

One hundred and sixty-five (165) randomly selected gynaecologists within Australia were invited to participate in a survey to determine their current clinical management of women with histologically proven CIN1, their attitudes to observational management and how they involved women in the decisions regarding the management of their condition. The survey also investigated gynaecologists views about HPV DNA testing and their willingness to participate in management trials. Of the 165 gynaecologists approached, 151 agreed to participate and 132 responses were received, giving a response rate of 87%. The geographic distribution, age range and sex of the gynaecologists were representative of the profession throughout Australia.

Women's Focus Groups - a qualitative study

Eighty-one women (81). These women represented residents of eight different area health services within NSW and participated in the study through ten focus groups. The majority were Australian born (73%), married (60%) and had completed some tertiary training (51%). Transcripts from the focus groups were coded for content and theme and the themes were grouped. The themes were checked for variability and consistency and for the function and effects of specific narratives. The women's views and those of the gynaecologists are reported here under the two headings "women's concerns about CIN" and "treating CIN1 what do women want?". The women's' comments are in italics.

Response to case history

The gynaecologists and the women were given an identical scenario and asked their management preferences. The scenario was of a woman with biopsy-proven CIN1.

Thirty-one percent (31%) of gynaecologists would treat or recommend active treatment of a proven CIN1 lesion, 22% would recommend observational management and 47% would give both options without recommending a particular course of action.

Two thirds of the women opted for observational management both before and after the focus group.

Women's concerns following diagnosis of CIN

This issue was not canvassed with the gynaecologists

Women expressed a high level of anxiety associated with the diagnosis of CIN and indicated that they would like an appointment, with a medical practitioner, to discuss the diagnosis as soon as possible after receiving information, through the post or by telephone, about an abnormal Pap smear. Many women are confused about the distinction between CIN and cancer and the term "pre-cancerous" is often initially interpreted as "cancer". Some women have difficulty in understanding unfamiliar medical terminology. Most women seek information from a number of sources after an abnormal Pap smear report, which may either reduce or increase anxiety. Some women expressed a lack of confidence in medical procedures and many were ambivalent about medical advice.

A number of women had experienced feelings of shame and increasing anxiety after encountering judgmental practitioners who commented on their sexual behaviour or that of their partners in relationship to the presence of HPV. The association between "wart virus" and CIN raised issues of concern for women in relation to their own sexuality or that of their partners. Concerns about possible effects on future fertility were also raised.

Treating CIN - what do women want?

a. Providing options

More than half the gynaecologists surveyed provide women with both management options, observation or active management, but will also make a recommendation for a particular course of management. The remainder do not appear to direct the woman in a choice of management.

Women would like to be given information about the management options and want the opportunity to ask questions or seek further information from the clinician to reduce anxiety. Women would like the implications of both options to be discussed.

b. Observational approach

Only twenty-two percent (22%) of gynaecologists recommend observation of a proven CIN1 lesion. Gynaecologists would be prepared to provide observational management to women who refuse treatment or who request observation but the

major barriers to recommending observation were uncertainty about its safety, and uncertainty about the reliability of women to return for regular six monthly Pap smears.

Many women would prefer to have the observational approach initially but many would seek treatment if the lesion persisted for a variable period of time after initial observation. A number of personal factors will influence a woman's decision about management.

c. Active treatment

More than half the gynaecologists gave reasons for recommending treatment with the majority believing that women preferred treatment. Some gynaecologists believe it is the only safe option and others recommend treatment because they believe women cannot be relied upon to return for regular smears. Medico-legal issues were the impetus, in only a small minority, for recommending treatment.

Some women prefer active treatment because they want to be rid of the pre-cancerous cells immediately, or because they do not want to risk being in the small percentage where progression occurs.

d. Involving women in decision making

Almost two thirds of the gynaecologists involve the woman in the decision-making process for management. At least a quarter of the gynaecologists do not involve the woman in the management decision mainly because they believe that women expect the specialist to tell them what is best. Only three felt that women would be confused or unable to make a management decision. Five felt involving the woman in such discussions was too time consuming.

Women want to be involved in the decision making process, with the majority wanting to be able to discuss options with the clinician. Involvement in the decision process increases satisfaction and decreases feelings of unhappiness or anxiety.

Many women are pleased to be advised by the clinician regarding the most appropriate form of treatment but would still like to be given the opportunity to choose which option is preferable to them.

If a trusting relationship has been built up between the medical practitioner and the patient, with information given and an opportunity for discussion, women are more comfortable accepting the doctor's advice and feel more confident that it is the right option. Women would like their choices respected but would like the implications of each option explained.

Human papilloma virus DNA typing

Almost half the gynaecologists expressed interest in HPV DNA testing and would recommend the observational approach if the lesion did not contain an oncogenic HPV type.

This issue was obviously not raised by the women, although the implications raised by a diagnosis of HPV about their previous sexual behaviour and the judgmental attitude of a number of clinicians caused some women considerable distress.

NH&MRC guidelines

The majority of gynaecologists did not think the NH&MRC guidelines for the management of histologically proven CIN1 needed to be changed.

Willingness of gynaecologists to participate in further research

Fifty-nine percent (59%) of gynaecologists would be willing to participate in a research project involving CIN1.

The willingness of women to participate in research was not raised in the focus groups.

Gynaecologists Survey

Section Content

Background

Aims of the gynaecologist arm of the study

Methodology

Results

- Study population
- Provision of colposcopy services by gynaecologists
- Average number of colposcopies performed per month
- Response to the case history
- Reasons for recommending treatment
- Comments about active treatment
- Age and marital status of the women
- Treatment modalities
- Involving the woman in the management decision
- Comments on involving the woman in decision making
- What would make gynaecologists more likely to offer observational management?
- Comments on conditions under which gynaecologists would be prepared to offer observational management
- Change to the NH&MRC Guidelines for the Management of screen-detected cervical abnormalities
- Comments on NH&MRC guidelines
- Willing to participate in a management study of CIN1
- Comments

Gynaecologists Survey

Background

Reports from the Victorian Cytology Registry in 1995 indicate that approximately 6% of Pap smears will show some abnormality of squamous cells of the cervix (Mitchell and Higgins, 1996). Of these the majority will show either mild atypia (49.8%) or CIN1 (17.7%). The published literature suggests that only 11% of CIN1 lesions on average progress to a higher grade of CIN with the remainder either regressing or persisting (Oster, 1993). A recent Canadian study of women with a Pap smear prediction of CIN1 found that progression occurred to CIN11 or CIN111 in 18.6%, persisted in an additional 18.6% and regressed in 62.7% of cases (Duggan et al, 1998). Another study found a regression rate of 81% within 24 months, prompting the recommendation that the lesion be observed for 24 months before adopting definitive treatment (Lee et al, 1998).

The management of CIN1 is still controversial. In 1993 the NH&MRC produced guidelines for the management of histologically proven CIN1 lesions of the cervix (NH&MRC, 1994). These recommended women be appraised of the natural history of CIN1 lesions and be offered the option of follow-up with six-monthly pap smears (observational approach) or immediate treatment (active approach). The attitude of gynaecologists to the dual approach is unclear, nor is there any information on how many gynaecologists inform women of the two options and involve them in the decision about management. Equally, there is no information on the attitude of women to being offered the two options, their preference for management and even whether they desire to be involved in the decision-making process.

A small qualitative study in 29 women attending gynaecology clinics in Australia found that most women wanted to participate in decisions about their care but found it difficult to get the information they required from doctors (Kavanagh and Broom, 1997). They were confused by what the doctors told them, did not understand the terminology and felt unable to ask questions in the consultation. An UK review of

women's attitudes, knowledge and behaviour found that the receipt of an abnormal Pap smear result, and subsequent referral, resulted in high levels of distress owing to limited understanding of the meaning of the test (Fylan, 1998).

The role of DNA hybridisation for typing human papilloma viruses in the management of pre-malignant lesions of the cervix is still controversial. A large study in the Netherlands (>2,000 women) found an increasing percentage of oncogenic HPV types between smears predicting CIN1 (74%) and CIN3 (84%) (Meijer, 1994). In women with normal smears, 7% carry an oncogenic HPV type which decreases to 1.5% in women over 30. It has been suggested that using a combination of cytology and HPV screening could reduce the number of women who would require colposcopy and treatment for CIN1 if oncogenic HPV types were absent.

Aims of the gynaecologist arm of the study

The aims were to:

1. determine the current clinical management of women with histologically proven CIN1 by gynaecologists.
2. assess the attitudes of gynaecologists to observational management of CIN1 lesions and ascertain the evidence required by them to offer observational management, including the use of other technologies such as HPV testing to direct such management.
3. determine the extent to which gynaecologists involve women in the management decision for CIN1.
4. elicit the willingness of gynaecologists to be involved in a prospective clinical study of both management approaches.

Methodology

A questionnaire was developed by the research team which started with a case scenario of a woman presenting to the gynaecologist with a biopsy-proven CIN1 lesion of the cervix (Appendix 1). The questionnaire was designed to elicit their management strategies, the reasons for their management decision, the factors which would influence them to change their practice and their attitudes to women being involved in the management decision. The gynaecologists were given the opportunity to expand on their answers with open-ended comments.

The survey was piloted among a group of 12 gynaecologists which included the executive of the Australasian Society for Colposcopy and Cervical Pathology, after which it was modified accordingly before being implemented as part of the study.

As it was impossible to obtain a list of practising gynaecologists from the Royal Australian College of Gynaecologists and Obstetricians within the time frame of the study, a reasonably comprehensive list of 899 gynaecologists was obtained from a pharmaceutical company specialising in women's health products. Gynaecologists, whose names appeared on the list, were contacted by telephone by a research assistant experienced in recruiting medical practitioners, until 150 had agreed to participate in the survey. Reasons for refusal to participate were noted. This list was developed according to a previously determined randomisation system.

Once consent had been obtained, a questionnaire was sent to each participant along with a stamped addressed envelope for return to the Research Centre. Those gynaecologists who had not responded within four weeks were contacted again by telephone and asked to send in their reply.

Data was analysed using Epi Info 6, version 6.04c updated in October 1997. This is a word processing database and statistics program for public health. It was developed conjointly by the Centre for Disease Control and Prevention (USA) and the World Health Organisation (Geneva) to provide estimates of the proportion of gynaecologists who answered with particular responses.

Results

Study population

Of the 165 randomly selected gynaecologists 151 agreed to participate in the survey. Of the 14 who refused, three were involved in subspecialties, which did not include colposcopy. Two gynaecologists were semi-retired, three were away for two months, two were too busy to participate, one was not interested and two gave no reason for their refusal. One gynaecologist's responded in writing to complain that "this was yet another survey that would be used to criticise gynaecologists for their practices".

One hundred and thirty-two responses were received, giving a response rate of 87.4%. Two further replies were received a month after the data analysis was completed and these were not included.

The percentage of replies from each state was not directly proportional to the number of practising gynaecologists as per the data provided by the Royal Australian and New Zealand College of Gynaecologists. (RANZCOG). Victoria had the highest rate of responses (16.2%) while Tasmania had the lowest (4.5%). However, the difference in response rates between states was not statistically significant ($p = 0.06$). Details of the response rate of gynaecologists per state are given in Table 1.

The median age of the study group was 50 -59 years-old and the median years for when gynaecological qualifications were obtained was 1980-1989. One female gynaecologist did not give her age. The percentage of females who participated in the study (19.7%) was slightly higher than the percentage of practising gynaecologists in Australia who are female (16%) but the difference was not significant. Although proportionately, the number of female gynaecologists to male gynaecologists among the study population increased with younger age and a more recent year-of-qualification, the difference was not statistically significant ($p = 0.07$ and 0.5 respectively). Demographic details of the study group are given in Table 2.

Provision of colposcopy services by gynaecologists

The majority of respondents provide a colposcopy service (89.3%) with no significant differences ($p = 0.9$) between male gynaecologists (90.4%) and female gynaecologists (88.4%). The provision of a colposcopy service was significantly related to the age of the gynaecologist ($p=0.008$) but not the year-of-qualification ($p=0.14$). In the group aged 50-59 years-old, 40 of the 42 gynaecologists provided a colposcopy service.

Average number of colposcopies performed per month

The average number of colposcopies performed by individual gynaecologists varied markedly from a minimum of two per month to a maximum of 88 per month. The median number performed was 15 per month, with a mean of 19.5 (SD =16.4, SE = 1.5). The number of colposcopies performed on a monthly basis was significantly related to older-aged practitioners and greater time since qualification ($p=0.0001$) but not to the sex of the practitioner.

Response to the case history

The gynaecologists were asked what their advice and recommendation would be to a woman in whom they had confirmed a CIN1 lesion with colposcopy and biopsy. Of the 129 respondents 22.9% (29) would use a treatment modality or give both options for management but recommend active treatment. A further 8.5% (11) would give the management options and involve the woman in the management decision but at the same time recommend treatment. Seventeen gynaecologists (13.2%) would give the management options but recommend observational management and a further 8.5% (11) would involve the woman in the decision for management but recommend the observational approach. The greatest number (61 or 47.3%) opted for providing a woman with the management options and involving her in the decision without recommending one or other approach.

Table 1 Gynaecologist response rate per state

State	Number contacted	Number replies received	Number practising per state	Percentage replies per state
NSW	47 (13.1%)	35	357	9.8%
Victoria	60 (20.9%)	46	287	16.2%
Queensland	29 (16%)	28	180	15.6%
South Aust.	15 (17.2%)	12	87	13.8%
West Aust.	6 (6.8%)	5	88	5.7%
North. Terr.	3 (18.8%)	2	16	12.5%
Tasmania	1 (4.5%)	1	22	4.5%
No postcode	3 (1.8%)	3		
TOTAL	164 (15.8%)	132 (12.7%)	1037	

The recommendation to treat was significantly related to the number of colposcopies performed per month (p= 0.0001):

twenty-two of the twenty-four gynaecologists (64%) who perform between two and ten colposcopies would either treat the lesion or recommend treatment
 ten of fifty gynaecologists (20%) who perform between 12 and 35 colposcopies per month would likewise treat or recommend treatment
 one of the fifteen gynaecologists (6.7%), who perform between 40-88 colposcopies per month, would treat and he would perform a loop excision.

Table 2 Demographic details of study group

Age	Male (%)	Female (%)	Year of qualification	Male (%)	Female (%)
30-39	13 (10%)	9 (6.9%)	1996+	8 (6.1%)	4 (3.1%)
40-49	30 (23.1%)	9 (6.9%)	1990-95	10 (7.6%)	5 (3.8%)
50-59	38 (29.2%)	4 (3.1%)	1980-89	33 (25.2%)	9 (6.9%)
60-69	23 (17.7%)	3 (2.3%)	1970 -79	33 (25.2%)	5 (3.8%)
70 +	1 (0.8%)	0	1960-69	20 (15.3%)	3 (2.3%)
			1950-59	1 (0.8%)	0
TOTAL	105 (80.8%)	25 (19.2%)	TOTAL	105 (80.2%)	26 (19.8%)

Reasons for recommending treatment

Seventy-four (56.1%) of the total respondents gave reasons why they might recommend active treatment, with some giving more than one reason. Eighteen (13.6%) gynaecologists felt that treatment was the only safe option. More than half (42 or 56.8%) would recommend treatment because they believe women prefer treatment and 16 (21.6%) because they feel women cannot be relied upon to return for regular Pap smears. Only 11 of the respondents were concerned about the medico-legal consequences if they did not treat while six felt that referring general practitioners expected the women to be treated.

Sex of the gynaecologist and number of colposcopies performed monthly did not influence their reasons but their age significantly correlated to reasons for recommending treatment with 47 practitioners (64.4%) being 50 years-of-age or older ($p= 0.0001$). Thirty-two gynaecologists, who gave reasons for active treatment, would be prepared to recommend observational management if they could be sure it was safe and thirty-nine if DNA testing was available and the lesion did not contain an oncogenic HPV type.

Table 3 Reasons for recommending treatment

Reasons for recommending treatment	Number of gynaecologists	Percentage of total respondents
Only safe option	18	13.6%
Women prefer treatment	42	31.8%
Women cannot be relied upon to return for regular smears	16	12.1%
Concerns about medico-legal issues	11	8.3%
Referring GP expects woman to be treated	6	4.5%
Number of gynaecologists who gave reasons for treatment	74	56.1%

Comments about active treatment

Do not trust small CIN biopsy

It has become very obvious that even if Pap & biopsy show CIN1 there may still be CIN11 or CIN111 present

Transient population in Darwin-recommend treatment for itinerant population

Find women want treatment after talking to many women

If the lesion is large

Women prefer treatment especially if lesion persists

In my experience the grade of lesion is frequently higher when histology of excised material is obtained

Patients are anxious with conservative treatment

Persistent CIN1 is a worry

Spontaneous remission rate low. Why wait for CIN11?

Treatment to break cycle of colp /pap /abnormality /colp etc.

Difficulty in recalling some patients

Depends on findings - colp negative observe focal lesion ie biopsy excises

observe, extensive ablate with diathermy - all with patient input

All options are equally relevant and any decision to treat is based on all these issues

If woman is itinerant and can't be relied to have follow up

Women expect specialist to tell them what is best but modified by her particular circumstance

Observational approach time consuming and expensive (particularly as there is no rebate for HPV DNA testing) and ultimately at least one third will require treatment

One can never be certain - statistics only. If DNA testing is available-not sure

All factors involved in decision to treat

Treatment must be cheaper than long term follow up

Age and marital status of the woman

Most gynaecologists would not change their management procedure if the woman was under 25 years of age and only thirteen (9.9%) gynaecologists would change their recommendation if the woman was within this age group. Seven would no longer involve the woman in the management decision, three would not recommend treatment and three would no longer give pros, cons, and recommend observation.

Only four (3.1%) would change their recommendation if the woman was married. Two would no longer recommend treatment and two would no longer recommend observation.

Treatment modalities

Of the thirty-four gynaecologists who specified a treatment preference fourteen (37.8%) prefer loop excision or diathermy, while nine (24.3%) prefer laser ablation. Three gynaecologists gave two preferences.

Table 4 Management of biopsy-proven CIN1 by respondents

Management option	Number gynaecologists	Percentage of total respondents
Give option plus:		
recommend treatment	29	22.5%
involve woman, recommend treatment	11	8.5%
recommend observation	17	13.2%
involve woman, recommend observation	11	8.5%
Give options involve woman in decision	61	47.3%

Involving the woman in the management decision

The gynaecologists were asked their reasons for not involving women in the management decision. Thirty-three of the total respondents (25%) would not involve the woman in the decision, mainly because they believe that the woman expects the specialist to tell them what is best (25 or 18.9%). Only one felt a woman could not be expected to make such a decision. Two felt that giving a woman options was too confusing and five (3.8%) felt it was too time consuming. There were no significant differences by age, sex or year of qualification. Eleven gynaecologists who do not involve the woman in decision making always offer both management options. Thirteen gynaecologists who believe women expect the specialist to tell them what to do would recommend the observational approach if a woman refused treatment. Only four gynaecologists, who do not involve the woman in the management decision, always offer the observational approach. Fourteen gynaecologists who do not involve the woman in decision-making would recommend the observational approach if they could be sure the woman would return for regular Pap smears.

Table 5 Reasons why gynaecologists do not involve women in decision making

Reason for not involving women in decision making	Number of gynaecologists	Percentage of total respondents
Cannot expect women to make such a decision	1	0.6%
Women expect the specialist to tell them what to do	25	18.9%
Giving women options is too confusing for them	2	1.5%
Takes too much time	5	3.8%
Other	6	4.5%
Number of gynaecologists who do not involve women in the decision for management	34	25.6%

Comments on involving woman in decision making

Involve women in the decision but recommend active treatment and then follow up.

Discuss pros and cons of both options and involve woman in decision making if they sensibly can

From talking to many women they expect specialist to tell them what is best

Most women seek treatment - find smears +/- colposcopy unsettling, intrusive and thus seek treatment provided there is biopsy proven CIN

Obviously each patient is to be treated as an individual and should understand what is going on

What would make gynaecologists more likely to offer observational management?

In reply to the question "what circumstances would make you more likely to recommend the observational approach?" 84 responses were received (54.5% of the total respondents). Seventy-two of these respondents stated that they always offered observational management.

Circumstances identified that would make a gynaecologist more likely to recommend observational treatment included:

if they could be sure it was safe (52 of 67 respondents 39.3% of total respondents)

If DNA testing were available and the lesion did not contain an oncogenic HPV type (65 out of 81 respondents being 49.2% of total)

if they could be sure the woman would have regular six-monthly Pap smears (54 of 73 respondents or 40.9%).

Only two of 80 respondents (1.5%) would not agree to observational management if the woman requested it, and six of 69 respondents (4.5% of total respondents) would not recommend observational management even when the woman refused active treatment.

The answers given for the situation where a woman requested observational management were: forty-three would agree if they could be sure it was safe, forty-six if DNA testing was available and no oncogenic HPV was demonstrated and forty-five if they could be sure the woman would return for regular Pap smears.

Comments on conditions under which gynaecologists would be prepared to offer observational management

May be an option only if I could be sure it was safe

Only if observation involved colposcopic biopsy as well in follow up. Smears are unsatisfactory for follow up and may undervalue the importance of follow up to the patient

No previous abnormal smears

Only if negative colposcopy

No lesion on colposcopy or removed by the biopsy

If a small lesion and the biopsy is adequate

If following discussion and the lesion is not extensive and the woman is happy to have observation

The patient wants a normal smear. Consider the cost of no long term follow up if woman treated

No previous abnormalities on regular screening or young woman with first abnormal smear

If CIN1 does not progress and the woman is reliable for follow up

DNA testing may only identify the most prominent types of virus present. It has a long way to go to prove to a woman that it is a safe surveillance method

DNA testing as an indication for colposcopy is probably going to be relevant but too early to be sure of place of DNA testing

DNA testing not readily available and therefore cannot be considered an option in treatment modalities

Change to the NH&MRC Guidelines for the Management of screen - detected cervical abnormalities

Almost two thirds of gynaecologists (87 of 129 or 65.9% of total respondents) do not think the NH&MRC guidelines should be changed. Eight of 45 respondents (6.1%) felt they should only recommend active treatment, seven (5.3%) wanted a recommendation for observational treatment unless the woman specifically wanted treatment, eight (6.1%) wanted a colposcopy recommendation only for women who had two consecutive CIN1 Pap smears and 13 (9.8%) wanted DNA testing for all CIN1 Pap smears. The remaining six (4.5%) wanted colposcopy recommended only for women with oncogenic HPV types on DNA testing.

Table 6 Circumstances that would make gynaecologists more likely to recommend observational treatment

Circumstances that would encourage recommendation of observational treatment	No. of gynaecologists with a yes response (% of respondents to question)	Number of respondents to statement	% of total respondents with a yes response
If I could be sure it was safe	57(85.1%)	67	43.2%
If DNA testing for oncogenic wart virus types were available and the lesion did not contain an oncogenic HPV	65(80.3%)	81	49.2%
If the woman requested it	78 (97.5%)	80	59.1%
Always recommend observation	16(27.6%)	42	12.1%
Always offer both options	72 (85.7%)	12	54.5%
If the woman refused treatment	63 (91.3%)	69	47.7%
If I could be sure the woman would have regular 6 monthly Pap smears	54(74.0%)	73	40.9%
Other	15		11.4%

Comments on NHMRC guidelines

Should recommend either active or observational only

Colposcopy

Need to be sure of place of DNA

NHMRC guidelines are irrelevant, intrusive to gynaecological practice

NHMRC guidelines are irrelevant and NHMRC involvement unnecessary if you are into specialist gynaecology practice!

Pap should be 3 months as women miss follow up-6 months is too long

There has to be scope for discretion in management

Should include an opt out of active treatment

Willing to participate in a management study of CIN1

The number of gynaecologists willing to participate in a research project involving CIN1 is 76 of 129 (58.9%).

Comments

Would want CME points

Discussion

Content Summary

- The study population
- Design of the questionnaire
- Management of the biopsy-proven CIN1 lesions
- Involving the woman in the management decision
- Factors that would influence gynaecologists to recommend observational management
- NH&MRC guidelines
- Conclusions

Discussion

The study population

The difficulty in obtaining a comprehensive list of gynaecologists in active practice in Australia is reflected in the unequal representation from different states and territories. RANZCOG has been forced to limit its distribution of the lists of fellows of the College because of the number of recent surveys involving their fellows. For the authors of this paper to have waited for the opportunity to carry out the survey through the College would have caused a long delay. Consequently we used a list obtained from Wyeth Ayerst which was incomplete and contained the names of only 899 gynaecologists through out Australia, some of whom appeared under two different locations. This made the randomisation of the contact list difficult. RANZCOG lists 1055 practising gynaecologists in Australia for May 1999 (RANZCOG, 1999). Although the proportion of gynaecologists surveyed in each state varies with Tasmania and Western Australia being under-represented, there is representation of all states and the differences are not statistically significant. However, since the ACT has the same postcode as NSW, ACT gynaecologists are included in NSW figures.

The sex ratio of males to females completing the survey was compatible with the number of practising male and female gynaecologists in Australia in May 1999 (RANZCOG, 1999).

The response rate of 87% was exceptionally high for a survey of this type and compares favourably with the survey of gynaecologists by Ward and Wain (1999) which looked at advice given to women with abnormal Pap smears with regard to smoking and achieved a response rate of 73% (Ward & Wain, 1995). An Austrian survey of the practices of all Departments of Gynaecology and Obstetrics in Austria in regard to diagnosis and management of cervical intraepithelial neoplasia (CIN) achieved a response rate of only 55% (Banher-Todesca and Gitsch, 1997).

A large Australian survey of GPs examining the impact of the policies of the organised

approach to preventing cancer of the cervix achieved a response rate of 67% (Ward, Donnelly and Holt, 1998).

As this study is the consolidation of surveys from a significant representation of gynaecologists practising in Australia, covering sex and age ratios, the results of this report should make it of use, in a general form, to all Australian gynaecologists.

Design of the questionnaire

The questionnaire was designed with multiple choice answers, to minimise the time required by busy practitioners although the multiple-answers-to-questions design of the questionnaire increased the difficulty of analysing the data. The questionnaire gave participants the option of ticking multiple answers and provided an opportunity for expansion of these answers by inviting comments.

The very brief case study was used to ensure that all respondents were giving their management procedures for identical conditions. Providing clinical vignettes has been used extensively to study decision making in medicine though doubts have been cast on the validity (Curtis et al, 1997). Clinical vignettes, or simulated patient management problems, have good construct and content validity but they often overrate performance compared to actual practice - the social desirability phenomenon (Jones, Gerritty and Earp, 1990). Assessment of opinions, attitudes and behaviour can differ when actions are directly observed (Sandrik, 1995).

Management of biopsy-proven CIN1 lesions

Twenty-three percent (23%) of the sample ticked two or more options in the management question (Table 3). Almost half the sample would give both options and not express a preference. Over eight percent (8.5%) would give options and involve the woman in the decision but state their recommendation for either active treatment or observation.

Many gynaecologists, who recommend treatment, are concerned about the safety

of observing a cervical abnormality, They are distrustful of the reliability of Pap smears and the adequacy of biopsies to ensure that a higher grade of CIN is not present. A number will base their decision to treat on the size of the lesion. Some question the belief that a high proportion of CIN1 lesions will regress and are alarmed by persisting CIN1 lesions.

The gynaecologists who recommend treatment are convinced that women prefer treatment. These practitioners express anxiety about the likelihood of women complying with follow-up regimens under the observational pathway. This is not without basis as studies overseas indicate that up to 20% may default from follow-up (Shafi et al, 1997; Woodrow et al, 1998). Medico-legal issues and the expectations of the referring GP do not appear to have a great influence on whether treatment is recommended.

Involving the woman in the management decision

Eighty-three gynaecologists (62.9%) indicated that they involve the woman in the management decision. Forty-six said they didn't involve the woman and almost half of these practitioners (34 or 25.8%) gave no reason for not involving the woman. The main reason that was given by respondents, for the failure to involve the woman, is their belief that women expect the specialist to advise them on the best option. Time factors and the ability of the woman to make such decisions were not major influences.

There were some minor anomalies in the answers. Eight gynaecologists, who said they would give a woman with a biopsy proven CIN1 the management options and involve her in the decision, also gave reasons for not involving the woman in decision making. The majority of respondents (28 or 82.4%) who would not involve the woman in the management decision are the ones who recommend active treatment and half of these respondents (14) are also of the group which believes that women expect the specialist to tell them what is best. Only six gynaecologists, who would recommend observational treatment, would not involve the woman in the decision.

Factors that would influence gynaecologists to recommend observational management

A variable number of gynaecologists answered each segment, relating to factors that would influence them towards recommending observation. Safety of the observational approach was confirmed as a major concern in this segment of the questionnaire. However, apart from exploring views on DNA technology this questionnaire provides only minimal information on how they would feel reassured about the safety of the observational approach. From the limited number of comments made in this section, size of the lesion appears to be a definitive factor in the recommendation of observation. A number of comments indicated that as long as the lesion was small or the biopsy removed it the observational approach would be appropriate.

Just over one third of gynaecologists would be prepared to recommend observation if they could be sure the woman would return for regular six-monthly Pap smears. Of the six who would not recommend observation, even if the woman refused treatment, three would be prepared to offer it if they could be sure that the woman would return for regular six monthly Pap smears. However, the questionnaire results did not give information about how gynaecologists would determine whether a woman could be relied upon to return for regular Pap smears and it is likely that this decision may be made as a value judgement, possibly based on previous experiences.

Almost half the respondents felt that the availability of DNA HPV typing would be useful in determining which women could be offered observation of their CIN1 lesion, although the place of DNA testing as part of a triage for determining management, is still controversial (Richart et al, 1998).

NH&MRC guidelines

Almost two thirds (87) of gynaecologists do not believe the NH&MRC guidelines for the management of CIN1 require changing however, only 57 of these practitioners

actually appear to follow the guidelines by giving women both management options and involving her in the decision making process. A similarly small number want only one management option of either active (8) or observational (7) management. The incorporation of the use of DNA technology in the guidelines was recommended by only four gynaecologists.

Conclusions

The majority of gynaecologists in Australia adhere in part to the NH&MRC guidelines on management of biopsy-proven CIN1. However, there are still a substantial number, who need to be convinced of the safety of the observational approach and the research was unable to determine what would be required to convince them. There is interest in the possible application of DNA technology to assist in decision-making in the management of low grade lesions of the cervix.

A number of gynaecologists believe women want treatment and therefore do not offer both approaches and some do not feel confident that women will return for follow up if they recommend the observational approach. It is unclear how they would decide which women were more likely to return than others. There does not appear to be any impetus from Australian gynaecologists to change the NH&MRC Guidelines. A substantial number of gynaecologists would be prepared to be involved in further research relating to CIN1 lesions of the cervix.

Women's Focus Group Study

Background to the research on women's preferences

Methodology

- Design
- Procedures
- Participants: composition of focus groups
- Analytic strategy
- Results

Detailed results of the interviews

1. Women's concerns about CIN

- a) Negative reactions to a diagnosis of CIN
- b) Is CIN Cancer?
- c) Difficulty in comprehending medical information and advice
- d) Absence of information increases anxiety
- e) Provision of information reduces anxiety
- f) Women seeking information for themselves
- g) Mistrust of the medical profession
- h) Mistrust of technology
- i) Feelings of isolation
- j) The stigma of an abnormal pap smear
- k) Concerns about fertility

2. Treating CIN: What do women want?

- a) Women want to be informed about CIN and about treatment options
- b) Women want to discuss the options and be able to choose
- c) I'm happy to take advice from the doctor
- d) Confidence in the medical profession leads to advice being followed
- e) Women wanting observation
- f) Women wanting intervention
- g) Self help and alternative treatments

Women's Focus Group Study

Background to the research on women's preferences

Methodological issues in research on issues relating to cervical screening

Previous research examining women's attitudes and awareness of issues associated with smear testing, abnormal smear results, and cervical cancer has in the main been of a quantitative nature, using questionnaires to collect information on attitudes or knowledge about this particular area of health (Grace, 1985; Orbell & Sheerab, 1998; Yu & Rymer, 1998).

While this research is of interest in giving us statistical data on the prevalence of particular attitudes, beliefs, or preferences for treatment, it does not allow us to examine the complexities in women's responses to questions asked of them, or the way in which apparently contradictory responses can be obtained from the same woman, or group of women. For example, Ferris et al reported that when asked how they would like a low grade cervical abnormality treated, 58.4% of women said they would prefer a repeat smear, 7.3% DNA testing, 20.6% cervicography, and 51% colposcopy. However, we do not know why women made each of these choices, their levels of satisfaction with each choice and whether there were any circumstances when they would choose a different option. In a study which examined women's awareness of smear testing and cervical cancer, Yu and Rymer (1988) reported that 80.5% had had a smear test, 66.9% thought the test was 'no problem', and 91.7% thought that cancer could be treated if detected early enough. However, there was no other information or insight into women's experiences of cervical screening or abnormal smear results, nor any information which placed these responses in the broader context of women's lives.

Qualitative research, in contrast, allows us to examine the richness and complexity of women's experiences, and allows women to explore their responses to particular questions in discussion with the interviewer. Qualitative methodologies are increasingly being used in women's health research, both in combination with quantitative methods, and as a method in their own right (Malson, 1996; Ussher, 1999; Willig, 1999; Murray & Chamberlain, 1999).

There has been a limited amount of qualitative research in the area of cervical cancer. Kavanagh & Broom (1977) conducted a qualitative interview study with 29 Australian women who had been told they had had an abnormal pap smear,

to examine the way women understood risk in relation to cervical cancer. Fish & Wilkinson (1999) interviewed lesbian women and examined their experiences of cervical screening. This study was undertaken based on the observation that this group is often overlooked in health campaigns as heterosexual sex is seen as a risk factor in cervical cancer.

However, there are many questions still unanswered, and further qualitative research in this area is necessary to aid our understanding of the many reasons why women respond in the way that they do to health campaigns, medical information, and individual advice about treatment.

The qualitative arm of this research project was conducted in order to assess women's attitudes to treatment options for histologically proven CIN1 lesions of the cervix and potential outcomes, including their desire to be involved in the decision making process.

Methodology

Design

Ten focus groups were conducted to examine women's experiences and treatment preferences for abnormal pap smears. Conducting interviews in focus groups allows for discussions between women, and for the examination of questions and issues in a context where mutual experience can elicit feelings of trust, prompt memories, and encourage sharing of experiences.

Procedure

Women were recruited to join a focus group if they fell into one of three categories:

- women who had active treatment for a CIN1 lesion of the cervix
- women who had observational management of a CIN1 lesion
- women who had never had a report of an abnormal Pap smear.

The women were divided into 10 groups on a geographic basis. The groups included women from each category as pilot work had shown that mixed groups stimulated a more robust discussion, with sharing of a variety of experiences.

Contact with potential group participants was achieved through the following strategies:

- referral of women by members of Area Health steering committees of the NSW Cervical Screening Program
- women's health nurses
- women who had attended for colposcopy at gynaecologist or FPA Health clinics
- distribution of fliers at FPA Health clinics
- advertisements in local community newspapers

Women who inquired about the study were given a brief explanation of the aims of the focus groups and briefly interviewed, by the research assistant, to determine their Pap smear history. Women considered eligible candidates for the focus groups were asked their availability to attend group meetings and were sent a more detailed information sheet through the post. Women were deemed to have given informed consent to the study if they attended a group session.

Women attending focus groups were given the same scenario as the gynaecologists as well as information on what was meant by observational and active management. (Appendix 2). Prior to participating in the focus group and again at the end of the session, they were asked to indicate their management preference. The women were then engaged in a discussion about their experiences of abnormal pap smears,

and any subsequent treatment, using a semi-structured interview. The questions focussed on the women's previous experiences; their reactions to abnormal pap smears; whether or not they had been given any choice or option for treatment; their views about any treatment they had had; and whether they would want things to be different in future. All discussions were taped and fully transcribed.

Participants: Composition of focus groups

Ten focus groups were held at a variety of locations in NSW. A total of 81 women participated and represented eight NSW Area Health Services (Table 7). Of this group, 30 women had only had normal Pap smear results, 23 had observational management of CIN1 and 28 had received active treatment.

Table 7 Number of women participating in focus groups from different Area Health Services in NSW

Area Health Service	Number of women	Percentage
Hunter	7	8.6%
Central Sydney	19	23.5%
Northern Sydney	12	14.9%
South Western Sydney	9	11.1%
Western Sydney	2	2.5%
South Eastern Sydney	17	21%
Illawarra	14	17.3%
Central Coast	1	1.2%

The mean age of the women was 36 years with a range from 19 to 55 years and a median of 37 years. Eleven (13.4%) women had completed school up to or below school certificate level (Year 10), 7 had completed to Year 12 and 45 (54.9%) had some post-school training below a tertiary degree. Twenty-seven (32.9%), almost one third had a tertiary degree (Table 8). The older women were less likely to have achieved higher levels of education ($p=0.0001$)

Table 8 Educational status of women participating in focus groups

Education level	Number	(%)
Primary	2	(2.4%)
Some secondary	3	(3.7%)
School certificate (year 10)	6	(7.3%)
Completed high school (year 12)	7	(8.5%)
Tertiary (no degree)	14	(7.1%)
Trade	4	(4.9%)
Certificate or diploma	17	(20.4%)
Tertiary degree	27	(32.9%)
Other	2	(2.4%)

The majority (60, 73.2%) of women were Australian born and only three were Aboriginal or Torres Strait Islanders. Of the women born overseas, four came from non-English speaking countries (Denmark, France, Greece and Jordan). Just over half the women (50 or 61%) were married (Table 9) and more than a third (31 or 37.8%) were childless. The average number of children in a family was 1.3, ranging from 0 to 4 children.

Table 9 Marital status of women participating in focus groups

Never married	19	(23.2%)
Married/de facto	50	(61.0%)
Separated	5	(6.1%)
Divorced	8	(9.8%)

Over half the women (48 or 58.5%) worked either full-time or part-time and 17 (20.7%) were occupied with home duties. The more highly educated women were more likely to be working either full-time or part-time ($p= 0.0001$). Very few were on social security (5 or 6.1%).

Of women who had a previous diagnosis of CIN1 on Pap smear, 49% had the smear within 18 months of participating in the focus groups (Table 10)

Approximately two thirds of the women opted for observation (53 or 64.4%, prior to the group and 56 or 68.3% after the discussion). Seven women who chose active management prior to the focus group changed to observational management at the end of the group while four of the women who had originally chosen observational management changed their preference to active management.

Table 10 Year of abnormal Pap smear for women with CIN1 who participated in the focus groups

year	number
1991	2
1992	3
1993	1
1994	2
1995	2
1996	4
1997	1
1998	9
1999	5

Analytic strategy

Thematic narrative analysis was used to examine the interviews. Narrative analysis assumes that the stories told do not simply mirror a world 'out there', but that they are constructed, creatively authored, rhetorical, replete with assumptions and interpretation (Reissman, 1993, p5). From a phenomenological perspective it was assumed that narratives act to constitute experience, meaning and reality, but that it is in the telling that we make sense of phenomena (Young, 1987) and are assumed to be doing particular 'identity work'. Thus the narratives served to help construct an account that was consistent and compatible with the women's experiences of cervical problems, their relationship to other women in the focus groups, and other factors such as age, social class and experience of illness.

This is not to say that the women did not experience the feelings, or events that they reported. The meanings and value the women gave to their experiences must be seen in the context of their current subjectivity, and the material-discursive-intrapsychic (meaning? Ed) factors that are associated with their experiences (Ussher, 1999). However, narratives do not simply 'speak for themselves' (Reissman, 1993, p22). They are both interpretive and open to interpretation. As every text is open to several readings or interpretations, our analysis is aiming at 'believability, not certitude, for enlargement of understanding rather than control' (Stivers, 1993, p. 424).

The approach to the coding and reading of the interviews was partially grounded, that is, we were 'open to the data', but we were also influenced by knowledge of previous research on cervical cancer, as well as our own personal experiences and professional backgrounds.

In terms of the current study, several issues are relevant here. The interviewer, Ellen Minehan, is a health professional who works for family planning and has clinical experience related to cervical issues. The two grant-holders were involved in the qualitative component of the study, supervising the interviews and coding the data, are health professionals. Dr Edith Weisberg is a medical doctor with extensive clinical experience in the area of cervical screening, and Professor Jane Ussher is a clinical psychologist who has not worked clinically in this particular area but, has personal experience of CIN. While each stage of the

research was discussed and agreed upon by all parties the initial reading and detailed coding of the data was conducted by the interviewer, Ellen Minehan, and Jane Ussher. The analysis and interpretation of the data presented here was conducted by Jane Ussher as the non-interviewer following discussion with Ellen Minehan and Edith Weisberg.

After transcription, the interviews were coded, line by line, according to content (descriptive category) and theme (interpretation or meaning). Themes were then grouped together. The resulting themes were then checked for emerging patterns (variability and consistency) and for the function and effects of specific narratives. The interpretation of these themes was conducted by a process of reading and re-reading, as well as reference to relevant literature and consultation with colleagues.

Results

The comments received through the focus groups have been summarised and reported in the earlier section titled Executive Summary. These comments and the conclusions drawn from them are published here in-full.

Detailed results of the interviews

As in the earlier section, we have reported on the interviews under the two main themes:

Women's concerns about CIN and Treating CIN: What do women want?

However, we have also included a number of sub-themes.

1. Women's concerns following diagnosis of CIN

Women expressed a number of concerns across the different groups, and these have been grouped under the heading 'women's concerns following diagnosis of CIN'. The majority of women reported an initial negative reaction to a CIN result, as is documented below. The reasons why women reported reactions such as shock or fear on getting a diagnosis of CIN are explored, which includes, concerns that a CIN diagnosis means cancer, difficulty in comprehending medical information and advice, the finding that absence of information increases anxiety, provision of information reduces anxiety, mistrust of the medical profession, mistrust of technology, feelings of isolation, the stigma of an abnormal pap smear, and concerns about fertility.

a) Negative reactions to diagnosis of CIN

As has been found in previous research (Fylan, 1998; Kavanagh & Broom, 1998), the majority of women, across all groups, reported that their reaction to a diagnosis of CIN was one of shock or fear. This illustrates the powerful emotional impact of an abnormal pap smear result.

Just having a 'very simply abnormal pap smear', that sort of news is quite terrifying. *Group 4*

Well I had an atypical. And it's pretty scary. *Group 3*

Fear, worry. Think I was 19 when it happened. *Group 5*

I went early in the year and had a Pap smear which came back CIN1, and so he rang on my mobile, "come and see me", and of course I freaked out and started to cry. *Group 6*

I was scared stiff, because I wanted to see a woman, but I couldn't get to see a woman anywhere...you know it was months and months, and so I was really scared. *Group 4*

Women regardless of whether they received the information in the post, by telephone or in person reported this reaction of fear. There was a slight trend for women to feel more concerned if they had to wait before discussing the diagnosis with a clinician, suggesting that information through the post, or a telephone call to ask women to come in for a visit may result in an increase anxiety.

I just got a thing in the mail saying there was an abnormality and I died a thousand deaths until I could get on the phone the following day - I was terrified, absolutely terrified. *Group 1*

No - other things happen, always seem to happen on Friday when you've got all weekend to worry about it. *Group 1*

Anxiety was also increased if women had to wait for any length of time to discuss the diagnosis in person.

And you can't get an appointment with the nurse or the doctor for another week or so - so it's ticking over in your head - about what's going on - what's wrong with the Pap smear. *Group 1*

Conclusions

1. Doctors and clinic staff involved in the diagnosis and treatment of CIN need to be aware of the high level of anxiety associated with a diagnosis of CIN.
2. Women should be given an appointment to discuss the diagnosis as soon as possible after receiving information about an abnormal pap smear through the post or by telephone.

There are a number of reasons why women react with anxiety to the information that they have an abnormal pap smear and are discussed in detail below:

b) Is CIN cancer?

One of the major themes which emerged was confusion surrounding the distinction between CIN and cancer. Many women, when given the news that they had CIN, or pre-cancerous cells, reacted as if they had been told that they had cancer - something which has also been reported in previous research (Kavanagh & Broom, 1998).

And I was...you always think of cancer. And so I got scared then.
Group 8

Because I think there's a lot of fear in the word. Pre cancer...I think the word cancer would put the wind up anybody. And I think that's half the trouble...it took me a long time to calm down after discovering that I had "major pre-cancer cells", because that's what I think it went into. And it took me a good 6 months to realise, OK it's not cancer, it could happen later.... But I think there's a lot of fear...

You're used to thinking "cancer is death, do something" you know?
Group 5

The majority of the women reported reacting this way when they were first told about the CIN, either by post or in person, and was more likely to be the case if they were not given information about CIN and about possible treatments at the time of the initial diagnosis.

I was just on a roller-coaster. It was just...they just didn't tell me anything, and then we get this letter, and I'm shaking to death. But it was just the lack of information, and the first thing you think is "oh my God, its cancer". *Group 9*

I'd only been in Australia about 4 months and I had my very first pap. And I got my letter on a Friday evening, and I imagined the big C word abnormal, pre-cancerous cells. *Group 4*

For a number of women, the fear of cancer was greater because of there being a history of cancer in the family or because of knowing about other women who had had cancer.

I just got a thing in the mail saying there was an abnormality and I died a thousand deaths until I could get on the phone the following day - I was terrified, absolutely terrified. A friend of mine at work, she had a Pap smear just because she wanted to have a baby - she was about 30 - and she was dead a year later - that was a few years before I got my thing in the mail - so I was terrified. *Group 1*

I have a situation with my neighbour, who did die. She had something a little more advanced than that, and she decided she wouldn't have surgery. And she was going to beat it with natural therapy and probably was thinking of health farms, when she lost her life. She let it go too far, and when she got well enough to say yes, help me they couldn't help her. So no I don't think....I would certainly be healthy, but I wouldn't do that as the only alternative.
Group 3

In previous research (Fylan, 1998), the beliefs that smear tests detect cervical cancer or that an abnormal smear means cancer, have been found to deter women from attending for screening, for fear of being given such a diagnosis. This has serious implications for both prevention and treatment of cervical cancer.

Conclusions

1. Doctors should be aware of the confusion between CIN and cancer in the minds of many women, and how the term 'pre-cancerous cells' is often initially interpreted as 'cancer'.
2. Clear information about CIN and cancer can alleviate this confusion.
3. Women who have personal experience through family or acquaintances of CIN developing into cancer may be more anxious about observation, and that should be taken into account.

c) Difficulty in comprehending medical information and advice

For many women the difficulty in comprehending medical information was a major source of anxiety and confirms previous research (Fylan, 1998) which reported that limited understanding of the meaning of the smear test was a cause of high levels of distress in women. In the present study, this appeared to be specifically related to medical terminology or to technical terms.

For other women, the information that pre-cancerous cells do not necessarily develop into cancer, and can thus be safely observed, was a source of anxiety or confusion.

I'm quite comfortable with them just keeping an eye on it, and fortunately the next one I had was clear but...the thing that confused me was, and if it is that situation that it's just turning and it could move on, you would think that it would just stay that way and not get worse, rather than completely revert back

Yeah well she explained it but I couldn't understand that it would actually go away of it's own accord, I didn't believe that something could just disappear. So I didn't know why I didn't go for the laser at the time when I really didn't believe that something could just, like a growth, could just go back in, but...it did. *Group 1*

If women trusted their doctors and were given information, this helped them feel reassured and often allayed their anxiety.

Yeah, I just couldn't, my mind just couldn't get around how it could disappear, but yeah, I suppose I trusted her enough, that, I mean, she knew better than me to say yes, it can do that, so I was more fearful about having the laser treatment than I was about having it watched.

Because it's an abnormality and I'm not in the medical profession I had very little knowledge about it - but I was having the reaction as I was being told about it. Something that I was just sitting there - this is the result what it means is - and went into it. So I just sat there and listened for a little bit- got a little bit more information about it - worry went out the window and went from there.

Conclusions:

1. Doctors should be aware of the difficulty women, who do not have a medical background, may have in understanding technical and unfamiliar terminology.
2. Some women have difficulty in comprehending, or believing that CIN cells will revert to normal, and doctors should take this into account when giving information and advice.

d) Absence of information increases anxiety

One of the most consistent themes to emerge in the interviews was of women wanting information to be given to them by the doctor or clinician. Women who weren't given information, or what they felt to be an adequate explanation of CIN and treatment options, reported that they felt anxious and confused.

It's that lack of a good explanation right from the word go that was stressful for me. *Group 1*

It was about...it was going on for near over a year. But I had no idea, she made it out like it was nothing. I wasn't basically told anything, or explained anything to me. And it was really scary.

Group 4

For some of the women, being given written information or a pamphlet wasn't sufficient. It didn't give them the opportunity to discuss treatment with the doctor or to have any ambiguities clarified. As one woman said:

I took one of those, (pamphlets) but it did seem like double Dutch to me... It wasn't clear enough. No, I actually needed it verbally to be told to me. *Group 8*

Well I went to just a local GP and she was very unhelpful. I had to go back twice, because she didn't get enough the first time, and when actually went for the results she didn't explain what it was, she just said "it's just some information" I didn't know what that meant at all. *Group 4*

For a number of women, one of the consequences of feeling that insufficient information has been given was a sense of disempowerment.

If they're informed that's fine, if they're giving you all sides of the story. I sort of feel that I was perhaps guided by their method of thinking at the time, or what they thought was best at the time, which I didn't like. I feel very disempowered by situations like that, and I feel I've been had. Whereas I probably haven't, and I do respect them they were very good, and what they've done for me so far has been excellent, but I still sort of disagree.... the no knowledge bit, the "we won't pass on this information because it's probably not necessary". I don't like that. Never like that. *Group 8*

Others reported feeling stupid and uninformed as a result of not being given information.

Yes, I did feel very uninformed and stupid, and the fact that I'd never given it much thought myself - I was uninformed and stupid. I thought I was being fobbed off in a way, like "you don't need this information". *Group 9*

I know I went to a gynaecologist once, he was male, and his whole attitude was well you're the patient, I'm the doctor, it's my job to know everything about the medical side of things, but you only need to know the key issues, the key points. When even though you're the patient you're still a very intelligent human being and everyone is quite capable of understanding all of the other issues and medical treatments and side effects and all that can go with something like this.

In a number of cases, women reported that their treatment had been commenced without any information or choice being given. This was described as a 'harrowing' experience.

But I was under the impression that I was just going in to see the doctor and he was going to tell me about the procedure, and then I was going to book in for the actual operation. That's what I thought was going to happen. But I turned up there and he basically said, "oh righto, hop up on the bed", and I wasn't prepared. I didn't know what was going to happen. And he just hooked me up to this electric current, and it was all over in 10 minutes. Afterwards, I felt so shaken and shocked, because it was ... it was a bit harrowing, because it was the first Pap smear and then all of a sudden I was getting cells cut out. *Group 9*

No. I thought he was going to sit down and talk to me and then book me in for a later date. But it was just, right-ho, here you are, lets go. And I was like.... Wow. And afterwards I was just so shaken, it was terrible. *Group 9*

From previous research (Ley, 1982), it is recognised that information provided by clinicians is not always remembered by the patient. A number of the women reported taking in very little after the initial mention of CIN by the clinician.

When I got my abnormal test I was in the middle of doing my half-yearly exams for my HSC. I rang up to get my results and these.... abnormal....they kept talking and I was going "oh no".

Group 8

I couldn't remember exactly what had been said. *Group 4*

This suggests that while a clinician may be giving information to a woman, she may not be able to understand it at the time, particularly if she is experiencing feelings of anxiety or shock. The clinician may believe they are providing information yet the woman doesn't feel that she has received it.

e) Provision of information reduces anxiety

Conversely, women who were provided with information which they were able to understand and comprehend, reported less anxiety.

I'd rather a choice on what to do. Because if someone just says "you're going to have to get it lasered off" I think I would freak out totally and think it was a lot bigger deal than it really is. But if I was given this information I think I'd be a lot more relaxed about it and not panicky at all, I'd just understand the whole thing. *Group 5*

It was explained when I came in, but when I just got the letter it just said I would need to make an appointment with them...referral for a colposcopy...didn't really understand what was involved or anything. Once he explained it was OK. But I think it was probably just the shock itself of getting the letter. It's not something you would expect would happen to you. *Group 8*

One woman described her greatest problem was that she had to go for further pap smears, which were an 'convenience' and a 'hassle', after it had been explained to her that there was nothing to worry about.

I guess I just thought of it as an inconvenience than anything else - it was pretty clearly explained to me that there wasn't anything in particular to worry about and it was going to be checked in a fairly thorough way for a certain amount of time and it was really just a hassle having to come in and have appointments for a couple of years and I have to confess at the end of it I thought - if I'd never had a Pap smear I never would have known and maybe it would have gone away! *Group 3*

This illustrates the way in which information can alleviate anxiety but may potentially increase or decrease patient compliance. Generally, it increases the likelihood of women attending for future pap smears.

Conclusions:

1. Women should be given information about CIN and about treatment options in both verbal and written forms.
2. They should be able to ask questions or seek further explanation from the clinician, and be a part of the decision making process
3. in order to reduce anxiety

f) Women seeking information for themselves

A number of women reported that following a diagnosis of CIN they sought independent information for themselves from the library or the Internet.

Well I did go down to the library and just try and look up things...but I couldn't remember exactly what had been said....trying to find things in these books. *Group 4*

I think we were taught in schools about information. For me, at least, I think it's something that just happened, I would just look on the Internet because it's really good. *Group 5*

I'd go straight up to the medical library. I really would. I'd be up there wanting to find out how does this develop and, you know, how did I get it, and if there's any way that you know that and what the answers are....you know, if I have it removed what if it pops up somewhere else, and how does cervical cancer kill you anyway, and stuff like that. I'd want a lot of information. *Group 2*

Other women turned to friends or family.

I was pretty horrified, I guess because I got the letter saying that I had an abnormal smear and could I make an appointment for a colposcopy. Because I was only 22 at the time so you don't expect that sort of thing at that age. And a friend of mine's Mum works in the Cancer Unit down at Canberra. So I was on the phone to my girlfriend and she rang her Mum and found out what a colposcopy was for me, and the whole thing. So I understood

what a colposcopy was....I was really shocked at first, because this wasn't something that I expected. *Group 8*

If I went back and there wasn't a problem, and they said OK you're CIN1, then I'd say, my standard question, now what's my choices, what do I do now, what are my options? And then, give me the information, let me go home and read it, I'm one of these people who think, you're just individual people....what would you do, let me discuss it, I'd go home and talk to my sister and say, do you know anyone who's ever had....you know, I'd probably go back, find a bit about it, just so that I had an idea of what it was all about and then I'd make a decision based on that and some facts.

Group 7

Although most women reported that independent research and discussions did help to reassure them, there were a number who reported that receiving information this way made them feel worse and did not decrease their anxiety.

I remember going to the medical library at the University to read up a bit of medical information about it but that sort of ended up making me feel a lot worse. I think I read somewhere a statement that women with the HPV virus can, during childbirth, pass it to the child and the child can have nodules on the larynx and all sorts of ridiculous things. It ended up making me feel a little bit worse about it, and I wished I hadn't done it. *Group 5*

Women will seek information for themselves particularly if they are not fully informed about CIN and treatment options by their doctor.

Conclusions

1. It is important for clinicians to be aware that they are not the only source of information for women.
2. Information received from others may either reduce or increase anxiety. It is important for clinicians to be aware of this and be able to discuss the information that women may have obtained from other sources.

g) *Mistrust of the medical profession*

A theme which appeared throughout all the groups was that of mistrust of the medical profession. This mistrust resulted in a lack of faith in advice given by doctors, anxiety about treatment and anxiety about observation. In many cases this led to women taking up a position where they felt solely responsible for making the decisions about their treatment.

I don't have much confidence in the medical profession and I'm like Nell, I figure my body is my responsibility. *Group 7*

For some women this lack of faith in the medical profession was the result of previous, difficult experiences. As one woman commented:

But because I have experience with doctors and I know how some, not all of them, but how some doctors are ... you know, I make my own decisions. And I might be wrong. I don't know anything, I go by my own thoughts and feelings, and my own experience about who I am and what I am. *Group 2*

For others there was residual anxiety.

When I had a colposcopy it was at Broadway and I had to go up and she came with me and held my hand, and she stayed in the waiting area and I was led down the corridor, and it was right at the very end and I had the so-called modesty sheet and there am I, like I've only had one pap smear, I'm a complete virgin in every which way you know. And I'm sat there and the woman's got the camera and she's going to go and get someone to have a second opinion. And I'm there in Family Planning, she goes and leaves the door wide open ... I might be at the end of the corridor and I may have the so-called modesty sheet, but the door's wide open, and I was terrified. I still shake thinking about it now. *Group 5*

Other women talked of not trusting doctors because of their poor communication skills or perceived lack of interest in the patient.

No, I don't have a practitioner that I would trust, not that much. No. I find practitioners are generally fairly poor and not offering this kind of information. Either they don't know, they don't tell you they don't know and they're not really interested in people coming along and quizzing them. And I would assume that if she gave me

a recommendation either way that she would have her own reasons for doing that. And they may or may not be appropriate to me. *Group 2*

There were also comments about doctors being perceived as mercenary and it affecting their decision making.

Well, I was referred to this gynae., I can't quite remember how long I had to wait to get in to see him, but he was in the city, and when I saw him to when I went in to St. Margaret's was about a week. He just rang up while I was in the surgery and booked me in. And he was probably really greedy... and wanted his money. *Group 4*

Alternatively, one woman commented that doctors might be motivated by fear and recommend treatment on this basis.

You'd have to be confident that they're not basing opinion on their own fear that's something you have to judge for yourself. That's hard to see, but of course we already said that often they're saying that just to cover themselves. *Group 7*

Others commented on their concern that they were being experimented on; that treatment was still in the experimental stage.

Are we guinea pigs? *Group 4*

It would concern me in a public hospital whether you were practised on. *Group 5*

One of the themes that emerged under the issue of trust was that of women wanting a woman doctor, either because they felt they could trust a woman more easily, or that a woman would be more gentle or understanding.

Because I was scared stiff, because I wanted to see a woman, but I couldn't get to see a woman anywhere ... you know, it was months and months and months. *Group 4*

I always felt more comfortable having a woman actually inspect me, because I felt that they knew what it felt like for somebody to put the speculum in there, and start poking around in there. Because I did see a nice gynaecologist once but he basically got a cold speculum, in it goes, “aaagh”, you know just be careful down there. And basically I always felt more comfortable with female doctors from that perspective, that they would understand how it actually felt to have something like that done to them. *Group 5*

Previous research (Fylan, 1998) has reported that unavailability of a female screener was a major reason for women not attending for regular cervical screening. However in the present study women commented that if their doctor was empathic and considerate then their gender was not an issue. Trust and consideration are important considerations not whether the doctor is male or female.

h) Mistrust of technology

A related theme concerned women not trusting technology, in particular Pap smear results, and this being a source of anxiety.

I guess I don't trust doctors, I don't trust the medical system and I don't trust pathology results. And I work in a women's health centre, and I'm in charge of pathology stuff, so that's where I'm coming from. *Group 9*

Well in that case, it does actually really rely a lot on, even if you have a Pap smear, how thorough the person doing the pap smear is, if they actually scrape around the whole of the cervix rather than one little bit and go, “that'll do”. *Group 9*

Widespread discussion particularly in the media of false negatives may also act to increase this particular anxiety. As one woman commented:

I'm worried about press release about false negatives. *Group 9*

Conclusions:

1. Clinicians should be aware that many women are ambivalent about medical advice and therefore information needs to be given in a sensitive and respectful way.
2. Some women lack confidence in medical procedures and may require detailed explanation and reassurance about safety.

i) Feelings of Isolation

Many of the women reported that they had not discussed their abnormal Pap smear with anybody and so felt a sense of isolation.

I was very isolated and I think that no amount of information in some regards would have helped, because I was still very isolated. *Group 5*

No, I still haven't (told anybody) apart from this room I don't think I know anyone else. *Group 4*

I didn't talk to anyone I couldn't think I'd know anyone in my work or my friends. Well it's not the kind of thing that you talk about while you're having tea. *Group 1*

For many women, their doctor is the only person with whom they will discuss issues associated with a abnormal Pap smear. If they are not able to discuss the implications of a CIN diagnosis with their doctor, and have their anxiety alleviated, they will not have the opportunity to discuss it with anybody else.

j) The stigma of an abnormal Pap smear

The association between CIN and sexually transmitted diseases, promiscuity, or numbers of sexual partners was reported to produce feelings of shame by a number of women. This was both associated with feeling unclean, because of having the wart virus, and in some cases with fears of contamination.

It's just that ... society ... feel quite dirty and worry that it's going to come out, and could you pass the virus to someone else. They made you feel promiscuous. *Group 5*

Many women felt that others were judging them because of CIN and in one case a woman reported judging her own daughter in this way.

When my daughter ended up with one of them I called her a slut. This is my feeling behind it all, I called her a slut. *Group 6*

This demonstrates the widespread nature of this condemnation and how it is expressed verbally to those who have an abnormal Pap smear.

The main source of condemnation of women's sexuality reported in the interviews was from members of the medical profession discussing a CIN diagnosis. One doctor was reported to have talked of women who 'sleep around' being candidates for cancer, and refusing to believe that a woman with CIN had only had one sexual partner.

"Oh well, that must mean that you're obviously a candidate for cancer and the reason women get this is because they sleep around". This was a GP, and it was like "I'm sorry, I'm sorry?" ... So, I explained ... the guy that I'm with, I've only ever been with this guy and he said "No you couldn't have been" and I said "What are you telling me that I'm sleeping with people and I don't even realise it?" ... it was really scary, to be in with a GP who was basically saying, cervical cancer is God's revenge on women.
Group 4

Other women reported that their doctor's attitude only confirmed their feelings of anxiety, shame and concern that they might be judged by other people as promiscuous.

I was really upset, I was really upset. I've only ever had one boyfriend and I felt like this big slut that had slept with everybody and had got this STD, and I was really upset about it. And I then went to two doctors, and then I went to a gynaecologist and he told me that people in my profession often get things like this...I'm a flight attendant. *Group 5*

Other women talked of feeling concerned or angry when they were asked about the number of sexual partners or their sexual practice, as part of a general medical assessment. This suggests that even when clinicians are not directly making comments about women being at fault "for getting pre-cancerous cells" through "promiscuity", that they may be perceived as implying this through general questions in assessments.

When I went to the clinic, one of the obstetrics gynaecology registrars down there, I think she started the ball rolling. When they quiz you about your sexual history, how many partners you've had, condoms. *Group 5*

But its absolutely pathetic that women do have to walk around like that, ... when I came in for my first colposcopy ... there was some other research going on here, and they had the boxes, you know, I think it was 0-3, or 0 or 4 to 5, and then over 5 and like... (much laughter) Can you imagine a man thinking "oh, more than 5, I should feel bad". *Group 5*

Its funny how all of us ... there's this distinct thing about being promiscuous, and that's a really interesting point from my observation anyway, like "oh my God, I'm promiscuous" ... so what if you've had more than a couple of lovers. *Group 5*

In one case the questions about sexual practice and number of partners raised issues concerning the woman's male partner and his sexual past. This was despite the fact that it had been explained to the woman that CIN, or the wart virus, is not necessarily sexually transmitted.

It still did not help me (to know that young children also carried it). I think it was because of the fact that my husband had been with somebody else many years before, it brought up the old issues. *Group 6*

Conclusions:

1. Doctors should be careful not to suggest blame or make comments regarding promiscuity when discussing CIN or the wart virus with women as this results in feelings of shame and increases anxiety about the diagnosis.
2. Doctors should be aware that knowledge of the association between CIN and the wart virus is widespread in society and that a diagnosis of CIN may raise issues of concern for women associated with their own sexuality or those of their partner.

k) Concerns about fertility

A further area of anxiety or concern for women was whether their fertility would be affected by CIN. As one woman commented:

I remember asking this other gynae, that I ended up with somehow "Will this have any risks to me getting pregnant?". *Group 4*

For some women it was the association between cancer and fertility that was a cause for concern.

And I was...you always think of cancer, and you always think of not being able to have any children. *Group 8*

For the majority, however, it was the effects of the treatment on their fertility that was an issue.

And I got it into my head that it was some sort of procedure that if it went wrong it could cause infertility. And I'm going "oh no"

Can I just say.. My biggest problem with having treatment is that I don't think they've done enough research into long term effects, and that's probably what worries me the most. I haven't had any pregnancies or any children, I don't really know what effect this treatment ... because I've had lasers 3 times what effect it will have on me when I decide to get pregnant?

Conclusions:

1. Doctors should be aware of concerns about fertility when advising or treating women with CIN.
2. Information about fertility should be built into training packages and information on CIN.

2. Treating CIN: What do women want?

A number of issues emerged during the interviews relating to the treatment of CIN. These related primarily to the issue of choice over treatment, and the decision about which was the best form of treatment. While the majority wanted to be involved in the choice of treatment some wanted to make the decision themselves, and others wanted to be advised by their doctor. There were reports of women having been involved in the decision-making, and reports of women who had not. In terms of the option of treatment they would choose women were split between wanting observation and wanting treatment. These differences are illustrated below.

a) Women want to be informed about CIN and about treatment options

Information is a significant factor in reducing a woman's anxiety. It is also something the majority of women said they wanted when asked about treatment options. Women who were fully informed, and therefore able to understand treatment options, reported the most satisfaction.

I had some concern, but I thought it was handled very well and the session was very comforting and it was quite a new experience to be asked to look inside and see the cells and the different cells. I thought it was a great educational experience. *Group 3*

I've got two really good GPs, two females, and they're wonderful. And I would probably look to them for advice. I probably wouldn't take it like straight down the line and this is gospel or anything, but they're on the Internet in their rooms. And when my daughter had meningitis they were on the Internet, everything there and then, so they could be giving me the information on where to find it. But no, I trust their judgement. *Group 2*

Women who are given full information about treatment options are more likely to be happy with whatever path is then chosen.

I don't think the GP s realise how much effect they can have on people. They can either give you the information you need to feel confident to wait the 6 months when I had my atypical I was shocked, I didn't have a clue what all this was about. But my doctor was very good, he explained it all to me, gave me good information to read about it ... and I felt confident in him, in my doctor. And I waited 6 months and I had quite normal result, and waited another 6 months and got another normal result. So I think that if you have enough to read and enough information given to you then you can make that decision. *Group 4*

Conclusion and recommendation

1. Women should be given information about CIN and treatment options so that any decisions are made from an informed viewpoint.

b) Women want to discuss the options and be able to choose

The majority of women wanted to be involved in the decision making process about treatment reporting that they would want to discuss treatment options with the doctor but still have the right to choose for themselves.

I'd like to make the decision but I'd like the opinion of the gynaecologist as well. And then take the information away and say I'd come back. *Group 5.*

However many women reported that they had not been given any options when a CIN 1 diagnosis was made, the majority of these women were told that treatment was the only option.

No, no (options) He just explained about the laser treatment, so I just did it. *Group 8*

He just said you've got to have this done, and you'll almost certainly have to have laser treatment. *Group 7*

I didn't realise that you'd have any choice. I just thought they'd just cut it out and that was it. I never really knew .I learnt something today. *Group 5*

I wasn't given any options at all, and I was only 19 at the time, and I was too young to question. *Group 4*

A smaller number of women reported having been offered observation without any other option being discussed.

None, nothing, nothing. I was purely, simply told to come back again. So obviously, I didn't know there were any other choices you could make, simply because I would say the hospital had made their own choice which they thought was best, and I'm assuming they were just telling people to come back for another Pap smear because their option....they'd chosen the option for you. *Group 9*

When women were *not* given the opportunity to discuss treatment options, and be able to take make a choice, they reported that they felt most dissatisfied.

I totally agree with what you had to say before about how you felt that you weren't given the opportunity, you just thought that you had to have treatment, and that's how I felt as well.

In some instances women were given the option to choose but they reported that they had not had sufficient opportunity to discuss the various options with the doctor. This also led to dissatisfaction and feelings of discomfort.

He really didn't have a very good bedside manner. He was in theory probably a very good technical person, but I felt extremely uncomfortable at the time. Extremely difficult to talk to, and I was wanting to say, well I don't quite understand what you're saying, could you tell me where do I go from here, what should I be doing? He said well it should be quite simple. And the measures were terribly harsh. He said look here's a piece of paper, take it away, make another appointment with me, and tell me what you've decided. But there were all sorts of very harsh measures.

And he said to me...well I was given the sheet...and he said what sheet? And I said, of the choices I have available. But I said to be honest I don't think he has very good communication skills, because he could see I was quite shocked. And he said well this should be done immediately, take this piece of paper, read it, tell me when you want to make another appointment. In other words, in-out, there are other people waiting for me. I came out and said (to friend?) I'm quite devastated, and there was no reassurance. It was all sort of...next please.

Conclusions:

1. Women want to be involved in the decision making process with the majority wanting to be able to discuss options with the doctor.
2. Women should be involved in the decision making process about treatment as this increases satisfaction and decreases feelings of unhappiness or anxiety.

c) I'm happy to take advice from the doctor

A common theme in the interviews was that of women wanting the doctor to give advice. For many of the women this advice guided their choice of treatment.

I'd like a pat on the head I think from my practitioner, and basically say it's all right, you'll survive this, it's just a thing isn't it. I just want a pat on the head basically. *Group 2*

So I've felt it was worthwhile waiting and taking the doctor's advice.

So even now I would just act on whatever advice they gave me.
Group 7

I'd think about it carefully but I'd still go with their advice. *Group 7*

A number of women went as far as to say that they didn't want to choose - they wanted the doctor to make the choice for them.

No, I didn't have any choice, mine came out, mine was taken out, it was lasered out both times, I didn't have any choices, and I really didn't want them either, to be quite honest, I would have opted to have it out. *Group 9*

Others commented that making a choice was very difficult:

I suppose if I had had the choice I wouldn't have known what to chose. *Group 1*

d) Confidence in the medical profession leads to advice being followed

Women who reported that they had confidence or faith in their doctor were the happiest about taking advice, and felt less anxious about the particular option chosen. This illustrates the importance of the doctor-patient relationship, and of building trust for the treatment of CIN.

I'd take a lot of notice of my doctor, because I have a lot of trust in him. *Group 5*

And I felt confident in him, in my doctor. *Group 4*

So I've felt it was worthwhile waiting and taking the doctor's advice. I had great faith in my gynaecologist. *Group 3*

He explained to me that it usually isn't cancer, doesn't develop into cancer, could just be that there's some sort of infection in your body somewhere, so it's showing up as an abnormality. So I just trusted that that was what would happen.

I've felt it was worthwhile waiting and taking the doctor's advice. I had great faith in my gynaecologist. And a friend of mine had previously been to him and been through the same thing, however, her's went to the next step so he then did a biopsy, a cone biopsy. So I knew that he would take the next step if necessary. And I was quite happy to go by his advice. *Group 3*

Conclusions :

1. Many women are happy to be advised by the doctor regarding the most appropriate form of treatment. Therefore it's appropriate for doctors to give advice about treatment or observation while ensuring women are still given the opportunity to choose which option they prefer.
2. A trusting relationship developed between doctor and patient, based on readily available information and opportunities for discussion, results in women being more comfortable and confident in taking the doctor's advice.

e) Women wanting observation

Many of the women were happy to go with the observational approach particularly if their doctor advised it to be the best course of action. However almost all women, without exception, gave a definite time limit to the period they were prepared to wait before opting for active treatment.

I'm in two minds. I think I might want to wait and see first, if it was normal. If it stretched on for any length of time I'd like to take action. *Group 3*

I think if it happened to me again I would head off in the same direction as I was going, which was, if on the second colposcopy, it turned up still there, I probably would have something done about it- but I'd leave that first period as still observing- I'm still of that mind set. *Group 1*

Many women mentioned a particular number of months as the period of time they would be prepared to wait before opting for intervention.

I give myself until the middle of next year, say March-April. If by that time it hasn't cleared if the inflammation hasn't gone. *Group 2*

I feel that if you get the right information from the doctor that I would probably wait....up to (the) 6 monthly check up. *Group 3*

Other women were prepared to wait for a longer period, or for an indefinite period, with regular checks.

I'd wait and it might take a year, it might take 2 years to see how it might go and if it looked bad, if it was getting worse then I would go for the active. *Group 5*

Me I know I'd wait and see what happens. I'm that kind of person...then if it gets worse than what it is then I'd go for treatment. *Group 4*

Conclusions:

1. Doctors need to be aware that while many women are prepared to opt for the observational approach, they may seek active treatment at any time during the observational process.
2. A number of personal factors, which may be unknown to the doctor, will influence a woman's decisions about treatment or observation.

f) Women wanting intervention

An equal number of women reported that they would want active treatment as those who would choose observation. For many women, this was as a result of wanting to get rid of any pre-cancerous cells immediately.

I think I'd, if it was me, I would be wanting to you know, like, get rid of it. I don't want it. *Group 3*

Doing this was said to lead to peace of mind.

Definitely (have active treatment) I just think for peace of mind, and things like that. *Group 3*

Women also reported the sense of getting rid of contamination, and of the treatment being relatively straightforward.

Once you went in there, you're out to it, they do whatever they do, and you wake up and you're told you've got a nice shiny new cervix. *Group 4*

No, I still think, if it just meant going to hospital for a day, having a quick laser bizzo and your home again, I think I'd rather have it done. *Group 3*

For other women, the decision to have treatment was made on the basis that they didn't want to take the risk of being in the small percentage of women where the pre-cancerous cells progress to cancer, or in case the change in cells progressed more quickly than would be expected.

I mean I know it's a good statistic, but to me waiting another 2 to 3 years is just too long..... I would rather have it a 100% gone,.....I could see why other people who don't have a history may think well OK 60% is pretty good. *Group 2*

I just thought well, what if I'm in the 40% and if it proceeded quicker than normal, I would rather get on top of it....if you were lucky enough to find out about it. *Group 5*

Conclusions :

1. Women are not a homogeneous group. Different women will choose different options for treatment, given relevant advice and information by their doctors. The implications of each choice should be explained, and the decision respected.

g) Self help and alternative treatments

The two options of medical observation or treatment were not the only ways in which women reported that they had, or would, deal with a CIN diagnosis. As has been found in previous research (Kavanagh & Broon, 1998), many women talked about adopting a healthy lifestyle, or turning to alternative medicine, as a way of combating cervical problems.

Changing patterns of thinking was one approach reported.

I follow the ideas expressed in Christine Nathrop's *book Women's Bodies Women's Wisdom* - showing respect for your own body and its ability to overcome disease with a positive mindframe.
Group 10

I think there's a lot of things that lower your immune system, and even having many depressing thoughts or negative thoughts can do that as well. *Group 2*

Other women talked about stress reduction or self care.

When I got this result my husband said "that's it you're not going to work full time anymore." He related it to stress. We've both worked out a lot of what's been happening to us lately....we went through periods of massive stress, I mean I went under stress it was so bad it could have killed me I think. And if this is the only manifestation of it, I probably am very fortunate, because everything else seems to be all right. I can't say that I would say no, stress didn't cause this. I'd say stress very likely caused it. *Group 9*

I know when I'm feeling like that. I think, bugger it, I'll just take a day off work, go to the beach, or have lots of coffee somewhere, that's nice, or have a manicure,...just something a bit of TLC for me. I live alone, so I have to look after myself. *Group 7*

Other women talked of meditation, yoga, changing patterns of thinking, and a healthy diet.

I'm now in less stress and I'm going to ensure there's less stress and again yoga, practice meditation, looking after the diet etc. Therefore it will go away, by visualisation. *Group 6*

I have chosen all the time to be conservative because I do believe that if you change certain things in your lifestyle and your diet, and even in the way that you think, you can help yourself. So I have chosen that approach. *Group 2*

I chose that and that meant I was pretty strict. I stopped smoking, I stopped coffee, and everything that I know makes your blood a bit acid. *Group 2*

This approach can be very empowering for women who feel that they have some control over what is happening to their bodies.

And I realised that I probably had become stressed over the previous time, and it was probable. And so I handled things in my own way, I'd taken a sort of New Age approach, and did a bit of meditation and tried to sort of relieve myself of stress and look at whatever stresses might be causing bodily stress..but I feel, that I was active in that as well,(the observational approach) because I did look at the stress levels and what to look up, and I didn't just sit back and think oh well. I did actually do something about it in my own personal way, my own approach to health, which is something I really I think...we should participate in our own health, not just rely on doctors to heal us. So that was my approach, and well so far it's worked. *Group 7*

However, it is important to note that while women were happy to try alternative health remedies this was invariably in addition to taking medical advice as a part of overall care-of-the-self. Only a small minority of women commented that they would use self help or alternative methods as the main means of dealing with an abnormal Pap smear.

Conclusions:

1. Many women believe that adoption of a healthy lifestyle, a positive mind frame, and practices such as yoga or meditation will help to deal with cervical abnormalities. Doctors should be aware of this and encourage it, as it will increase general well being.
2. Taking personal control of health, in this way, can also improve women's feelings of self-control and self-efficacy, and thus be beneficial to physical and psychological health.

Recommendations

1. A more in depth study of what would be necessary for gynaecologists to feel safe in recommending the observational management of CIN1.
2. An Australian study of the possible role of DNA HPV typing in the management of CIN1 lesions
3. A study of return rates of women for follow up when undergoing observation of a CIN lesion, followed by the development and evaluation of possible strategies which would encourage women, who opt for observational management, to return for regular Pap smears.
4. Dissemination of information from the focus groups of women to gynaecologists regarding women's preferences for management and women's concerns. An evaluation of the effect of this information on gynaecological practice and women's satisfaction.

Appendices

Appendix 1: Scenario

Your Pap smear result showed CIN1 which is the 1st stage of pre malignant abnormality.

You've had a colposcopy and biopsy confirming this result.

Your doctor has discussed the situation with you, telling you that 60% of CIN1 lesions will return to normal with no treatment but this may take two to three years.

Your doctor tells you that there are two choices.

One is an observational approach, where Pap smears are taken every six months. If the Pap smear indicates that the abnormality has progressed, it will be treated. If it remains unchanged, pap smears will be taken every six months until two consecutive smears are normal. You would then have annual smears for two years. If these smears are normal you will revert to smears every two years.

The other approach is active management. This involves removing the abnormal cells with a laser beam or an electric loop which cuts out the abnormal area. This is followed by a Pap smear and colposcopy two - six months later, and then 2nd yearly Paps.

Now we are asking you to decide what you would choose.

So tick:

- OBSERVATIONAL
- ACTIVE

Appendix 2: Information for gynaecologists from the women's focus groups

Data obtained from the women involved in the focus groups shows that women vary in their responses to a diagnosis of CIN1. Most women would like more information given in an understandable form, would like both options presented to them, and want to be involved in the decision-making to variable degrees.

Gynaecologists have the difficult task of tailoring their approach to the management of CIN1 to the individual needs of the woman. This will require them to assess how best to provide the information and ensure the woman understands it, as well as determining which option best suits the woman's needs as far as management is concerned and how much involvement the woman wants in the decision.

Many of the women stated that they would like to have some involvement in the decision but would ultimately accept the recommendations of their clinician if they had developed sufficient trust and understood the reasons for the management decision.

Although many women would opt for the observational approach initially a number would revert to treatment if the lesion did not regress within six to twelve months. This suggests that gynaecologists need to be flexible in their management approach and consult with the woman at each follow-up visit regarding her concerns about the cervical lesion.

Appendix 3: Gynaecologists survey on management options for CIN1

Age	Sex	Year awarded gynaecological qualification	Postcode □□□□
30-39	<input type="checkbox"/> male	<input type="checkbox"/>	1950-59 <input type="checkbox"/>
40-49	<input type="checkbox"/> female	<input type="checkbox"/>	1960-69 <input type="checkbox"/>
50-59	<input type="checkbox"/>		1970-79 <input type="checkbox"/>
60-69	<input type="checkbox"/>		1980-89 <input type="checkbox"/>
70+	<input type="checkbox"/>		1990-95 <input type="checkbox"/>
			1996 + <input type="checkbox"/>

Do you provide a colposcopy service? Yes / No

If yes how many colposcopies do you do on average per month ‡‡

Case history: A woman is referred to you by her GP with a Pap smear prediction of CIN1. Your colposcopic examination and biopsy confirms CIN1.

Which option best suits your advice to her :

recommend ablation with :

- diathermy
- laser
- loop excision
- recommend observation with six-monthly paps
- discuss the pros and cons of active and observational management but recommend active treatment
- discuss the pros and cons of active and observational management but recommend observational treatment
- discuss the pros and cons of active and observational management but involve the patient in the decision-making

If you recommend active treatment which answer best covers your reason:

- women can't be relied upon to return for regular pap smears
- the only safe option is to remove the lesion
- women prefer treatment
- the referring GP expects treatment
- I'm worried about medico-legal consequences if I don't treat
- other (please specify)

Would your recommendation be different if the woman was :

Yes\ No under 25 years? Yes\ No
 married ?

If you do not involve the woman in the decision regarding management which of the following best approximates your reasons:

- cannot expect a woman to make such a decision
- women expect the specialist to tell them what is best
- giving women options is too confusing for them
- takes too much time
- other (please specify)

What circumstances would make you more likely to recommend the observational approach?

- Yes / No if I could be sure it was safe
- Yes / No if DNA testing for oncogenic wart virus types were available and this lesion did not contain an oncogenic HPV
- Yes / No if the woman requested it
- Yes / No always recommend it
- Yes / No always offer both options
- Yes / No if the woman refused treatment
- Yes / No if I could be sure the woman would have regular six-monthly paps
- other (please specify)

Do you think the NH&MRC guidelines for the management of biopsy proven CIN 1 should be changed?

yes no

If yes should they recommend:

- only active treatment
- only observational management
- only observational management unless woman desires treatment
- DNA testing for all CIN1 pap smear results
- colposcopy only for women who are found on DNA testing to carry an oncogenic HPV type
- colposcopy only for women who have had two consecutive CIN1 smears 6 months apart
- colposcopy unnecessary for CIN1 paps

Would you be prepared to participate in a clinical trial on management of CIN 1 lesions of the cervix.

yes no

Thank you for completing this questionnaire

Tables	Page
Table :1	Gynaecologist response rate per state 13
Table: 2	Demographic details of study group 14
Table :3	Reasons for recommending treatment 15
Table :4	Management of biopsy-proven CIN1 by respondents 17
Table: 5	Reasons why gynaecologists do not involve women in decision making 18
Table :6	Circumstances that would make gynaecologists more likely to recommend observational treatment 21
Table: 7	Number of women participating in focus groups from different Area Health Services in NSW 33
Table: 8	Educational status of women participating in focus groups 34
Table: 9	Marital status of women participating in focus groups 34
Table:10	Year of abnormal Pap smear for women with CIN1who participated in the focus groups 35

Abbreviations

CIN1	Cervical Intraepithelial Neoplasia Grade 1
Colp	Colposcopy
CME	Continuing Medical Education
EPI	Epidemiology
FPA	Family Planning Australia
FPNSW	Family Planning New South Wales
HPV	Human papillomavirus
NH&MRC	National Health and Medical Research Centre
RANZCOG	New Zealand College of Gynaecologists

References

Bancher-Todesca D, Gitsch G (1997). Diagnosis and therapy of cervical intraepithelial dysplasia in Austria : a survey. Weiner Klinische Wochenschrift 109:878-83

Curtis P, Mintzer M, Morrell D et al (1997). Recall and treatment decisions of primary care providers in response to Pap smear reports. American Journal of Preventive Medicine 13 (6): 427-31.

Daste G, Butet MH, Viraben R. et al (1994). Typing of human papillomaviruses in intra-epithelial lesions of the cervix uteri: correlation with cytohistological grade and progression of the lesion. Journal of Gynecology and Obstetrics Biology of Reproduction 24: 28-34

Duggan MA, McGregor SE, Stuart GC, et al (1998). The natural history of CIN1 lesions. European Journal of Gynaecology and Oncology 19(4): 338-44

Ferris DG, Kriegel D, Cote L, Litaker M & Woodward L (1997). Women's Triage and management preferences for cervical cytologic results demonstrating atypical squamous cells of undetermined significance and low-grade squamous intraepithelial lesions. Archives of Family Medicine 6: 348-353.

Fylan F (1998). Screening for cervical cancer: a review of women's attitudes, knowledge and behaviour. British Journal of General Practice 48(433) 1509-1514.

Grace VM (1985). Factors affecting the response of women to cervical screening. The New Zealand Physician. 12: 139-142.

Jones TV, Gerritty MS, Earp J (1990). Written case simulations: do they predict physician's behaviour? Journal of Clinical Epidemiology 43: 805-15

Kavanagh AM, Broom DH (1997). Women's understanding of abnormal cervical smear test results: a qualitative interview study. British Medical Journal 314: 1388-91

Kavanagh AM, Broom DH (1998). Embodied Risk: My Body My Self. Social Science and Medicine. 46 (3): 437-444.

Lee SS, Collins RJ, Pun TC et al (1998). Conservative treatment of low grade squamous intraepithelial lesions (LSIL) of the cervix. International Journal of Gynaecology and Obstetrics. 60(1): 35-40

Ley P (1982). Understanding, memory, satisfaction and compliance. British Journal of Clinical Psychology, 21, 241-54.

Malson H (1996). The Thin Woman: Anorexia Nervosa. London, Routledge.

Meijer CJLM, Snidjers AJC, Van der Brule TJM et al (1994). Can cytological detection be improved by HPV screening? Experts Consensus Conference, European Research Organisation on Genital Infection and Neoplasia

Mitchell H, Higgins V (1996) Statistical Report 1995. Victorian Cervical Cytology Registry, Carlton South.

Murray M & Chamberlain K. (Eds) (1999) Qualitative Health Psychology: Theories and Methods. Sage Publications, London.

NH&MRC Guidelines for the management of women with screen detected abnormalities Report by the National Health and Medical Research Council for the Organised Approach to Preventing Cancer of the Cervix. Australian Government Printing Service 1994

Orbell S, Sheeran P (1998). Inclined abstainers: A problem for predicting health related behaviour. British Journal of Clinical Psychology. 37:151-165.

Ostor AG (1993). Natural history of cervical intraepithelial neoplasia: a critical review. International Journal of Gynecological Pathology 12: 186-92

RANZCOG personal communication

Reissman CK (1993). Narrative analysis. Qualitative Research Methods, Volume 30. London: Sage.

Richart RM, Masood S, Syrjanen KJ et al (1998). Human papillomavirus. International Academy of Cytology task Force summary. Diagnostic cytology towards the 21st century: An international expert conference and tutorial. Acta Cytologica 42(1): 50-8

Sandrik H (1995). Criterion validity of responses to patient vignettes: an analysis based on management of urinary incontinence. Family Medicine 27: 388-92

Shafi MI, Luesley DM, Jordan JA et al (1997). Randomised trial of immediate versus deferred treatment strategies for the management of minor cervical cytological abnormalities. British Journal of Obstetrics and Gynaecology 104: 590-4

Stivers C (1993). Reflections on the role of personal narrative in social science. Signs: Journal of Women in Culture and Society 18(2), 408-425.

Ussher JM (1999). Women's Madness: A Material-Discursive-Intra psychic Approach. in: Fee, D (ed) Psychology and the Postmodern: Mental Illness as Discourse and Experience. Sage, London. (In press)

Ward J, Donnelly N, Holt P (1998). Impact in general practice of the policies of the organised approach to preventing cancer of the cervix. Australia and New Zealand Public Health. 22 (3 Suppl.) 336-41

Ward J, Wain G (1995). Gynaecologists' advice to smokers with abnormal Pap smears: a survey of current practice and opportunities to improve. Health Promotion Journal of Australia. 5(2): 37-40.

Willig C (1999). Applied Discourse Analytic Research. Sage Publishing, London

Woodrow N, Permezel M, Butterfield L, et al (1998). Abnormal cervical cytology in pregnancy: experience of 811 cases. Australian and New Zealand Journal of Obstetrics and Gynaecology. 38: 161-5

Yu CKH & Rymer J (1998). Women's attitudes to and awareness of smear testing and cervical cancer. The British Journal of Family Planning. 23:27-133.

Young KG (1989). Narrative embodiments: Enclaves of self in the realm of medicine. In J. Shappter & K.J. Gergen (Eds) Texts of Identity 152-165. London: sage.

NSW CERVICAL SCREENING PROGRAM

A Joint Commonwealth and State Funded Program



NSW HEALTH
Better Health, Good Health Care



Sydney Centre for Reproductive Health Research
Research Division of FPA Australia