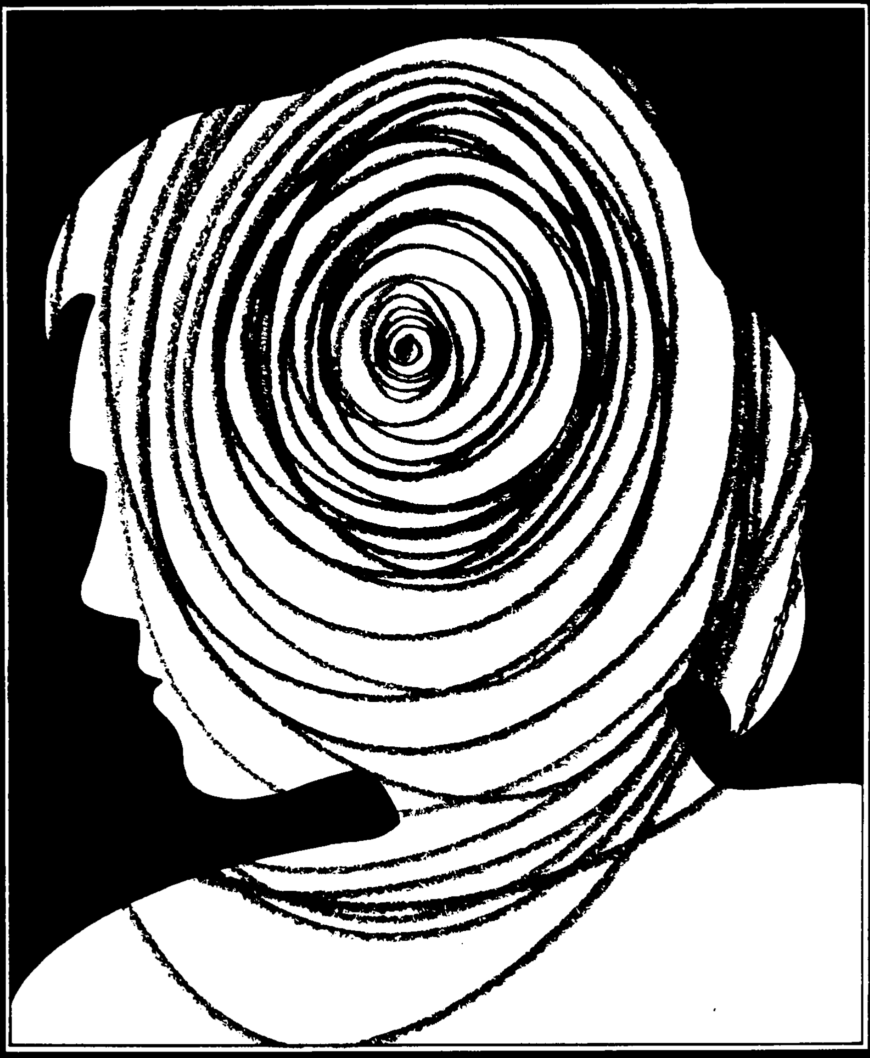
PREVENTION OF CERVICAL CANCER
The Patient's View

TINA POSNER
MARTIN VESSEY



King Edward's Hospital Fund for London

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To Anne V, Anne W, Evelyn, Rachel, Sarah and Valerie

'They know it's common; they know it's only a small thing – to you, it's the end of the world.' Patient in colposcopy clinic

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1 INTRODUCTION

Background to the study

The prevention of cervical cancer through the implementation of efficient screening programmes has been the subject of much debate and media coverage. Seldom in medicine is there an opportunity to intervene at the very start of a disease. In the case of cervical cancer, a disease which develops insidiously and which, once established, carries a poor prognosis, it is possible to prevent its development before any symptoms are experienced. Nevertheless, 2000 women a year, most of whom have never been screened,[1] still die of cervical cancer. This unnecessary (that is, possibly avoidable) mortality has been the cause of impassioned concern.

There is evidence of an increase in the rate of premalignant lesions of the cervix, particularly in the younger age groups:[1] estimates range from 6 to 13 per 1000 in previously unscreened women.[2,3] Research attention has been focused on various epidemiologically relevant characteristics of women with abnormal cervical smears – for example, their age, sexual history, social class,[4,5] contraceptive use,[6] smoking history, area of residence and partner's occupation.[7] However, in this area of preventive medicine where success is dependent not only on motivation to take part in screening, but also on acceptance by well women of any subsequent medical procedures, the patient's view has been given significant attention only in so far as it affects the uptake of screening. The impact on women of the medical process following an abnormal smear – how the prevention is experienced in practice – has not been properly investigated. The possibility of unnecessary *morbidity* in terms of psychosocial, psychosexual or physical distress resulting from medical intervention has been overlooked. This omission was readily recognised by medical personnel – gynaecologists, colposcopists, nurses and general practitioners (GPs) – and our research was given support and encouragement. The women involved in our work welcomed the opportunity to express their thoughts and feelings about what was happening to them. In this report, 'the patient's view'[8] is given voice. Patients' views are, of course, not unidimensional or homogeneous.

We have tried to do justice to the variety, and sometimes, complexity of views. Our sparing use of the term 'patient' reflects the essentially preventive nature of the medical process and the 'well woman' status of most of the participants in our study.

In biomedical terms the treatment of cervical intraepithelial neoplasia (CIN) is a triumph of preventive medicine. CIN is the medical term now given to cell changes which can develop into cancer; but frequently the lesion is referred to simply as 'abnormal' cells. It is established that such developments do not necessarily proceed to invasive cancer and that some revert to normal,[9] but estimates of the proportions vary considerably and at present a definite prognosis cannot be given. The abnormal cells are therefore recognised as a risk to the future health of the woman and it is assumed that she would be better off without them. Cone biopsy operation for diagnosis and treatment was the standard intervention for many years, but the procedure is associated with a significant complication rate in terms of haemorrhage, cervical stenosis, cervical incompetence and pre-term labour. The advent of colposcopy has meant that the abnormal area of epithelium can be accurately mapped and assessed, and technically sophisticated means now exist to eradicate the cells without interfering with the woman's reproductive functions. Outpatient treatment has the advantages of not requiring hospitalisation or a general anaesthetic, having a low complication rate and leaving the cervix in an anatomically normal state. Laser treatment has been found to be 'a safe, effective, quick, easy, and cheap way of treating CIN',[10] and cryocautery 'an essentially nonmorbid procedure that affords ideal outpatient treatment of a significant number of precursors of cervical cancer'.[11] Removing the abnormal cells eliminates the threat to the woman's future health and prevents possible cervical cancer. The success of the treatment of CIN has up until now been judged simply in terms of the disappearance of signs of disease – the obliteration of the abnormal cells.

Screening is different from usual medical practice in which the doctor is asked to provide relief for the illness brought to him or her and in which patienthood is self-defined.[12,13] In screening, the medical profession is seeking out signs of disease – looking for deviations from the norm – and it makes patients of people who feel well: 'The essence of secondary prevention is to go and look for disease at a stage when the victim may not even be aware that he has it or even that he is liable to get it.'[14] An abnormal cervical smear produces no clinical abnormality, but is recognised to be statistically and prognostically abnormal: 'If early diagnosis when we notice something amiss is a good thing, the argument goes, then early detection before we notice something is amiss must be even better.'[15] The medical dilemma is to know when to treat and when to leave alone. It may be that some abnormal cells are harmless and will not cause any ill effects, whereas physical symptoms and other consequences may arise from investigation and treatment. This is an example *par excellence* of the sort of diagnostic uncertainty analysed by Scheff.[16]

Scheff described 'decision rules' for guiding behaviour under conditions of uncertainty which he suggested become established in professions such as medicine where uncertainty is a frequent occurrence. In order to cope with the uncertainty, informal rules develop based on assumptions which normally go unquestioned – that some types of error are more to be avoided than others. Scheff analysed the underlying assumptions and consequences of a rule for handling uncertainty in medical diagnosis: that judging a sick person well is an error more to be avoided than judging a well person sick. He concluded that the operation of this 'decision rule' was likely to result in a bias towards medical intervention, and suggested that the logic of the rule rests on two assumptions. The first assumption is that 'disease is a determinate, inevitably unfolding process, which if undetected and untreated will grow to a point where it endangers the life and limb of the individual'.[17] The second assumption is that medical diagnosis and investigation are, in themselves, harmless to the patient.

It is the task of biomedical research to throw light on the first assumption. The purpose of this report is to describe and analyse the impact on women of an abnormal smear finding and the subsequent medical process of investigation and treatment. As Freidson has pointed out,[18] medical concern has concentrated on the biophysical consequences of diagnosis and treatment, their accuracy and efficacy, and has not focused on any social consequences to the person who becomes a patient. Such consequences can be significant because 'Some illnesses may not be undone . . . in the world of the patient . . . If one is diagnosed as having a *stigmatised* illness, being cleared of it is not possible: simply having been suspected of it is stigmatising.'[19] Understandably, there is anxiety that a potentially preventable cancer may be missed by the screening programme, and there has been more concern with the problem of 'false negatives' than that of 'false positives'. The problem of false positives was, however, recognised by Love and Camilli, who suggested that 'Outcome measures of screening programs tend to focus on conveniently measured quantities, cost or cost/case diagnosed, and mortality from the disease in question, and we tend to forget other effects. In assessing the overall value of the program, we must consider the following side-effects: 1) the psychologic cost of a false positive test; 2) unnecessary work-ups of persons with false positive tests; 3) the morbidity associated with diagnostic tests performed on persons with false positive tests ... Though not easily quantitated, these side-effects of screening must be recognized and weighed.'[20] Such 'side-effects' are possible not only in cases of false positives where, upon further investigation, nothing abnormal is found after all, or in that unknown proportion of cases which would have become normal without medical intervention, but in many other cases. Rational evaluation of screening needs to take account of these psychosocial costs. In order that the benefits of screening are maximised, any unintended negative consequences need to be reduced as far as possible; they first need to be acknowledged and understood.

The interviews

The focus of our study was on women with abnormal cervical cells (mostly CIN) since some attention has already been paid to the problems of women with uterine cancer.[21,22,23] The Cancer Research Campaign funded our research for two and a half years. Our study began in the autumn of 1982 with the researcher (TP) spending a few weeks observing in the outpatient department and particularly the colposcopy clinic of Hospital A. This allowed the researcher to understand the complexities of the medical process and to set up a system for making contact with interviewees. An initial pilot study, with tape-recorded interviews among women attending the colposcopy clinic, was very useful in directing attention to significant areas on which to focus questions.

The main interviewing began in February 1983. The intention was to follow a series of women – the first 100 referred to the colposcopy clinic with a positive or abnormal smear – through the medical process from first referral for investigation to treatment and subsequent check-up. By September 1983, 102 women had been interviewed, but inevitably a few were missed.

The women were interviewed two or three times, the initial interview being carried out around the time of the first colposcopy examination – just beforehand, in as many cases as possible (see Appendix). The last contact was made approximately six months after the first interview. The post-treatment interviewing, which was mostly done in the women's own homes, was more drawn out than anticipated as Hospital A had referrals from a very wide geographical area. The re-interviewing continued for a year from August 1983 with most of the women being seen six to nine months after their first interview.

In order to broaden the study, a second centre was sought. The colposcopy clinic at Hospital B provided a centre where laser rather than cryocautery was used, where the medical process after an abnormal cervical smear was organised differently in some respects, and where the patients referred came from a different population. As it was not our intention to compare centres (or differences between colposcopists), but to look at the responses of a range of women from various backgrounds to the medical process organised in different ways and with different treatment regimens, any differences between the centres are mentioned only where they are particularly noteworthy or related to the different organisation or treatments. Interviewing at the second centre began towards the end of October 1983. Fifty-one patients had been recruited to the study by the beginning of February 1984. It was not possible in this colposcopy centre to see a consecutive series of patients since a number of them had been referred from other hospitals in the region and could not be included. Re-interviewing started in April 1984 and was completed by the autumn. The patients attending this clinic generally came from a smaller geographical area. Altogether 359 interviews involving 153 women were carried out (see Appendix for details). All of the women had had an abnormality on their cervical smear, mostly a 'positive' result,[24] but 20 were found subsequently to have either a negative smear result or no abnormality requiring treatment in the colposcopy clinic. Five, possibly six women were found to have early cervical cancer.[25]

The interview questions (see Appendix) were designed to provide both factual information and a record of the women's thoughts and feelings about the medical process at different stages. The interviews were structured but included many open-ended questions to which the researcher recorded the answers verbatim, subsequently subjecting them to content analysis. We were concerned not to suggest ways of conceptualising what was going on or reacting to it, and not to 'put words into the mouths' of interviewees. In the first interview we were particularly careful not to use any words which might indicate a diagnosis. The word 'cancer' was used (in question 52) only if the woman herself had already used it.

The interviews would in themselves unavoidably have had some slight effect on the women's experience of the process. The opportunity to talk about a stressful situation with a listener who apparently understands can be in itself therapeutic. Certainly to have someone interested in how one has fared, and in one's own reactions and thoughts, can be affirming and is unlikely to have any detrimental effect. Recognition of this helped the researcher to overcome a sense of voyeurism resulting from the necessity to record others' distress without doing anything immediately to alleviate it. There were two circumstances in which the researcher intervened by giving information in the interviews. The first was in an initial interview where women were about to have colposcopy and still had no idea what it involved. The second was at the end of the last interview, in a few cases, where a woman was still talking in black and white terms about the smear test and clearly had not understood the preventive nature of the treatment she had had.

Our thanks go to all those people who made this study possible: the Cancer Research Campaign for their funding; the women themselves for their willingness to give their time and share their thoughts and feelings with the researcher in the hope of helping other women in the same situation; and the staff of the outpatient departments involved (gynaecologists, other doctors, nurses, receptionists, secretaries and, in particular, the colposcopists) who were unfailingly helpful and supportive. We are also grateful for the patient and careful secretarial help we have received from staff in the University of Oxford Department of Community Medicine and General Practice, and from Mrs Hilary Coppen, who typed the final draft of this report.

The sample

Demographic characteristics[26]

Most women interviewed were under 35 years of age (Table 1), less than a third (29 per cent) were 35 years or older. Very few were over 54 (3 per cent), but some were under 25 (16 per cent). Many of the women were childless (39 per cent) and a quarter were single. Of those who had children, the highest proportion had two (Table 2).

Just over half the women (54 per cent) were married, a further 8 per cent were cohabiting, and 12 per cent were separated or divorced (Table 3). There was one widow in the sample.

The educational level of the sample (Table 4) reflected a predominantly younger (under 40) age group in which the majority of people have some educational qualification.[27] Social class was assessed according to the Registrar General's 1980 classification on the basis of both the women's own and their husbands' occupations. In Table 5 each woman's social class is given according to her husband's occupation if she was living with her husband, otherwise according to her own occupation. Social classes 2 and 3NM appear over-represented and social class 5 under-represented.[28] In Table 6 the social class distribution is given according to each woman's own occupation. There was a difference between the samples attending the two hospitals, with more unemployed women attending Hospital A. This difference may reflect the differences in the proportions who were married and had children: more women attending Hospital A were at home looking after children.

Table 1 Age distribution of sample

	Under 25 years	*25–34 years*	*35–44 years*	*45–54 years*	*55 + years*	*Totals*
Hospital A	16	55	22	5	4	102
Hospital B	9	30	11	1		51
Totals	25 (16%)	85 (55%)	33 (22%)	6 (4%)	4 (3%)	153 (100%)

Table 2 Parity distribution of sample

	Number of children					
	*None**	*One*	*Two*	*Three*	*Four or more*	*Totals*
Hospital A	32	18	32	16	4	102
Hospital B	28	5	9	6	3	51
Totals	60 (39%)	23 (15%)	41 (27%)	22 (14%)	7 (5%)	153 (100%)

*Includes 2 women with 1 adopted child each

Table 3 Marital status distribution of sample

	Married	*Cohabiting*	*Separated or divorced*	*Widowed*	*Single*	*Totals*
Hospital A	64	8	11	1	18	102
Hospital B	20	4	7		20	51
Totals	84	12	18	1	38	153
	(54%)	(8%)	(12%)	(1%)	(25%)	(100%)

Table 4 Educational level of women in sample

	No additional schooling	*Additional 1 or 2 years at school*	*College**	*Nurses' training*	*Teachers' training*	*University or polytechnic*	*Totals*
Hospital A	41	20	17	8	5	11	102
Hospital B	24	5	9	10	1	2	51
Totals	65	25	26	18	6	13	153
	(42%)	(16%)	(17%)	(12%)	(4%)	(9%)	(100%)

*Includes day-release, secretarial and vocational courses at further education colleges

Table 5 Social class distribution of sample (Registrar General's 1980 classification)

Social class 1	7	70 (46%)
Social class 2	34	
Social class 3NM	29	
Social class 3M	31	53 (35%)
Social class 4	19	
Social class 5	3	
Students	10	30 (19%)
Armed forces	5	
Unemployed	15	
Totals	153	(100%)

Table 6 Social class distribution of sample (according to woman's occupation only)

	Social classes 1 & 2	*Social classes 3NM & 3M*	*Social classes 4 & 5*	*Students*	*Unemployed*	*Totals*
Hospital A	17	29	12	4	40	102
Hospital B	10	16	11	5	9	51
Totals	27 (18%)	45 (29%)	23 (15%)	9 (6%)	49 (32%)	153 (100%)

Table 7 Psychological health

	% *(n = 153)*
Depression associated with life event	20
Depressed in past year	22
Post-natal depression	4
Ever badly depressed (not in other categories)	8
Total % badly depressed at some time	41
Stress experienced during past year	44
Stressful life events involving loss (mentioned elsewhere)	8
No mention of *either* depression *or* stress	34

Health

These were well women – most (78 per cent) considered that they were 'generally fit'. There were eight women in the sample with serious chronic diseases; nine others considered they had been in ill-health recently and an additional five women complained of menstrual problems. In contrast, the picture we have of the psychological health of the women as a result of asking them if they had ever suffered badly from depression and if they had been worrying about things (other than the abnormal cervical smear) is very different (Table 7). Only 34 per cent of the sample answered negatively to both these questions. (This proportion includes five women who said they suffered from pre-menstrual tension.) There appeared to be a great deal of stress, anxiety and cause for depression in many of their lives. Forty-four per cent of the women said they had been under recent stress (in the past year); 28 per cent had suffered a serious loss at some time (a marital break-up, a death of a close friend or relative, or loss of a baby), 20 per cent mentioning this in relation to suffering from depression; 22 per cent said they had been depressed in the past year; and at least six women had suffered from post-natal depression. The proportion of the sample who said they had been badly depressed at some time was 41 per cent. If a depressive reaction to a life event is considered to be a possible factor in the aetiology of this condition, any depressive episode in the adult life of these women could be relevant since the postulated developmental period through the grades of CIN to invasive carcinoma is suggested usually to be anything from five to twenty years.[29]

Though there may be some degree of over-estimation involved as a result of women wanting to 'offer' something in answer to these questions, none the less the proportions appear high. Abortions, miscarriages, moves and job losses have not been included in the 'serious loss' category unless the women mentioned them in terms of the resulting depression or anxiety. The causes of worry were often major concerns by any standards, and it was emphasised that the question on depression was asking about significant episodes rather than minor upsets.

Over half of the women in the sample (53 per cent) had experienced either pregnancy or childbirth difficulties, or some other gynaecological problem. Forty-one per cent had previously been referred to a gynaecologist with a variety of problems other than abnormal cervical cells. At least 7 per cent of the sample had had a pregnancy termination, and 7 per cent a D and C operation. The rate for these operations was higher among women attending Hospital B where 12 per cent had had a termination and 12 per cent a D and C (as opposed to 5 per cent of women attending Hospital A who had had a termination and also 5 per cent a D and C).

Cervical screening history

Most of the women in our sample had been screened regularly either by their GP or at family planning or cytology clinics.[30] Because the women were almost all in the pre-menopausal age group, many, probably most, of these tests would have been taken when the women were attending for family planning checks. Of the 14 per cent who had had no other test within the last six years, over half (57 per cent) were under 35 years of age and would not until recently have been included in the DHSS recommendations for screening unless they had three or more children. Twelve women (8 per cent) were having a smear test for the first time, but only two of these women were 35 years of age or more, and in both cases the test was taken as part of an investigation of symptoms.[31]

Analysis of the smear tests which resulted in referral to the colposcopy clinic (or hospital), showed that 54 per cent (Table 8) of tests were taken in association with the investigation and treatment of symptoms. This category includes 'routine' ante- and post-natal tests (7 per cent) and tests taken during infertility investigations (3 per cent); 31 per cent appeared to be routine repeat tests, and 13 per cent were repeats of earlier abnormal tests. Among the women attending Hospital B, proportionately fewer tests appeared to be routine repeats and more women were referred from a sexually transmitted disease (STD) clinic.

The distinction between a routine repeat 'screening' test and a 'diagnostic' test is not as clear-cut as it might at first seem to be. The doctor may have taken the test because the woman was due for another one rather than for diagnostic purposes, though the woman may have gone to her doctor at that time because of symptoms. Similarly, the woman's motivation for going to the doctor may have been to seek a repeat test, but her doctor may have done the test at that time because of co-existing symptoms. It may be quite a frequent occurrence that the woman has a diagnostic intention while the doctor has a screening intention in taking the test, or vice versa.

Table 8 Occasion for cervical smear test

	Routine repeat	*Abnormal repeat*	*First smear (not in other categories)*	*Ante- or post-natal*	*Infertility investigation*	*STD clinic investigation*	*In association with symptoms*	*Totals*
Hospital A	37	13	2	9	2	4	35	102
Hospital B	10	7	1	2	3	10	18	51
Totals	47 (31%)	20 (13%)	3 (2%)	11 (7%)	5 (3%)	14 (9%)	53 (35%)	153 (100%)

2 *THE ORGANISATION OF THE MEDICAL PROCESS*

Differences between the hospitals

There were four main points of difference between the two hospitals in the organisation of the medical process after referral of a woman with an abnormal cervical smear.

1 The colposcopy clinics

The colposcopy clinic in Hospital A was held on three mornings a week alongside the outpatient gynaecological clinic. Women referred for investigation of an abnormal cervical smear went straight to the colposcopy clinic. Where the case was straightforward and required cyrocautery, the colposcopist would go ahead and arrange an appointment for the patient to re-attend for treatment. In other cases, the patient's treatment would be discussed with the consultant, who would come into the room to meet her and sometimes to examine her himself with the colposcope. Arrangements for admission to hospital could often be made there and then. Alternatively, if the woman was a patient of one of the other two consultants whose outpatient clinics were held on the other two mornings, an appointment was made for her to return to discuss her treatment. One female doctor with experience in family planning and colposcopy did most of the colposcopy clinics and cryocautery. However, during the study approximately one-sixth of the clinics were done by one or other of two male gynaecologists with an interest in colposcopy.

In Hospital B, only women referred from the STD clinic or prison went straight to the colposcopy clinic without first attending the outpatient gynaecological clinic which was held in the mornings. The colposcopy clinic was conducted in a room (otherwise used for follow-up visits to the gynaecological clinic) on two afternoons a week by the consultant cytologist or her assistant (both female doctors). Quite often during the time of the study a male gynaecologist being instructed in colposcopy would be in attendance at the consultant cytologist's clinic, and he also would examine the patient with the colposcope.

2 *Informing the patient about treatment*

The colposcopists in Hospital A would often feel able to tell the patient after her first examination whether she would be suitable for outpatient treatment or whether she would require a cone biopsy operation. Sometimes, though, a further examination was arranged in order to review the situation before deciding on treatment, and to allow time for the colposcopist to receive the results of the biopsies and smears from the pathology laboratory. The cytological, colposcopic and histological assessments of the patient's condition were recorded together on the colposcopy clinic file card. In cases of discrepancy, where a more serious condition was indicated than was evident on colposcopy examination, a diagnostic cone biopsy would be done. On average a larger number of punch biopsies were taken by the colposcopists in Hospital A than in Hospital B.

The process of finding out what treatment they were going to have was in general a lengthier one for women attending Hospital B. They were informed of the final decision about which treatment was suited to them by letter during the week after their colposcopy examination, when the colposcopists, who were also cytologists, had examined the biopsies and the cervical and endocervical smears they had taken. They would then write to the patient saying that she was or was not suitable for laser treatment and enclosing an appointment either for the laser clinic or for the gynaecological outpatient clinic where the gynaecologist would have the colposcopy report and a recommendation for the cone biopsy operation. This procedure meant that the colposcopists would not say anything definite about treatment after the examination in the clinic except in cases where they had at that point decided to recommend a cone biopsy operation.

3 *Outpatient treatment*

A woman attending Hospital A would return for her treatment to the same room in the outpatient department. Not only the room but very often the faces too would be familiar, as there was a good chance that she would see the same colposcopist and nurse on each of her visits to the clinic. This allowed a personal relationship between the patient and the medical personnel to develop. A woman having laser treatment in Hospital B, however, would need to find her way to another part of the hospital where the laser room was accommodated in a day-case ward (otherwise unused at the time of the study). The consultant cytologist carried out the laser treatment so that, if the patient had seen her assistant previously, both the room and the doctor would be unfamiliar to her. The two nurses in attendance in the laser clinic would also be new faces because they were not the ones who worked in the outpatient department. For her follow-up check three months after treatment, the patient would again have to come to this clinic where she could be seen by either of the colposcopists.

4 Surgery

Patients from Hospital A undergoing surgery would be admitted to another hospital where the gynaecological surgery was carried out by the doctors working in Hospital A. They would return to Hospital A for their post-operative check-ups in the colposcopy and gynaecological clinic. Women attending Hospital B who were due for surgery would come to the outpatient department to attend a special clinic for a pre-operative check-up a week before admission. They would not usually return to the colposcopy clinic post-operatively.

Referral

The majority of the women (71 per cent) in the sample were referred to the hospital by their GP (Table 9). Usually they were asked to make an appointment to see their family doctor either by the GP himself or herself after the result of the cervical smear test had been received or by the clinic where the test had been taken. Women were also referred to the colposcopy clinic directly by the STD clinics (10 per cent), and by prison medical officers (one woman in the study). Three women were referred to the colposcopist after seeing a gynaecologist privately, and the others (16 per cent) by doctors in outpatient clinics in the hospitals or as a result of a smear taken while they were inpatients (two women).

Waiting times

Most of the women attending Hospital A saw the colposcopist within a month of learning about the abnormal smear; over a quarter attended the clinic within a week of hearing that the test was abnormal, and a further quarter within two weeks (Table 10). Women attending Hospital B had to wait longer. The wait for an appointment in the outpatient gynaecological clinic, from which the patient was referred to the colposcopy clinic, was often over a month,

Table 9 Source of referral

	General practitioner	Outpatient clinic	STD clinic	Prison	Private gynaecologist	Totals
Hospital A	87	10	5	–	–	102
Hospital B	22	15*	10	1	3	51
Totals	109 (71%)	25 (16%)	15 (10%)	1 (1%)	3 (2%)	153 (100%)

* Includes 2 referrals as a result of cervical smears taken while in hospital.

Table 10 Length of wait for hospital appointment

	One week	Two weeks	Three weeks	Four weeks	Five or six weeks	Seven or more weeks	Totals
Hospital A	28	27	24	24	7	2	95*
Hospital B	4	7	3	6	11	16	47*
Totals	32 (22%)	34 (24%)	27 (19%)	13 (9%)	18 (13%)	18 (13%)	142* (100%)

*The totals are reduced because seven women attending Hospital A and four women attending Hospital B gave answers which were too vague for classification.

though 30 per cent were seen within a month. The subsequent wait for a colposcopy clinic appointment was normally over two months. A woman referred to Hospital B might therefore wait over three months altogether before she could be put more in the picture about the nature and extent of her condition and told what treatment, if any, was likely to be needed.

There were also differences between the hospitals in the length of the wait for treatment. Most women (76 per cent) attending Hospital A for cryocautery had had the treatment within a month. A month's wait was the average for laser treatment in Hospital B. The usual wait for a cone biopsy operation was three or four weeks in Hospital A; for women attending Hospital B it was two to two and a half months. The wait for hysterectomy varied considerably from a few weeks up to four months, according to the main reason for the operation.

Those women who attended the outpatient clinic before being referred for colposcopy were asked how long they had had to wait before being seen by a doctor. Of those who could remember well enough, 86 per cent in Hospital A said they were seen in an hour or less (59 per cent in half an hour or less). Again those attending Hospital B had to wait longer, only 40 per cent being seen in an hour or less; another 40 per cent waited one and a half hours, with 20 per cent having to wait from one and a half to two and a half hours.

Treatments

Thirteen per cent of the sample had no treatment to the cervix, though a few of these women were treated for vaginal infections. Two women referred to the outpatient clinic in Hospital B had a repeat cervical smear test with no further investigation (no colposcopy). Most women, however, were treated, 41 per cent having outpatient treatment and 43 per cent inpatient surgery – 35 per cent cone biopsy operation, 8 per cent hysterectomy (Table 11). The proportions of our samples from the two hospitals having outpatient treatment were very similar (41 per cent and 39 per cent) as were the proportions having cone biopsy operations (34 per cent and 35 per cent). There were slight differences in the proportions having no treatment (Hospital A, 12 per cent, Hospital B, 16 per cent), and the proportions having a hysterectomy (Hospital A, 10 per cent, Hospital B, 6 per cent).

Table 11 Treatment

	No treatment	*Cryo-cautery*	*Laser*	*Cone biopsy*	*Hysterec-tomy*	*Other**	*Totals*
Hospital A	12	40	2	35	10	3	102
Hospital B	8	1	19	18	3	2	51
Totals	20 (13%)	41 (27%)	21 (14%)	53 (35%)	13 (8%)	5 (3%)	153 (100%)

*Includes biopsies and laser treatment done under general anaesthetic because of the location of the abnormal area of tissue or multiple lesions other than on the cervix, and diathermy to the cervix.

3 *THE COLPOSCOPY EXAMINATION*

Many women came for the colposcopy examination not knowing what to expect and fearing the worst about their condition. Even if a woman was fortunate and had been given an explanation about colposcopy and some reassurance about her likely condition, she had inevitably to cope with considerable uncertainty prior to her examination. 'It's the not knowing...' women explained: not knowing whether you have the most feared disease, whether you will live or die, whether you will be able to have children, what, if anything, is wrong, and what it means in terms of treatment and future prospects; what must be faced in the short term and in the long term. Such uncertainty caused very considerable stress prior to the colposcopy examination. Depending on which hospital she was attending, a woman might have to wait two months or more to see a colposcopist.

Women's experience of the examination

The examination was described by the women as 'uncomfortable', 'distressing', 'unpleasant', 'inelegant' and 'undignified'. Many described themselves as being tense, anxious and nervous beforehand, and very relieved when it was over. Several described how they were gripped with fear and panic either when they came into the room and saw the machinery or during the course of the examination. One woman said, 'When I first went in, I was frightened to death – the thing looked so big.' Another said that when she came in the room and saw 'the binoculars', she thought, 'How are they going to get them in there?'[1] Two women who had felt panic while being examined said they had been helped by the nurse who would talk with the patient, or might hold her hand, or tell her to breathe deeply. There were some complaints about the number of people in the room during the examination, one woman saying this 'made it feel rather overbearing, claustrophobic because of the room's small size.'

Embarrassment and passive acceptance of the situation were commonly expressed feelings. The immediate causes of embarrassment were the position necessary for examination (in order for the doctor to have a full view of the cervix, the woman needed to be in the lithotomy position with the vagina held open with a speculum); the presence of observers, particularly if they were male; and people coming into the room during the examination. It would be difficult not to feel one's vulnerability acutely in such a situation:

> 'You can't move. They say "Not long". You're stuck in that horrible position.'
>
> 'You put yourself in their hands and trust they're going to treat you nicely.'

The situation was sometimes likened to being at the dentist's:

> 'It's a bit like having a tooth drilled ... you're clamped open the same... It's worse having the clamps than it is actually being treated, if you see what I mean.'[2]

There were times when the needs of medical education clashed acutely with patients' needs for privacy while in such an exposed position. Embarrassment was caused by the presence of people who were clearly not necessary for the examination, particularly if no explanation of their presence was given and if the patient was not asked if she objected – that is, if there was no recognition of the intrusion. People coming in and out of the room during the examination also caused distress:

> 'There were rather a lot of people wandering in and out of the room. [You] just have to put up with it... They were all a bit matter of fact really. They ignored you. You can't help thinking "God, here I am..."'

In Hospital A the clinic door was not locked during examination or treatment and medical personnel would intrude with queries, to consult the file, or to observe. Usually two or three people were present during the examination. In Hospital B, the clinic door was locked, but a doctor wishing to observe could enter from the corridor at the back of the examination rooms through the curtain at the other side of the room. There were normally three or four people present during the examination.[3] Women appreciated having a sheet draped over their hips and legs – a technically unnecessary but symbolically important gesture, which helped a little to reduce the sense of being publicly exposed. Allowing people to come in and out of the room during the examination is an avoidable violation of the woman's sense of privacy.

Many women expressed their enforced passivity and resigned acceptance of the colposcopy examination in terms such as: 'If that's what they've got to do'; 'It had to be done'; 'You just have to put up with it/let them get on with it'; 'There's nothing you can do.' As Emerson[4] has said, 'Patients actually have strong negative reactions to gynaecological examinations which belie their acquiescence in the actual situation'. Emerson's analysis of the gynaecological examination suggests that there is an inherent conflict in the doctor's role. The medical definition of reality calls for a matter-of-fact stance in which the patient is a technical object: 'If not for the medical definition the staff's routine activities could be defined as unconscionable assaults on the dignity of individuals.... As for exposure and manipulation of the patient's body it would be a shocking and degrading invasion of privacy were the patient not defined as a technical object.'[5] Ignoring the patient as a woman is not the best way to maintain her full acceptance of medical procedures. It is also very hurtful.

However, maintaining the balance between the matter-of-factness necessary for a technological examination, and the personal treatment of a patient is a complex matter, particularly for a male doctor with a female patient: 'The doctor must convey an optimal combination of impersonality and hints of intimacy that simultaneously avoid the insult of sexual familiarity and the insult of unacknowledged identity.'[6] The patient's identity as a person was recognised for at least part of the time she was in the clinic. Sometimes this involved a splitting of roles: the doctor concentrating on technicalities, while the nurse talked with the woman about her personal life. One woman said she and the nurse, who was standing by her head, talked together, while the two doctors 'were talking in a different language' at the other end of her body! There were many compliments on the approachability of the medical personnel and their care and concern for their patients:

> '[It was] embarrassing but the fact that they talk to you puts you very much at ease.'
>
> 'I thought they were lovely. They chatted all the way through to put you at ease. They were marvellous, the two of them.'
>
> '[They were] very warm. There was a lot of rapport ... kind, caring.'

When there were additional people in the clinic it made a personal relationship between doctor and patient less likely, particularly where it was necessary for the colposcopist to instruct observing doctors. Some women said they felt, or would have felt, more comfortable with a female doctor and with no males present, but about half as many women said it made no difference to them.

Discomfort

The examination in general was experienced as painful by only 8 per cent of the women (Table 12). However, 41 per cent said they found it uncomfortable, and 16 per cent mentioned that the punch biopsies hurt.[7] While a few experienced it as an ordeal,[8] others found the examination was not as bad as they thought it would be and said 'there's nothing to it really'. The taking of biopsies seemed to be the most physically painful and symbolically significant aspect of the examination:

> '[It was] not too bad until I saw the scissors and the doctor said "I'll have to cut another" and that made it worse.'
>
> 'The biopsies really got me . . . it was not even that they might find . . . something, it's the fact that . . . there's a part of you . . .'

More than twice as many women (22 per cent) attending the colposcopy clinic in Hospital A complained that the biopsy/ies hurt as did in Hospital B (9 per cent). This may be related to the fact that more than one punch biopsy was often taken in the colposcopy clinic in Hospital A.[9] Taking multiple biopsies is likely to cause some suffering. Colposcopists may sometimes rationalise their enthusiasm to leave no stone unturned by telling their patients and themselves that there are few nerve endings in the cervix. The word 'biopsy' is more frightening because of its associations and telling the patient that a 'small sample' is being taken will sound less threatening.[10] One woman said that if they had told her they were taking biopsies she would have refused the examination altogether.

At the suggestion of one of the colposcopists, an attempt was made to throw light on the question of whether to tell women that a punch biopsy was going to be taken. The women were asked whether they were told before or after having the biopsy/ies and whether they would rather have been told beforehand or afterwards. The largest percentage of women (39 per cent – see Table 13) said they would have liked to know beforehand; just over a quarter (26 per cent)

Table 12 Colposcopy examination

	% *(n = 144)*
Not painful	41
Painful	8
Uncomfortable	35
Uncomfortable and biopsy/ies painful	6
Biopsy/ies only painful	10

Table 13 Warning of biopsies: women's preferences

Prefer being told beforehand			
Told before and this was OK	47	52	(39%)
Told after and this was *not* OK	5		
Prefer being told afterwards			
Told after and this was OK	16	34	(26%)
Told before and this was *not* OK	12		
Not told at all and this was OK	6		
No preference		28	(21%)
Unaware biopsy/ies taken		18	(14%)
Total		132	(100%)

would rather *not* have known beforehand; 21 per cent had no clear preference; and a further 14 per cent were unaware of whether a biopsy had been taken or not.[11]

A considerable number of women reported symptoms following the colposcopy examination. The most common symptom was bleeding which ranged from 'spotting' for a few hours to 'quite a lot' for several days. Some women also complained of discomfort or aching lasting up to two days and a few complained of discharge.

The colposcopist as a source of reassurance

Reassurance came from being given enough information to understand what was happening, what the examination was all about and what would be done. Too often, the women had very little idea of what was involved, and thus fear of the unknown was magnified. Some women thought that treatment was to take place there and then, one or two coming without having had breakfast in case they might need a general anaesthetic. The colposcopists usually explained briefly what they were going to do just before the examination started, often giving additional explanations of what was happening as they proceeded. (Eighty-seven per cent of the women said they had some explanation of the examination in the clinic.)

On the colposcope in Hospital A, there was a teaching aid through which another person besides the colposcopist could look. Not infrequently, the patient was asked if she would like to look and many were grateful to have done so. In this way the patient could feel less excluded from knowledge about her body to which others had access. However, a few women said afterwards that they would rather not have looked and were concerned because of the apparent size of the abnormal area (magnified by the colposcope). The reaction to being shown the photographs which were taken as a matter of routine for the records in Hospital B was similar.[12]

When asked how they felt after the colposcopy examination, women often said they felt better and reassured. Looking at their faces when they went in and again on coming out, often so obviously happier and more relaxed, there was sometimes little need to ask! A woman could feel relief after her examination if she believed that nothing was being hidden from her, and that what there was to take account of would not be an overwhelming threat to her future, but something she and the medical profession could quite confidently cope with:

> 'Dr A was wonderful. I didn't feel in the dark. I felt she told me everything I wanted to hear, which was everything. I'd trust her with my cervix or any other part of me.'

Women were reassured first and foremost by being told that they definitely had not got cancer, that the condition was 'only a minor abnormality', that it was confined to surface tissue and a small area, that it was 'common', and that laser treatment was 'simple' or that the cone biopsy operation was 'quite a routine thing'. They were also reassured by the manner in which they were treated:

> Dr A was 'straightforward – every confidence in her'.
>
> Dr B was 'very down to earth and straight'.
>
> Dr C was 'very straightforward – openly answered questions – didn't hide anything'.
>
> Dr D's manner was 'matter-of-fact – honest – showing all the pros and cons and possibilities – felt I could trust her'.

The colposcopists would give varying amounts of explanation of the condition and any necessary treatment after the examinations. It was clear, though, that women found it difficult to take in much detail at this time because of their nervous tension and anxiety; their overriding concern being with whether or not they had cancer. Where the treatment could be decided upon in the clinic, rather than depending on the results of punch biopsies or a diagnostic cone biopsy operation, the uncertainty about the implications of the abnormal cervical smear could be most fully resolved. Recognition of the patients as people, and reassurance wherever possible, helps, at least to some extent, to resolve the stress and heal the emotional hurt of the medical investigation.

4 *TREATMENT*

Anxieties about treatment

Outpatient treatment

The most common anxiety about outpatient treatment was whether or not it would be painful. A third of the women having cryocautery or laser treatment had no particular worries about the treatment. However, there was generalised apprehension in the face of the unknown, something not experienced before, because 'you don't know what to expect', 'not knowing what they are going to do'. Having the treatment explained did not entirely remove this anxiety:

> 'They can tell you what they're going to do – use so many fancy words, but they don't really prepare you.'
>
> 'They explained everything, but it's natural to get worked up and nervous.'

In addition, as one woman said:

> 'Anything gynae you've got to get over the hurdle of losing your pride.'

The word 'laser' had more frightening associations than 'freezing treatment' (as cryocautery was normally referred to). A few women confused laser treatment with radiotherapy and assumed from this that they were being treated for cancer.

Surgery

For women having surgery, the need for a general anaesthetic was a major concern. It was mentioned by 56 per cent of the women who said they had had anxieties prior to their operation. The words of one woman sum up the nature of the fear:

> 'I don't like anaesthetics – you're not in control at all. I'm afraid of being given too much or too little, and worried about waking up halfway through. Your dignity is violated.'

A few women mentioned that they had been visited by the anaesthetist before their operation, and they seemed to have been reassured to some extent.

Women were also concerned about how they would feel afterwards: whether they would be sick, whether they would be in much pain, whether there would be much bleeding, and how long it would take for them to get back to normal again. Some expressed anxiety that the cone biopsy operation might not be a success, fearing that they might need a hysterectomy later;[1] and there was always the underlying fear, voiced by a few women:

> '... that they would find more than they thought was there during the operation.'

There was apprehension about going into hospital and undergoing an operation, accentuated for those women who had never had an operation before (mentioned by six women):

> 'There's always a terrible fear of going into hospital and of the anaesthetic. I had confidence in what they were doing.'

> 'I don't like hospitals. I didn't like being there as a patient. I was apprehensive because I'd never had an operation before and being a nurse, neurotic...'

But not everyone was fearful of going into hospital. Over a third had had previous experience of surgery.[2] For some there was an overriding concern 'to get in and have it done', felt acutely by one young woman having laser treatment for multiple lesions in the vagina and on the cervix, who said:

> 'I was worried about the warts. I wanted to get rid of them as soon as possible. I couldn't wait – couldn't sleep.'

Three women mentioned that they had been concerned over arrangements for having their children looked after. One of these women was allowed to take her small baby with her into hospital. Twenty-one women (40 per cent) answered 'no' to the question asking whether there was anything that particularly worried them about having the operation.

The experience of treatment

Outpatient treatment

Of the 31 women interviewed after having cryocautery, nine (29 per cent) said it did not hurt (Table 14), though it may have been uncomfortable; an equal number found that it did hurt, but was not too bad; and 13 (42 per cent) had severe symptoms during the treatment. Ten of these 13 women also had severe symptoms afterwards, along with three other women. Altogether 16 women (52 per cent) had severe symptoms during or after cryocautery. Severity was judged by the woman's account of her symptoms. Use of terms such as 'intense', 'really bad', 'severe', 'terrific', was taken to indicate that the woman experienced considerable suffering. Pain is essentially a subjective phenomenon and we believe there is no way of making a valid assessment other than relying on the patient's account.[3] Nine of the women said the treatment upset them more than they thought it would. The pain was described as being like a very bad period pain, as cramps or spasms, labour pains, or as a stabbing pain. One woman said it was 'excruciating' and that she was 'in agony while they were doing it'. She added that her cervix was very sensitive – she had been assured that as the cervix contains few nerve endings, it was relatively insensitive.[4] Another woman said she felt as if she was 'being kicked in the abdomen', and a third felt as if her bladder were 'about to burst'. Two women complained about not being given a painkiller, one of them saying:

> 'It's rather barbaric that they can do it without anything for it before or after ... in this day and age, it's a bit much.'

Besides pain, some women having cryocautery also experienced burning feelings, 'a weird hot flushing sensation', dizziness, short-lasting severe headaches and nausea.

Table 14 Outpatient treatment symptoms

	Cryocautery (n=31) %	*Laser (n=16)* %
Didn't hurt	29	19
Hurt, but not badly	29	38
Severe symptoms during treatment	42	44
Severe symptoms after treatment*	42	38
More upsetting than expected	29	31

*Includes physical and psychological distress.

The women having laser treatment at Hospital B were routinely given a paracetamol tablet beforehand and a local anaesthetic into the cervix just before treatment started. Of the 16 women interviewed, three said it did not hurt (Table 14), while for six the pain or discomfort was not too bad; for seven others it was severe, and six of these women had severe symptoms afterwards. Five said that the treatment had upset them more than they expected. The pain from the laser treatment was described as cramps, a burning feeling, stomach ache, 'backache and pain towards the front', and like severe period pains. One woman said it was the worst pain she had ever experienced. Another said:

> 'It was hard to describe – coming from the inside. Worse than the dentist.'
>
> 'Like a red hot poker, but it wasn't a pain that made you scream out. Very uncomfortable. Cramp in the abdomen. You feel as though everything is being pulled away.'

Other immediate factors beside the pain which contributed to making the treatment an ordeal, were the position the women had to be in, the length of time they sometimes had to remain in that position, and the embarrassment caused by observers. Two women complained that the cryocautery took a long time – over three-quarters of an hour. The average time taken was somewhere between 10 and 20 minutes, the laser treatment tending to take less time. Besides this, the door to the room in which the cryocautery was done was not locked during the treatment (as it was in the laser clinic), so that people could intrude on the process. One woman expressed annoyance that an observing doctor had left before the treatment was completed: that he 'did not see it through'. This dropping in and out of their ordeal was clearly embarrassing and hurtful for the women.

The outpatient treatment caused considerable distress (severe symptoms as described by the women), either at the time or afterwards to 49 per cent of those who received it and were subsequently interviewed. For some women, the treatment was not an ordeal. They were not distressed and went about their business much as usual afterwards. One such fortunate woman said she was surprised how well she felt afterwards and how simple and quick it was. For others, it could not be dismissed so lightly. Fourteen women (30 per cent) experienced pain after the treatment was finished. Twelve (26 per cent) said that they were emotionally upset or depressed afterwards. They described themselves as being, in the days shortly after treatment, 'very low', 'weepy', 'delicate', 'as if a bit shocked', 'washed out', and 'quite shaken and knocked about'. A woman who said the colposcopist was 'super' and 'couldn't have been a better doctor', found the treatment 'more traumatic' than she thought it would be, and that it was 'a shock to the system' which left her feeling 'really wobbly and ill afterwards'. She had expected it to be 'just like going to the dentist, but it wasn't'. Two other women said they were taken aback by their psychological reaction to the treatment.

One patient who had come on her own and later wished her husband had been there, said that after the treatment she was:

> 'In quite a state – shocked, and feeling battered. Very upset about it – emotional, hysterical even.'

One of the youngest women to have treatment said that it had made all the difference that her boyfriend had not only accompanied her to the hospital, but had been in the treatment room with her. This was usually discouraged – see page 79. She believed that she had taken many less weeks getting over it because her boyfriend was there. 'For a start', she said, 'it brought humour into the situation. They asked *him* if *he* was going to be all right!' She needed 'to know someone knew what I had been through', as she 'couldn't have explained it'. At the time, she had not felt as if the treatment was curing her. She had thought 'this is damaging me', and had 'a feeling of assault', and had felt 'almost raped – violated'.[5] Afterwards she was, she said, 'terribly cut-up emotionally' and had felt 'an emotional and physical mess'.

The 'physical mess' resulting from the cryocautery was a watery discharge which could last for three or even four weeks, and was complained about by 30 per cent of the women, several saying it was the worst thing about the treatment. The first few days, when it could be particularly heavy, were described as 'horrendous', 'dreadful' and 'very bad'. One woman who said that she had been 'gushing gallons' for two weeks at least, reported that she had needed to change her towel every hour; another said she needed to get up in the night to change her towel and described her state as 'sopping wet'; and a third complained that she was 'damp all the time like a baby' and that she had got 'nappy rash'.[6]

It was clear that both the heaviness and the duration of the discharge was a shock to many of the women, one or two of them saying that they thought it would never stop. It was not only a nuisance but depressing – feeling wet, having to use sanitary towels for weeks, a continual reminder of their treated condition. It made it more difficult for the women to feel well and whole again, and to put the episode behind them. Two women admitted they had been reluctant to venture outside their homes for some days.

There were four comments about the cream which women were given to use after outpatient treatment. Three of the women said they had been very anxious about inserting the applicator in case they hurt themselves. In one case the woman thought that she had inserted the applicator too far, found it painful and fainted. A nurse who had had laser treatment complained that it was embarrassing to be given the cream and instructions about using it in the corridor in front of other people by the ward clerk. She felt this was 'unprofessional'.

The motherhood effect

Motherhood appeared to be a significant determinant of whether a woman would experience severe symptoms or not. Of the 16 women experiencing severe symptoms from cryocautery and the seven as a result of laser treatment, 12 and five respectively were nulliparous (Table 15). In his study of the psychological and physiological factors related to discomfort during laser vaporisation done on the cervix and the influence of psychological preparation or local anaesthetic upon the discomfort, Ward[7] also found a relationship between motherhood status and the pain experienced, but was unable to demonstrate clearly whether the lower pain evaluations in mothers were due to their motherhood status or their pre-treatment preparation.

Table 15 Motherhood effect

	Experience of symptoms				
	Women with severe symptoms		*Women without severe symptoms*		*Totals*
Mothers					
Cryocautery	4	6	13	17	23
Laser	2		4		
Nulliparous women					
Cryocautery	12	17	2	7	24
Laser	5		5		
Totals		23 (49%)		24 (51%)	47 (100%)

$x^2 = 9.75$, d.f. = 1, $p < 0.01$

Table 16 Women interviewed after surgery

Cone biopsy alone	37	50
Cone biopsy followed by 2nd cone biopsy	1	
Cone biopsy combined with D and C	5	
Cone biopsy combined with sterilisation	1	
Cone biopsy followed by hysterectomy	6	
Hysterectomy without prior cone biopsy		7

Surgery

Fifty women were interviewed after having a cone biopsy operation (Table 16). One woman had two cone biopsy operations, the second four months after the first. In five cases at least the operation was combined with a D and C, and in one case with a sterilisation operation. Five women had a subsequent hysterectomy and one other woman was due to have a hysterectomy when she was last seen by the researcher. Seven women had a hysterectomy without first having a cone biopsy. The length of stay in hospital was three to five days for a cone biopsy and six to fourteen days for a hysterectomy.

The women were asked whether the operation and staying in hospital was worse or not as bad as they had thought it would be. Most of the women who answered the question directly said either that the experience was not as bad as they had thought it would be (67 per cent) or much as they had expected it would be (20 per cent). Only six women (13 per cent) answered that it was worse than they had expected. One of these women had had a hysterectomy: she was a 26-year-old having radical surgery who felt her diagnosis (adenocarcinoma) had been kept from her.

The most striking thing about women's descriptions of having an operation and staying in hospital was the positive aspect of the experience – a few women saying they enjoyed it:

> 'I hadn't had an operation as an adult before. I didn't mind at all. It was really nice, lovely, very relaxed and informal. . .'

> 'Everybody was very, very friendly. I enjoyed staying in hospital and the company. I was sorry to leave.'

A key factor in this experience was the nursing care received. Fifteen women complimented the hospital staff, saying the nurses 'really looked after you', they were 'very good', 'very efficient', 'very nice', the whole staff were 'absolutely marvellous', 'wonderful', 'sympathetic', 'the care and attention second to none'.

After having a cone biopsy operation few women suffered any acute symptoms, so that once they had recovered from the effects of the anaesthetic, they could enjoy their patient status:

> '. . . sitting down with no pain and having books and meals brought to me . . . fussed over at home and by the medics . . .'

Only five women mentioned feeling any pain while they were in hospital,[8] though several said they had 'period pain' at a later stage. Others commented on the lack of pain or discomfort and on how well they felt after the operation:

> 'No pain, wind or discomfort – no pain-killer needed. I treated it as a rest.'
>
> 'I felt very well. Some bleeding – no pain.'

One patient was unusual in her complaints. She said that the experience had been worse than she thought it would be, that she had felt terrible for two days and had been in much pain – she had not anticipated it could be so painful – and that she had been unable to sleep. Most women experienced some bleeding post-operatively. This varied widely both in the length of time it lasted (from a few days to three or four weeks) and in amount (from slight to very heavy).

There was only one complaint about the nursing, from a nursing sister who felt she was not cared for as a normal patient, was not in fact 'allowed' to be a patient. Other complaints were about being moved from one ward to another (two women); having to have a 'pre-med' twice because the operation was delayed (one woman); the hospital food (two women, one in each hospital); patients having abortions who were 'wearing it like a badge' (one woman); and not being told about vaginal 'packing' – this caused some temporary concern which could have been avoided.

Cone biopsy operation

Major complications occurred in ten (19 per cent) of the cases requiring cone biopsy operations, all of whom were attending Hospital A.[9] No post-operative complications were reported among women attending Hospital B. (The complication rate after cone biopsy for women attending Hospital A considered alone was 29 per cent.) Two women haemorrhaged post-operatively while still in hospital and were re-sutured under general anaesthetic. Three other women were re-admitted to hospital because of haemorrhage: two were given blood transfusions, one woman requiring five pints of blood, the other four pints, and they were operated on again; the third woman was kept under observation for a few days. There were four cases of cervical stenosis requiring post-operative treatment. In two cases the attempted dilatation failed and a further operation was required. Emergency resuscitation was required for one woman who suffered cardiac arrest as a result of the general anaesthetic.

The average time taken to recover from the effects of surgery was two weeks. Some women recovered from the cone biopsy operation within a few days; others said they took longer (up to six weeks). Obviously the woman's circumstances were a factor influencing recovery time: whether she had children, whether she had help at home, what sort of work she did, whether she lived on her own. Two women came out of hospital on a Thursday and went back to work on the following Monday. One of them did sedentary administrative work in her own business, and the other would have lost wages had she not returned to work. Whether women were told to 'take it easy' for one or for two weeks varied between consultants. Women were usually hospitalised for five days in Hospital B, but only three days in Hospital A; furthermore, the GPs of the women attending Hospital B more frequently encouraged their patients to take three rather than two weeks off work. Several women said they felt they could have gone back to work earlier. Having left hospital on the Saturday, one young woman who went to a party and danced on the Sunday evening subsequently suffered a heavy bleed and had to spend a day in bed. Another woman, who said she had been made to feel guilty in hospital because she had been reluctant to get out of bed, tried to start work again, then collapsed for two days feeling unable to do anything. Both these women complained of post-operative depression. No other woman mentioned feeling depressed after having a cone biopsy operation.

Hysterectomy

There were a number of 'complications' following hysterectomy. One woman had a serious haemorrhage shortly after the operation and was rushed back into the operating theatre. Another had bleeding after she left hospital because of 'trouble with her platelets', and was re-admitted for a week. Three women said they had infections afterwards: one a pelvic infection, another a stitch abscess which was treated by the district nurse, and the third an infection which resulted in 'muscle spasm'. A woman whose surgery had included treatment of a cystocele was still suffering from incontinence when the researcher saw her weeks after the operation. In the case of a woman with pre-existing Crohn's disease, the radium treatment she was given after her hysterectomy resulted in a deterioration in her condition so that she had to spend a further month in hospital.

It is difficult to make any general statement about the time taken to recover from the surgery since the age of the women concerned ranged from 26 to 57 years and the extent of their operations from simple removal of the uterus to pelvic exenteration. For most, it was two months at least before they were feeling stronger, more comfortable and more able to begin to resume their normal activities, and three months at least before work outside the home was resumed. The common feeling of frustration and weakness after the operation was expressed by one woman when she said:

> 'You sit here for four weeks and feel "I must do something – even just go and get a cup of tea," and you physically can't do it.'

Discussion

The women's presentation of the experience of outpatient and surgical treatment is strikingly different: the more minor procedure appeared to produce more physical and emotional distress (except perhaps in the case of the few women who had the traumatic experience of haemorrhaging after a cone biopsy operation). Recognising that pain, shock and post-treatment depression in addition to copious discharge are consequences of the outpatient treatment is the first step towards finding ways of alleviating the distress. To understand the pain, it is necessary to look at the context in which it is experienced; to understand the shock and depression, the important contribution that sympathy and 'tender loving care' can make to the healing process needs to be recognised. Hospitalisation and surgery are treated by lay people and the medical profession alike as a life event of some consequence and, potentially, traumatic. The patient is given special treatment by her family and friends and nursing care while in hospital. With outpatient treatment there is no such special treatment or recognition of the significance of the woman's experience. The patient is expected to get up a short time after treatment and walk off as if nothing had happened. But for the women having outpatient treatment, as for those having an operation, the treatment is the anxiety-making climax of a stressful period of uncertainty about the significance and likely consequences of their abnormal cervical smear – a key point in an episode which is likely to be prominent in their memories of that year.

It is clear that the standard gynaecological teaching that the cervix has few nerve endings so that treatment to it cannot be painful[10] needs to be revised in the light of our findings – based on patients' reports of their experiences, and the observations of colposcopists.[4] In trying to make sense of widely differing accounts of the pain of outpatient treatment of abnormal cervical cells, it has been felt essential to accept the validity of each individual woman's account and to allow that pain may be more than a purely physical entity; that it is a form of suffering with a number of dimensions which is affected by its meaning for the individual.[11]

To try to separate the various possible components of meaning one can ask what would have made the outpatient treatment a different experience. It would have been different if:

1 the piece of tissue to be destroyed had been on the outside of the body – visceral pain is harder to bear, to detach oneself from;
2 the lesion had been something visible, such as a wart on the hand or foot, rather than something unseen, unknowable, lurking in the depths of the body, threatening a part vital to the woman's sense of identity and to her prospects;
3 the condition had had no association with cancer, so often thought of as a scourge and a malign, indestructible consumer of the human body and spirit;
4 the condition had nothing to do with sex, with no hurtful assumptions being made about past sexual activity;
5 the discomfort could have been readily understood and conceptualised, and had been experienced before. (However, the techniques of both outpatient treatments are difficult to understand, requiring a grasp of concepts in chemistry and physics. It is unlikely that the woman will have had experience of such treatment before and it is difficult for her to know what to expect. Erroneous expectations may make things worse. Fear of the unknown certainly increases anxiety.)

It is difficult to alter those aspects of the situation which result in what was termed by one patient 'the spiritual hurt'. In the end, there is no circumventing the sense of violation that the outpatient treatment involves: a private, intimate, potentially pleasurable and creative, certainly special, domain of life, is transmuted into a public, observable, possibly painful, necessarily destructive and routinely technical experience. There were a number of indications that this was a source of much hurt and a possible cause of depression after outpatient treatment. Emotional distress was seldom experienced by women after a cone biopsy operation. They are, of course, unconscious during their treatment, and afterwards given nursing care and special treatment by friends and relatives. The finding that motherhood is a significant determinant of whether women will have severe symptoms from the outpatient treatment may not be related merely, or even mainly, to physical factors. In discussing the invasion of their privacy, women have suggested that they have become immune to it during their pregnancies because of their repeated experience of medical examinations. The 'spiritual' hurt of the outpatient treatment goes unrecognised while attention is focused on the physical condition of a woman's cervix, ignoring the possible damage to her feeling of integrity as a person. Healing requires attention to both. Medical intervention could be less damaging in this sense, if there were to be greater understanding of the hurt caused by the treatment and means found to alleviate it.

5 REACTIONS TO THE MEDICAL PROCESS

Initial feelings

After inviting the woman to explain how she first heard that anything was wrong with her smear, we asked how she had felt when she knew. The women described feelings of shock, horror, alarm, extreme anxiety and some disbelief, anger and helplessness. Over a quarter of the women (27 per cent) described themselves as being 'shocked', 'stunned', 'surprised', 'devastated' or 'very upset' when they first knew they had an abnormal smear. The shock and sometimes disbelief was related to their expectations that nothing was wrong and that they were not likely to get an abnormal (positive) smear:

> 'My smears had always been clear before...'
>
> '[I felt] completely horrified, shocked, devastated. I couldn't go back to work that day. I'd never really had any illness.'
>
> '[I was] shocked, really shocked – I didn't expect it because of my age.'
>
> '[I felt] stunned. I never thought it could happen to me.'

Where a woman 'had a suspicion something was not quite right – knew something needed sorting out' (as one woman explained), she could feel that the finding confirmed her suspicions and she might not be so shocked, depending on her interpretation of the smear result:

> 'If I'd just gone for a routine smear and they'd found something, I would have been surprised. But I expected something because of the trouble I've been having and I'm keen to get it treated.'
>
> 'I thought something must be wrong. I've been trying for a year to be pregnant. I've only had two or three periods. I'm pleased something wrong has been found and could be treated.'

The feelings of alarm, extreme anxiety and horror related to beliefs that the abnormal (positive) smear implied cancer, necessitating a hysterectomy, an end to childbearing, and possible death. One woman said she 'planned her funeral'; two others took out life insurance for the first time. Sixty-five per cent of the women said that they were 'worried', 'alarmed', 'concerned', 'anxious' or 'nervous':

> '[I felt] awful, very frightened, very upset. The first week I was quite hopeless...'
>
> '[I was] petrified – worried sick about it for one month.'
>
> 'The letter from the GP came on Saturday morning. I couldn't see her until Tuesday. I convinced myself during those few days I was going to die.'
>
> 'I lost half a stone in weight. I lost my appetite, felt sick. I had this awful feeling it was going to be cancer.'

The anxiety was primarily because of the threat of cancer and possible death:

> 'The GP put me in quite a state. I walked out with jelly legs. It left you with a horrible dread ... I kept looking at the children. We had a terrible weekend... Cancer's a dreaded word. Known friends with cancer – always fatal.'
>
> 'The word cancer, or anything associated with it – immediately you think you're going to die. You can't do anything but worry. The family worried. Everybody thinks cancer is unstoppable. It's a nasty black word. When you don't know what's happening, you start imagining...'

There was much anxiety surrounding the possible implications of the condition as far as childbearing ability was concerned:

> '[I was] very anxious ... worried about cancer at first – obviously uppermost in my mind. Worried about the possible effect on my fertility. I'm in my thirties and not had children yet.'
>
> '[It was] all a bit traumatic. Hoping to start a family and then this ... I was afraid of not being able to have children. [It's the] worry and not knowing, doubts and questions. The family planning clinic gives the impression you won't ever hear anything... You put two and two together and make fifty...'

Fear of the unknown, particularly in regard to what colposcopy entailed, increased anxieties:

> '[I was] very upset and shocked – afraid of the unknown – basically don't know what to expect – it's long and drawn out . . . I just want to get it over and done with.'

The necessity for a gynaecological examination increased some women's anxieties:

> '[I was] upset. I feel the examination is humiliating and embarrassing . . .'

Feelings of anger, annoyance and resentment were also expressed. These feelings related to women not being told earlier about the abnormal smear (in one case, for two years, and in another, nine months), or to the way in which they were informed of it, or to feelings of victimisation:

> '[I felt] anger. I thought I should either have been told more, or should have been told less in the letter . . . I felt that it was unfair – why did it have to happen to me? . . . I felt victimised . . .'

> '. . . I've never had a threat to my life. I felt angry at the "grim reaper" and that it wasn't fair because I'd struggled not to give up life when I was very depressed after my daughter was born . . . and now this . . .'

> '. . . I felt resentful at the doctors for having diagnosed me. I felt I didn't deserve it. I started having sexual intercourse at 24 and I haven't been promiscuous . . .'

Some women seemed to be philosophical about the situation and appeared to be taking the medical process in their stride:

> 'If there's something the matter with you, [it's] better to have it seen to.'

> 'If there's anything there, the sooner they find it the better.'

However, it is likely that the amount of upset caused initially by the news of the abnormal smear was sometimes under-reported. On occasions when partners were present at the interview, their interjections implied that some women were playing down the distress. For example:

> Patient: 'I was a bit worried.'
> Husband: 'The house went up in flames. Everything was cancer . . .'

The women whose diagnosis was found to be more serious (because they had an invasive lesion) did not seem to be more worried initially than anyone else:

> 'Quite honestly I'm not the sort to worry very much. I wait till I know what's wrong. I've had lots of smears in recent years – they've obviously caught it early.'
>
> 'I'm a bit worried – not panicky. It's a damned nuisance.'

By the time of the first interview when they came to see the colposcopist, some women were recognising that they had 'over-reacted' at first and they described themselves as calmer:

> '[I was] panic stricken. I got it out of proportion. My sister came up from South Wales the next day...'

Some women came to the conclusion from the length of time they had to wait for an appointment that the condition did not require urgent medical attention:

> '... because there was a two-month wait before I was to see anyone, I assumed it couldn't be that drastic.'
>
> '[I was] alarmed for the first day. After the second I put it out of my mind. If it was that serious they would have had me in straight away.'

For a few women the anxiety did not diminish at all during this time, and the waiting was difficult to bear:

> 'I found the waiting absolutely terrible. I wanted the thing removed rapidly. I wanted to get back to normality. It was difficult to be entirely rational.'
>
> '... I feel I've had to wait a long time to see someone. Either not knowing or knowing a little makes it difficult. I wished I could have seen someone, for example a nurse-counsellor, to talk to.'

Feelings after colposcopy

Most women were first interviewed on the day they came to see the colposcopist (see page 102) either shortly before going into the clinic, or immediately afterwards. Those who had been seen beforehand were re-interviewed not long afterwards. The women were asked: 'How did you feel about things after you'd been to the colposcopy

Table 17 Women's feelings after colposcopy

	% *(n = 134)*
Better	52
Worse	19
No different	18
Both better and worse	5
In limbo	6

clinic?' Just over half (52 per cent – see Table 17) felt better. They were reassured and relieved for several reasons. In the first place the examination – the prospect of which had caused much anxiety because of lack of information about what was entailed or what was its exact purpose – was 'over and done with'. Secondly, the women could feel they now knew 'what was going on', 'what was happening', and nearly always had been reassured that their condition was 'nothing drastic' and 'not too serious'. Thirdly, they could feel 'things are progressing' after a long wait to see the colposcopist – that 'something had actually been done' and 'they've got the situation in hand'.

Whereas the woman's medical condition before was an unspecified threat to her future, now the threat was limited and much reduced, and the condition was going to be dealt with:

> 'I felt rather happier – cheered up, because of the idea it was contained.'
>
> 'Relieved knowing what I've got and they can do something about it.'
>
> '[I felt] reassured – a lot better knowing the date for laser treatment.'
>
> 'Just the fact that I wouldn't have to go into hospital made me feel better and its only being a small area.'

For these women the visit to the colposcopy clinic reduced the uncertainty and the anxiety which accompanied it:

> 'Relieved – the worst thing is not knowing what's going to happen or what it is.'
>
> 'Quite relieved. The uncertainty is resolved mostly. When you don't know, you magnify things.'

> 'I felt a bit happier after I'd been and discussed it and had the test. I'm wanting to get it sorted out. It's nagging away at the back of my mind. Really the whole thing is the uncertainty.'

Reassurance came not only from the information given, but also from the examination itself:

> 'I was reassured by what was said. I felt a lot better. Our doctor hadn't really said anything.'
>
> 'I feel better. You've no idea. Before examining me, the doctor said "It's not cancer". It didn't help being told this until after the exam.'

The tones in which the condition was discussed and the lack of urgency about arranging treatment, along with the fact that the treatment was either a small operation or outpatient treatment, was also reassuring. Thus, by what was actually said and by implication, women could be reassured that they had not got cancer and were probably not going to need a hysterectomy, though they might still be unclear about what their condition was if it was not cancer. Women said they felt:

> 'Relaxed, because you automatically think it's cancer.'
>
> 'Better because it couldn't be too serious because they hadn't done anything there and then.'
>
> 'Relieved. I still don't know what I've got . . . I felt if it had been really serious . . .'
>
> 'Better – now that I know exactly what it is. Well, I don't know what it is exactly.'

A few women (6 per cent) felt they were left 'in limbo' waiting to know the results of tests, to know what would happen; or waiting until the treatment had been completed, before they could feel relief:

> 'You couldn't be entirely happy because of the biopsy. You sit there and worry whether you're going to . . .'
>
> 'Disappointed because something's wrong but I'm not told what. It's the waiting . . .'
>
> 'I'll be happier when I've had the freezing treatment done and I know that's going to be enough.'

Eighteen per cent of the women said they felt no different or had no particular feelings after the colposcopy examination. Many said they had not been particularly worried beforehand:

> 'I wasn't worried unduly about my health. I haven't treated it as that serious.'
>
> 'I feel just about the same. I never really dwelt on it. If there's anything there I know they've caught it early.'

Nearly a fifth (19 per cent) of the women said they felt worse after their first visit to the colposcopy clinic, for one reason or another. This was partly a reaction to the stress of the examination for them, and partly that, in a number of cases, the result of the examination had been at variance with their expectations. Some women described their state immediately after their visit to the colposcopy clinic as 'upset', 'emotionally ragged', 'a bit shattered', 'shocked', 'tired', 'very low', 'shaky on the legs', and as having had 'a good cry and a good think about it'. Colposcopy may have confirmed that there was something wrong which needed treatment when the woman was hoping there was nothing 'really wrong':

> 'I thought I was being referred to the colposcopy clinic just for a check. They implied there was nothing really wrong... [I was] not prepared for something to be definitely wrong and needing treatment.'
>
> 'I felt a bit dazed after, I had thought they'd made a mistake.'
>
> '[It's] not very nice. It's horrible. You don't know what to think about it. It makes me feel ill having something wrong with me. [It's] the stigma of being ill.'
>
> 'I feel shocked again because it's confirmed it's cancerous. With a smear, there's always an element of doubt. [It was] a shock to see the photos.'
>
> 'It was more than I'd bargained for, because of the possibility of an operation and its possible effect on my fertility.'

Or they may have been expecting that they would just need treatment for a vaginal infection:

> 'I was not relieved really. I thought I would be given some pills or pessaries or something. Not expecting to have treatment.'

Other expectations which caused disappointment were that 'they would be able to tell me today' and that the treatment would be done there and then. Unless patients are forewarned that they may have to wait for confirmation regarding any necessary treatment, this is likely to be a cause of disappointment. Several women were also worried by the implications of having one or more biopsies:

> '[I felt] slightly shattered – I wasn't expecting the biopsy.'
>
> 'I don't feel too bad [before] . . . I was worried by the cutting [five biopsies].'

There were some women (5 per cent) who said they felt both some relief and some anxiety after the colposcopy examination:

> '. . . both better and worse. I was hoping that they wouldn't find anything. [It's] confirmed that there was something there. However, I feel if something's slightly wrong, it's best to find out about it.'
>
> 'Felt a bit sore; less worried, but still concerned about the possibility of an operation.'

Some of the relief after the colposcopy examination resulting from the reassurance that the condition was not as serious as the woman had at first feared was replaced with apprehension about the forthcoming treatment.[1]

The most anxious time

In the last interview women were asked when was the most anxious time. More women (46 per cent – see Table 18) mentioned the initial period after they were first told about the abnormal smear and up to the time they saw the colposcopist than any other time. They often recalled their shock on first hearing and the circumstances in which they were informed of the result:

> 'When I first heard about the smear – you immediately think the worst – until the colposcopy clinic appointment.'
>
> 'The night the doctor phoned and told me about the appointment at the colposcopy clinic – I was on my own that evening – from that night until I'd been to the colposcopy clinic.'

Table 18 Time of greatest anxiety*

	% *(n = 119)*
Before colposcopy	46
Waiting for treatment	33
During and immediately after treatment	17
Waiting for check-up	11
None	8

*Some women gave more than one answer.

The period during which they were waiting to have treatment was the second most frequently cited (by 33 per cent) time of anxiety. There was anxiety about exactly what outpatient treatment entailed; and about going into hospital, having a general anaesthetic and whether surgery would reveal a more serious condition than anticipated:

> 'Before the operation, you don't know what's going to happen. If I hadn't asked – no idea – I could still have thought it was cancer. The worst thing is not knowing.'
>
> 'Before the laser treatment. I worried about how it would be done. I didn't know what it would be like.'
>
> 'Before I went in. I was afraid that it was cancer and worse than they said.'

For a small number of women the period shortly after the colposcopy examination was the most anxious time, because they were not reassured:

> 'Just after the first time I went because I had just broken up with my boyfriend and my parents were going through a difficult patch – I was feeling ill and depressed. I was told they might have to cut a whole lump out of the cervix plus no sex before marriage!'
>
> 'After colposcopy: the investigation was a bit gruelling – I thought something must be wrong...'

Two women said the most anxious time for them was while the treatment was actually being carried out. Three others having surgery said they felt panic when they were going to the operating theatre. Seven women said they felt most anxious immediately after their treatment. In three cases this was associated with the trauma of a haemorrhage:

> 'When I was haemorrhaging, I was shocked and frightened. I was told that they couldn't do an operation to re-stitch straight away because I had eaten and drunk. I could feel the blood pumping out – horrifying. I was told that if I couldn't be re-stitched successfully I might need to have a hysterectomy...'

In another case, anxiety after treatment resulted from being told by the surgeon that it had been necessary to cut three-quarters of the cervix away when the patient was anxious to have a baby. A second woman was made extremely anxious by being told after her cone biopsy operation:

> 'We'll be sending you home, and if there's anything seriously wrong we'll send for you to come back again.'

Waiting for the results of smears on follow-up checks, or the examination of cone biopsy specimens, was the most anxious time for 11 per cent of the women:

> 'When I was waiting to get the histology results to see if they'd got it all out.'

> 'The first few days after going to the colposcopy clinic and they had taken the biopsies of the little patches. I had to wait three weeks for the results.'

Ten women said that there was no time when they had been really anxious.

> 'It didn't really bother me. I didn't really have time to think about it. When you have got something you just get it cleared up.'

> 'No anxious time. The doctor explained everything so well and she was so down to earth.'

The proportions of women attending Hospital B who replied that they were most anxious at stages after colposcopy were somewhat higher than those attending Hospital A. This may have been associated with the organisation of the medical process (see Chapter 2); patients in Hospital B were often not told what treatment would be needed at the first colposcopy examination, but had to wait for a letter; they had to go to a new place for the outpatient treatment; and they did not necessarily see the same doctor or nurses.

The answers to a subsequent question which asked how long the cervical condition had been 'on your mind a lot of the time' (see Table 19), reflected the time of greatest anxiety for most of the women, 24 per cent replying 'at the beginning' or until they had seen the colposcopist; a further 22 per cent said until they had had treatment:

> 'Before going to the hospital it was a blight on my life.'
>
> 'Before the operation I constantly thought about it.'

Nine per cent replied that it had been constantly on their minds:

> 'It never completely left my mind.'
>
> 'In the evening when I am on my own, I think about it all the time.'

Just over a fifth (21 per cent), however, said that it had never dominated their thoughts:

> 'Not really – I put it to the back of my mind. Other people were more worried.'

Three women said that their husbands were more worried than they were.

The abnormal smear finding caused many women a great deal of anxiety, particularly in the period before their colposcopy examination and while waiting to have treatment. For some this meant many months in which the cervical condition was a constant concern, and, for a few, it remained a continuing threat.

Table 19 Length of time cervical condition dominated thoughts

	% *(n = 116)*
Until colposcopy	24
Until treatment	22
Until post-treatment check-up	9
Intermittently	9
Other	6
All the time	9
Not at all	21

The worst fear

When the women were next asked what their 'worst fears' had been when they first heard anything was wrong their answers were parallel with what had been said about initial feelings. By far the most common reply was fear of cancer (56 per cent mentioning it), immediately linked with the assumed consequences: hysterectomy, an end to childbearing and possible death:

> 'That I had actually got cancer and it was the end of everything.'
>
> 'Immediately I thought I had cervical cancer because that was what the smear was for. I had the impression that either you were all right or you weren't.'
>
> 'Cancer, I suppose, and the possibility of a hysterectomy before having married and had children.'

Along with the immediate fear that what was wrong was cancer went a readiness to assume the worst:

> 'I thought it was terminal. Anything asociated with cancer, you always think the worst . . .'
>
> '[I was afraid] I had cancer and a poor prognosis and wouldn't see the children grow up or my grandchildren.'

Some women talked of fear of the consequences they assumed would follow from an abnormal smear without mentioning cancer in their answers – three mentioning hysterectomy, four death, and nine infertility.

In some answers cancer was an underlying rather than overt fear:

> 'Although you get a lot of reassurance, I think you really think: "Are they telling me the whole truth?"'
>
> '[I was afraid] that it was worse than they were saying.'

The fears of four pregnant women centred on whether their pregnancies would be affected. Seven other women said they were afraid of the unknown:

> '[I was afraid of] what was going to happen and what it was.'
>
> 'I didn't know what colposcopy was, and there seemed no way to find out. I wanted to know if this led to cancer and what alternatives there were – really frustrating not knowing.'

The image of cancer

By the time of the last interview anxieties about diagnosis had been resolved, and women who did not have invasive lesions were asked how they would describe cancer as a disease. Most (68 per cent – see Table 20) of the women who felt able to describe the disease at all spoke in metaphorical and very negative terms of an unstoppable destruction of the human body and spirit. The descriptive terms used were extremely negative ones such as 'horrible', 'pure agony', 'emaciation', 'terrible', 'malignant', 'the most dreaded word'. The pictures presented were equally black:

> 'Vision of a dirty, horrible festering growth festering inside you.'
>
> 'Imagine a black fungus, creeping, mouldy.'

These descriptions of cancer are similar to the cultural image which has been described before.[2] Metaphorically, cancer is the triumph of death over life, evil over good. Nearly a third of the women interviewed (32 per cent) equated the disease with death:

> 'Grandmother died of it. A very painful, lingering, very nasty dreadful death . . . Worst thing you could possibly have.'
>
> 'Very difficult to cure – it seems to get you in the end. A terrible thing. A great fear. No hope.'
>
> 'Terminal, very frightening, almost unmentionable.'

A fifth talked of the body, or more specifically, normal cells being eaten away, devoured, invaded or destroyed:[3]

> 'Just a terrible disease. It just seems to eat people away – to eat at the body. It really devours the body. [You're] perfect one day and within a year, dead.'

Table 20 Description of cancer

	% *(n = 115)*
Negative, metaphorical description	68
Technical description in terms of cell changes/ growth/different types	17
Hopeful	3
Unable to describe	12

> 'Looking down at your stomach you think "What's eating away in there?"'

> 'Bad cells that eat away your good cells. In the end they outbalance the good, normal cells.'

Thirteen per cent said that cancer 'takes over the body completely', that 'the body gives up', or the body or cells 'get out of control':

> 'The body turning in on itself – inside out – like a will to die.'

> 'One of those things that you're not aware that you've got. It takes over without your being aware it's there – that's the frightening thing about it. You're carrying on a normal life...'

So strong is the cultural image that it is very difficult to think of the disease in purely nominalist terms. A minority (17 per cent) of the women gave answers which described the disease in technical or medical terms only, mentioning cellular abnormalities, a growth, or different types of cancer with different prognoses. Only four women (3 per cent) spoke in terms which could be considered at all hopeful. They said:

> 'If you've got strong defence, you will overcome the onslaught...'

> 'I used to think of cancer as a terrible thing. I know it's curable and you can fight it. It's not talked about and brought out into the open.'

> 'People don't die of cancer of the cervix anymore.'

> '... too many people think of it as a killer.'

Future prospects

Women's views of the curability of cervical cancer

Over 80 per cent of the women (Table 21) thought that cervical cancer was curable 'if caught early'; a further 11 per cent that it was 'usually curable'; and only 8 per cent were more guarded, saying that it was 'sometimes curable'.[4] No one said it was 'not curable', or 'seldom curable'. (The respondents were offered these five options as answers, on a card.) The striking conflict between the dreadful image of cancer described above and the optimism of the majority of answers to the question 'How curable would you say cervical cancer is?' was contained in a nurse-tutor's description of cancer as 'A

Table 21 Curability of cervical cancer

	% *(n = 121)*
If caught early	81
Usually	11
Sometimes	8

Table 22 Is recurrence likely?

	% *(n = 104)*
No	20
Not likely but possible	17
Possible	23
Yes	20
Don't know	20

disease which kills you (even though I know it can be cured)'. These women were knowledgeable and optimistic about a specific cancer relevant to them, but this was not always enough to undermine their picture of the disease in general, which remained dominated by the prevailing cultural image of cancer.

It is thus not surprising that there was an ambivalent response to questions in the second interview about future prospects. When the women were asked: 'Do you think the condition is likely to recur?', 37 per cent thought this was unlikely; however, a slightly greater percentage (43 per cent) thought that it was either likely (20 per cent) or certainly quite possible (23 per cent) (Table 22). A further 20 per cent were unsure, so that altogether 63 per cent could not be confident that recurrence was unlikely. A frequent comment was that 'No one's said anything', but the many repeat smears at follow-up visits implied that recurrence was quite likely:

> 'Yes – regular check-ups suggest it is . . . Just a feeling you get once it's happened.'

> '[I] assumed it could happen again because they said they would keep a close eye on it.'

The patients who had asked doctors about the possibility of recurrence reported being told rather different things:

> 'It was very unlikely . . . not statistically prejudiced by having had it once.'
>
> '[I was] assured not. The chances were that it was unlikely that it would happen again.'
>
> 'I was told I was slightly more prone.'
>
> 'One doctor said I would have to have tests the rest of my life.'

Whatever the doctor says about future prospects will carry great weight and affect the way the patient thinks about her health status.

There was also an ambivalent response to the question: 'Do you feel at all threatened by the possibility of cancer now?' Forty-five per cent of the women replied 'No' or 'No more so than before/than anyone else'; but 35 per cent said they felt *more* threatened, 13 per cent talking in terms of it being an ever-present threat and 7 per cent being uncertain (Table 23). Those who said they felt more threatened, said this was because they were more aware of the possibility of cancer – it was always in the back of their mind; or because they felt themselves to be more vulnerable, more prone to develop it:

> 'Yes. I think I will when I get older. Once it's got you once . . .'
>
> '[I'm] more conscious of a fear of cancer. I've been very low for quite some time – morbid thoughts.'
>
> '[It's] always there in your mind. [It] feels as though one is more susceptible.'

Only one woman said that she was less likely to get cancer:

> 'As [my husband] pointed out – it's less likely because I will be so checked up on.'

Table 23 Cancer: a continuing threat?

		% *(n = 118)*
No/no more so than before or than anyone else		45
Yes	35	55
Yes: ever-present threat	13	
Uncertain	7	

This rational point needs more emphasis, because here again the view of cancer as essentially unbeatable is often counterbalancing the knowledge these women possessed by this stage of the medical process of the protective function of the cervical smear test and the essentially optimistic outlook with CIN.

Changes in body image

Towards the end of the first interview, the women were asked whether knowing that they had an abnormal smear had made them feel differently about their bodies. About 45 per cent said it had not, some saying that they were surprised that they did not have any symptoms:

> 'Not really. I don't know I've got it.'
>
> 'No. [I've] seen no changes.'

Among women who did feel differently, the most common expressions were of feeling 'detached', being out of control of the body, and of being defiled. One way of coping with the knowledge of abnormal cells in one's body is to feel alienated from them. 'It makes you feel a bit distant from your body', as one woman said. Another who had wart virus infection said she felt disgusted by the warts, had tried to ignore them and was unable to relate the condition to herself. These feelings of alienation and being out of control were expressed in terms such as:

> '[It's] as if I'm not in control. [There's] something inside. I can't do anything about it and can't see it.'
>
> '. . . things going on I didn't know about.'
>
> 'I'm subject to it – it's decision.'

The feeling of not being in control was related to anxiety about what else was going on in the body unbeknown to its owner:

> 'If it's sort of just shown up, I wonder whether there's anything anywhere else. I don't know about this – what else don't I know about?'

Clearly it is unnerving to one's sense of confidence and security to have a hidden defect discovered which represents, in whatever sense, a threat to one's life and the integrity of one's body. These were women mostly in the prime of life, mostly well women, suddenly faced with their mortality, vulnerability and the body's imperfection:

> 'It brings home that things can go wrong. You tend to take your body for granted.'

There was a difficulty involved in visualising the condition and knowing how to think about it:

> 'Originally I had a vision of a normal uterus and a grossly enlarged cervix.'

> 'You just want to know what it is and then you can think about it.'

There was also a difficulty about reconciling feelings of being healthy with the feeling of being vulnerable produced by the knowledge of the abnormal cells. A woman who said she knew that she was healthy (because she had not long ago had a 'medical') said she felt 'frightened' and a 'bit fragile'. One way to cope with this ambivalence about the body's state was to cordon off the cervix, so to speak, and this is evident in two women's answers. One woman, who said she did not feel any differently about her body, then added:

> 'Not about the rest of it. I don't feel my body's turned into a monster. I don't feel the rest of me is contaminated.'

Another woman, who said that she had read about self-healing, explained that it

> 'concentrates the mind on good cells destroying the bad cells. Makes you feel as if you're reducing it.'

Feeling of defilement were sometimes difficult for women to acknowledge. There was often a hesitant admission that they felt 'unclean' or 'dirty'. One young woman said she no longer felt good about her body – that it felt 'old and mouldy'; another that she wanted to 'wash them away' ('them', presumably being the abnormal cells), and that there was something inside her 'that shouldn't be', 'that wasn't her'. A third woman chose a very telling metaphor to express her feeling that she was 'diseased, like a leper', and did not want anyone to come near her, did not want to be touched. (She knew that her condition was not contagious.) In many ways cancer, or anything associated with it, is viewed now as leprosy was: a disease with strong moral and emotional overtones, associated with uncleanness and death. Lepers were treated in biblical times as both defiled and defiling, as leprosy was viewed as a disease of the soul, the outward marking which branded the sinner.

Sexual relations

Such feelings of defilement, vulnerability and alienation were likely to affect women's feelings about sexual activity. The first interview included a question which asked whether knowing she had an abnormal smear had made the woman feel any differently about sexual relations. Forty-two per cent of the women said that it had. There were four questions in the last interview relevant to sexual activity. The first of these was 'Did the abnormal smear finding, in any way, disturb your sexual relations?' (in addition, that is, to the post-treatment interruption). Excluding those who complained of concomitant symptoms, 43 per cent of the women interviewed replied that it had.*

Those who replied that the abnormal smear finding had made them feel differently about sexual relations, explained:

> 'I'm dubious. I haven't at all, not since I was told something was there.'
>
> 'Yes, it's put me off until everything has cleared up.'

In Hospital B it could be at least five months before the condition was 'cleared up'. There was concern firstly that sexual intercourse might 'do more damage' or 'aggravate' the condition:

> 'When I first found out something was wrong I was not interested in having sex. [It] could irritate it or something.'
>
> 'It took some time to get over it. [It was] painful because I was tense. You want to leave it. [It's] the thought of what it would do to yourself.'

Secondly, there was an anxiety that it could somehow be transmitted to the sexual partner, and this was accompanied sometimes by a recognition that this might be an irrational feeling:[5]

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*Altogether 52 per cent of the women replied either (early in the medical process) that their feelings about sexual relations had been changed by knowing that they had an abnormal smear, or (later) that it had in some way 'disturbed' their sexual relations. The two questions are not entirely parallel because a woman's feelings but not her actions might be altered, and vice versa. None the less, the two questions together allow some assessment of the psychosexual impact of the abnormal smear finding and subsequent medical process.

> 'I didn't want sex if I thought about it. I worried about my husband's getting it, [though] I knew he couldn't.'

The concern about passing the condition on was often more complex than a simple anxiety that the condition might be 'catching'. It appeared to arise from feelings of bodily defilement which led women to worry that their partners might not want to touch them:

> 'I felt my boyfriend wouldn't want to make love to me. I felt dirty and horrible.'
>
> 'I was a little bit worried that my boyfriend might not want to come near me. I felt unclean.'
>
> 'I sort of thought about it. My boyfriend doesn't seem to mind. I thought he might think, "Dear, there's (something) wrong down there – I don't fancy it".'

The partners for their part seem to have been reassuring. This sense of contamination came from the image of cancer as a scourge; from the stigma attached to the condition of cervical cancer or its precursors because of the associations made with promiscuity (see discussion of 'stigma', page 67); and from the sense of violated private space. One woman with only complimentary things to say about the female colposcopist, vividly expressed this sense of invasion:

> 'When you go to the hospital again, it all comes back: the feeling you feel, should be unreasonable. [You] can't take it out on anyone. I felt violated. I felt I knew what it was like to be raped. My privacy had been breached – [it] wasn't private any more. Sexually, I didn't want to know Ian for a few days.'

The need for an interruption of sexual activity after treatment was well accepted and as far as could be assessed, the advice to abstain was mostly taken. Women said of this time:

> 'It's like having a baby.'
>
> '[It's] the last thing on your mind when you've been messed about.'

The recommended length of time of abstention varied from two to six weeks with the most frequently recommended time in Hospital A being three weeks and in Hospital B, four weeks. Some women reported having to ask about the resumption of sexual intercourse and being told different lengths of time by different medical personnel.[6]

Changes in contraception and co-existing symptoms were other factors which could complicate the situation and further disrupt sexual relations. As one woman explained, she had 'had to come off the pill' and this had meant a lack of spontaneity and an inability to relax as far as she was concerned because she felt unsure of the safety of the alternative contraceptive used. It is hoped that greater awareness of the possible psychosexual effects of an abnormal cervical smear will encourage more sensitive handling of any changes which are advised in patients' contraception, in order to avoid adding to the stress of a situation which may be a source of anxiety already.

Awareness of sexually transmitted infections and their origins was a further complicating factor for a few women. Four complained of having been infected by their partners. One woman referred to her previous partner's 'indiscretions'; another to what was, for her, the traumatic experience of having to attend an STD clinic after contracting chlamydia from her husband; the third said that she was 'cross' with her partner of ten years' standing who had at different times transmitted to her herpes, gonorrhea and wart virus infection; and the fourth spoke with much bitterness of remaining 'faithful' to her partner who had 'strayed' and how it was *she* who had something wrong and was in addition *now* told that taking oral contraception might have been a factor, and this made her feel that she might just as well have been 'sleeping around'.

A few women reported some discomfort on resumption of sexual intercourse after cone biopsy operation but this was usually temporary. For the most part any changes in women's attitudes towards sexual relations were short-lived, as in the following examples:

> 'Just after each internal exam I felt a bit tense for two or three days about sexual intercourse.'
>
> 'It wasn't the smear. The time the doctor tried to dilate the womb, I had pain after. They were very sweet about it. It put me right off sex for two weeks and I hated everybody in the world that afternoon.'

However, 14 per cent of the women answering the question: 'Is your sex life back to normal?', replied that it was not. (This percentage does not include the few respondents who were still in the post-treatment stage.)

Some idea of the negative impact the episode could have on a woman's sexual relations can be gained from the following replies to the question in the last interview: 'Did the abnormal smear finding in any way disturb your sexual relations?'

> 'I didn't want to know about that side of my life for quite a while, I'm afraid. I was giving him the cold shoulder all the time. He was angry, until he understood what was going on – then he was understanding. I was worried and depressed and thought sex was disgusting.'
>
> 'I wouldn't let my husband near me until I'd been to the colposcopy clinic. He was fine about it all. I was worried that really he was repulsed and was lying about it. I feel now that I was too self-pitying and was rejecting him and ignored what he was going through.'
>
> 'I tended to get irritable when it came to sex because that was the part that was infected. It brought it back to mind, knowing that there was disease there.'
>
> 'Yes, from the beginning and even now. I'm a little bit more wary. I tend to push men away and to clam up.'

The women were asked whether their GP or the clinic doctor ever discussed sexual relations (other than suggesting a period of post-treatment abstention). Only one woman spoke of being reassured by her GP. Three women said they were asked about sexual relations at their post-operative check-ups. One of these was a woman of 26 who had had a hysterectomy for adenocarcinoma. She said that nothing was said about sex while she was in hospital. When she asked the staff nurse, she was advised to wait until her post-operative check six weeks later. During that check-up the consultant asked: 'How's your intercourse?' The patient said that she would have liked to discuss it with him if he had been on his own, but there was a nurse present. Another of the women who was asked had also had a radical hysterectomy for cervical cancer and said that no one had discussed sexual intercourse in hospital. At her check-up, she was asked: 'Have you tried sexual intercourse yet?' When she replied that she had not, the consultant said that she should, adding, 'It's a smooth job – smooth as velvet'. Two other women said they were asked if they had pain on sexual intercourse and another said that she was asked about bleeding after intercourse.

When sexual activity is so publicly linked with the aetiology of the condition, it is striking that it should be treated so brusquely in the condition's management and with so little apparent awareness of a possible need for sexual counselling. Some of the interviewees mentioned that, if they had *not* been in stable relationships, if their husband or partner had *not* been supportive and understanding, any difficulties they experienced could have remained. The sexual 'sphere' is where the medical process takes place. It is the relevant area of concern, and it is in this domain of life that some patients understandably placed themselves in the 'sick role', at least temporarily:

> 'The first sign of normality is when sex is back to normal. [You] do think of yourself as a bit of a freak. I felt maimed.'

Bearing in mind the preventive rationale for the treatment of CIN there is a real problem which needs to be faced. Intrusion into this private sphere cannot be avoided, nor can the essence of the medical problem be easily circumvented. As one woman expressed it:

> 'You know there is something there. I worried that it would aggravate something else, start something else. Sexual intercourse makes you more susceptible to getting abnormal cells.'

One 22-year-old said that she asked herself 'Is it worth the risk?' Undoubtedly she was not the only woman to do so. A rational discussion of the medical risks involved in the light of current knowledge of aetiological factors and the various forms of contraception available might have been helpful. But what was offered was a series of injunctions: 'Don't take the pill', 'Don't get pregnant...', 'Don't use tampons...', 'Don't have sex for four weeks', 'Don't have sex before marriage'. Four young women complained about being given this last piece of 'advice',[7] one saying that she was 'rather shocked by this attitude' because she 'believed a doctor's personal morality should not intervene' and that it was 'important for the doctor to suspend ethical judgment'; another that she felt she could not discuss sexual relations with the colposcopist because of this attitude; and the third that she 'would like to be chaste before marriage', but felt that she 'can't save herself for Mr Right – not in this society'.

Whether the colposcopy clinic is the place for such a discussion of risk factors and whether there is a role for a sexual counsellor in the gynaecological outpatient clinic is a matter for debate. Certainly it is possible to avoid clinically unnecessary and unhelpful invasions of privacy (such as asking the age when sexual intercourse first took place – see page 94). One woman reported being asked by the colposcopist: 'I don't know if you or your husband have different partners?' As the answer would have made no difference to the management of the condition, the risk of causing distress that the enquiry carried would not seem worth taking. This woman told me that her husband was her only partner and that he had denied having another partner, and that she wanted to believe this. However, she was still clearly worried by the suggestion when I interviewed her many months later, as 'she had seen in the papers about promiscuity...'

Stigma

The interviewees were asked if they had ever felt at all embarrassed or guilty about having an abnormal smear. Many women felt embarrassment, a few had guilt feelings. Some of the embarrassment has been described before and resulted from the invasion of privacy during medical procedures. Women were also very embarrassed because of the *implied* guilt – the stigma of having an abnormal smear. This stigma was linked with how the condition had been presented in the media and meant that women were hesitant to talk to others about their condition, embarrassed if they had to explain, and very concerned about what others would think of them. This is a clear case of stigma as 'spoiled identity'[8] for the public image of the condition made the women feel 'tainted'. One woman explained that she had read an article in the *Observer* newspaper which linked cervical cancer and abnormal cells with promiscuity. Several women had seen a television programme 'insinuating that only women who slept about got it'. One of them said:

> 'I felt dirty because of the documentary on TV ... talking about the permissive society and cervical cancer reaching epidemic proportions. I was worried that everybody would think I'd been sleeping with everybody.'

Another was concerned that her boss and others might 'think badly' of her if they had seen this television programme. She added that she had had only one other partner prior to her marriage. A third woman said:

> 'I heard on TV it's [caused by] sleeping around. I've only ever had three men – if that's being promiscuous...'

A feeling of victimisation resulted from the sense that the stereotype of the promiscuous woman who 'deserved' the condition did not apply. Feelings of 'why me' were common and led to a search for a cause:

> 'It made me wonder if I'd done something wrong to make it develop. Perhaps it was something I did, or I and my husband did, that encouraged it?'

Where women felt guilty, they did so for a number of reasons. In the first place:

> '. . . something wrong with you, does make you feel guilty.'

One woman said she felt guilty towards her husband and family at the time she thought that she had cancer, 'as if I had let them down'. Another felt guilty about 'the fuss'; and another for having smoked cigarettes. Only six women expressed guilt in relation to sexual activity: 'because of the 1960s way of life', 'when asked about age of first intercourse'; because of having had several previous sexual partners (two women); because of having had a boyfriend prior to marriage; and one young woman felt 'guilty because found out' – a sense of exposure that she was having sexual relations at all.

The overall impact of the medical process

Several questions asked at the end of the last interview allow an assessment of the overall impact of the investigation and treatment the women had had, and the extent to which they felt 'back to normal'. The women were asked: 'Would you say that the investigation and treatment you've needed after the abnormal smear finding has been a bit of a nuisance but not much more; [or] a big upset and disruption in your life?' It became clear that the use of the word 'nuisance' was often considered inappropriate, some women saying that it was, on the contrary, 'interesting', 'quite enlightening', 'necessary', 'for your own good', or suggesting words in place of nuisance such as 'inconvenient', 'uncomfortable' or 'unpleasant'. The word 'upset' was endorsed more frequently than the word 'disruption'. One interviewee elaborated on this by saying it was an upset emotionally but not in practical or physiological terms. Of those who felt able to opt for one or other statement, nearly three-quarters (73 per cent) chose the first, implying that the episode seemed to them, looking back upon it, more 'a little hiccup in life' than '[something which] caused a lot of upheaval and distress'. Five patients mentioned the difficulty and expense of getting to the hospital when answering this question.

The second part of this question asked: 'Would you say that the investigation and treatment you've needed after the abnormal smear finding has been something you haven't really got over; [or] something you've already largely forgotten about?' Most respondents (80 per cent) chose the second statement, but several added that they 'had got over it but hadn't forgotten', or some comment such as:

> 'It's always something I'll think about.'
>
> 'I don't think about it now, but I'll never forget the worry.'

Among those who said that it was something they had not really got over, a few suggested:

> 'You never really get over it.'
>
> 'It'll always be there. Not something I've taken lightly, but not a catastrophe.'

Others felt the process was continuing because they were waiting for the results of check-up tests, or because they still had symptoms.

The extent of remaining symptoms was investigated more directly in the next question which asked: 'Do you feel that you are back to normal in all respects now?' The majority of the women (73 per cent) said 'Yes', but over a quarter felt they were not entirely back to normal (Table 24). For nine women this was because they were waiting for another check-up or procedure, or for the results of tests. As one woman put it, 'Not till I get the all clear.' Two women were still recovering from treatment, which had been delayed because of pregnancy in one case, and difficulties about diagnosis in the other.

Table 24 Whether feeling 'back to normal'

			% *(n = 119)*
Yes			73
No	Waiting for check-up/results/another procedure, or treated recently	9	27
	Symptoms	12	
	No symptoms	6	

Fourteen women reported that they had symptoms – in four cases they were the symptoms for which they had originally been referred to the gynaecological outpatient clinic. Of those who had had a hysterectomy, three complained of suffering from tiredness still; one of being afraid to lift anything; and two of difficulties with controlling the bladder's functioning. There were five complaints of discharge. Seven other women said they were not entirely back to normal, but gave no physical reason for this.

We next asked the women if they had ever wished they had not had the (cervical smear) test. Only three expressed any regrets. One of these respondents, a woman who had been treated for cancer of the cervix, said that although she had once wished that she had not had the test, she recognised that she would have consulted her GP again because she would not have tolerated the bleeding she was experiencing. The second respondent said that she had sometimes wished she had not gone for the test because:

> 'You feel as though you're ill and you're not. If I hadn't gone I'd be going on as usual.'

However, this respondent replied to the next question (whether she would advise other women she knew to have the smear test), '[It's] a foolish thing not to have one'. The third expressed regret in her reply to the question (during the first interview) asking how she felt when she first knew anything was wrong.

All the women said that they would advise other women to have a smear test. No one would have discouraged a friend from having laser or freezing treatment, or an operation. They were asked, 'If a friend needed the treatment you have had, how would you explain what was done?'[9] The women often answered this question in terms of how they would present the treatment, and except in a very few cases, this would be positively and encouragingly, making light of any unpleasant effects they themselves knew about from experience[10] by saying something like:

> 'There's nothing to it.'
>
> 'It's nothing to worry about at all.'
>
> '[It's] quite simple, nothing drastic.'
>
> '[It's] just a small operation.'

Some would have explained the preventive nature of the treatment or some of the technicalities. Even those (12 women) who said they would mention that the treatment was uncomfortable or unpleasant said they would have added something to the effect that:

> '... but once it's done it's a great relief.'
>
> '... but [it's] like going to the dentist, a necessary evil.'
>
> '... but [it's] for the best.'

Only four women talked negatively about the treatment at this point, saying:

> 'They're onto a fast one, they don't tell you [about the pain].'
>
> 'I don't think anyone should be told about that or they wouldn't go in.'
>
> 'Well, you go into hospital feeling okay and come out feeling urgh...'
>
> 'The food's crappy and the sheets left you feeling sore because of the starch.'

Two other women said they would warn a friend about the after-effects of treatment they had experienced (pain and emotional upset).

Thus whatever treatment they had had, and whatever their own experience of it, the women were in favour of screening and very few had any doubts about recommending the treatment they had received to a friend.

Finally we asked whether having the abnormal smear had made the woman 'think differently about things in any way'. The question was deliberately very general to invite the woman to answer in whatever terms she wished, and there were many different answers. Forty-five women answered the question negatively. Of the 77 comments in answer to the question, the largest group (21 answers) expressed an increased commitment to cervical screening or a concern not to take one's health for granted and to take more care and pay attention to symptoms:

> 'It's made me more aware of my body and less inclined to think: "Oh, it will be all right. It will go away on its own". It's necessary to seek prompt treatment. You tend to go blithely on thinking "I'm all right".'

> 'You can't take your health for granted. Just because you feel well . . .'
>
> 'I'd go regularly for the tests now.'

The next largest group of answers (14) were indicative of a process of 'taking stock' and re-evaluation of life in the face of a reminder of one's mortality:

> 'It's made me value my life a lot more . . . For me it meant a reassessment of my life and getting my priorities right.'
>
> 'I realised I was just as vulnerable as the next person. I'm not in an at-risk group and it still got me. In a funny sort of way, it makes me mortal.'

Ten answers expressed appreciation of medical developments which had made the detection and treatment of abnormal cervical cells possible:

> 'It's done a lot to restore my faith in hospital doctors. It's been a positive experience. The thing itself was relatively minor.'
>
> 'It gives you more hope about disease really.'
>
> 'I'm glad of the service I got and of the progress in medicine which has enabled them to find these things.'

Nine women said that they were now more conscious of the possibility of getting cancer:

> 'Worry there now that you can get cancer – the possibility that it can happen.'

Three women expressed relief that the cells had been found and dealt with, and three others talked of the uncertainty the medical process had entailed:

> 'I was always looking on the black side. I was quite concerned until three months ago. [The check-up was the first one after treatment.] I dreaded every post or phone call for the two weeks after treatment. It's the uncertainty.'
>
> 'At first it's quite a shock. It gradually recedes, then all this happens. It's a sense of relief. I'd far rather know that I had something wrong.'

> 'I'm worried that there's some unknown thing wrong elsewhere. I felt so well and this was going on. Being told it's nothing to worry about isn't reassuring. You've entered a dark area.'

Four women said in answer to this question that their view of contraception had changed, in three cases in regard to the pill, and in a fourth about having an intra-uterine contraceptive device (IUCD):

> 'About methods of contraception. I'm more in favour of not really interfering with things [and using a method such as the sheath].'

> 'I'd think twice about going on the pill.'

There were a variety of other answers including the following:

> 'Life goes on.'

> 'One more pitfall in life.'

> 'It's made me not categorise people so much as I didn't fit into any of the categories supposed to get cervical cancer.'

Finally, the words of one woman sum up several feelings expressed in many of the answers:

> 'It's nice to remember what's important and what isn't. I look at life in a slightly different way. In a way, [I] was very lucky – it could have been worse – though at the time it was awful.'

6 *THE ROLE OF OTHERS*

Women turned to others for information, comparison, reassurance, support and practical help. The women were asked at different stages of the medical process whether they had spoken to other people about their abnormal smear, whether they had found it helpful to discuss it with others and what the reaction of other people had been. It was clear that it was not only the women themselves who were shocked, upset and worried by the news of the abnormal smear finding.

Partners, family and friends

Nearly a third (31 per cent) of the interviewees mentioned that their partner had been very concerned about the implications of the abnormal cervical smear:

> '[He was] frightened to death. [He's] not a talker. I was totally insensitive to how he felt. He couldn't concentrate at work.'
>
> '[He's] normally pale – he went white. It frightened him. He was anxious . . . very helpful. He treated me as if I was pregnant.'

In a few cases the man was apparently more worried than the woman herself; more often the men were, according to the women, worried 'but not showing it', or not apparently worried. Some tried to counteract the women's concern by telling them not to worry, or to wait to see if there was anything to be really concerned about before getting worried. Forty-three per cent of the women mentioned that their partners were supportive:

> '[He's been] very good, understanding, helpful. [He] took the day off work – very unusual for him.'
>
> '[He's been] very matter of fact. Very supportive and understanding. A very calming influence really.'

A few women made it clear that their partners were not supportive:

> 'My husband has not taken any notice. I can't talk to him. He's not supportive. He was away the weekend when I was most anxious.'

> 'He's hopeless. He doesn't like to be disturbed. I look after myself. I don't trouble him.'

A few women said they felt their partner was 'not the person to talk to' about it, because he 'passes it off' or 'doesn't like to talk about it – doesn't like to talk about emotions', or because he 'doesn't know what it is'.

On occasion, the partner was with the woman when she was being interviewed, and answered the question himself. One replied:

> 'You're going along with life – no problems – all of a sudden ... doubt.'

Another said that he felt he really did not know what was going on:

> 'It makes you think the worst, not telling you what it's about.'

A third expressed his concern for how his partner felt and said that he had tried to make her feel better about it, but it was hard for him to find out about the condition.

When asked in the second interview whether it had 'helped to talk to anyone about it', 64 per cent replied positively and 34 per cent negatively (Table 25). Of the latter, eight women said they had not felt the need to, or that they were 'not the type to' discuss their condition with others; four said they had no one to talk to, and five said that there was no one they knew in the same situation:

> 'I don't know anyone with it. No one can really understand.'

Among those who had been helped by discussing it with someone else, 26 mentioned friends, neighbours or colleagues, 22 mentioned

Table 25 Whether it helped to talk to anyone

Yes			78 (64%)
No	Not felt a need	8	41 (34%)
	Not talked to anyone	8	
	No one to talk to	4	
	No one in the same situation	5	
	Not found discussion helpful	16	
No answer			3 (2%)
Total			122 (100%)

husbands, companions or boyfriends, 20 mentioned others who had also had a similar condition, 12 spoke of female relatives (mothers, sisters or sisters-in-law, and a daughter) and four of 'the family', and 16 mentioned doctors (GPs or doctors in the hospital they were attending). These women felt they had benefited from the support, reassurance and information they had received:

> 'They were supportive, very understanding. No one was dismissive . . . I talked with Dad – [we] haven't talked like that for years. [It was] a lot easier. [You] felt you'd got friends. [It's] nice to feel you're cared about.'
>
> 'My husband – he was very good. I was irritable. He was patient and reassuring. Everybody was good but nobody knew much about it.'

The reactions of others

In describing the reactions of others with whom they had talked about their medical condition, one-fifth mentioned family members, particularly mothers, who were 'shocked', 'horrified', 'very worried', 'really upset' or alarmed about it. Although it helped women to know that others were concerned for them, alarmist reactions were unhelpful and they sometimes expressed an ambivalence about telling others because it had compounded their own fears or caused others distress:

> '[They were] horrified. A lot of people were shocked . . . [it] didn't help my peace of mind.'
>
> '[There was] over-reaction always – immediate association with cancer in its worst form . . . then I had to go back and sort myself out.'
>
> 'They say things to you that makes things worse. [They] ask questions – how you feel all the time. Makes you feel worse when you're trying to forget. No point in brooding on it.'
>
> 'Shock, horror: you're dying of cancer – they were measuring me up for the wooden box.'

Several women mentioned that they did not tell (or waited until they had been treated before telling) friends or relations because they anticipated that they would 'worry too much':

> 'I didn't tell until just before the operation. I didn't want to cause unnecessary concern or make a great event for others to get worried about.'

Women found that few people 'had come across it' or 'knew anything about it' and, 'not knowing what it was, always think the worst'. They found that it was they who sometimes had to do the reassuring, that they had to explain the nature of the condition and its treatment, and occasionally, 'to proselytise' as one woman said, in trying to overcome other women's reluctance to go for a cervical smear test in case they too had something wrong. It was the realisation of just this possibility which seems likely to have prompted a number of friends, neighbours, colleagues and relations to go for cervical screening – eleven women mentioned this:

> '[They] just wanted to make sure they were okay. It just opened their eyes.'

Information and practical help

That people had been very concerned and supportive, but that they did not know enough about it, was a frequent comment. In their attempt to find out more about the condition and its treatment, particularly in the initial stages, women sought out people with 'medical contacts' in the hope that they could give them more information. These contacts were usually relatives in the medical profession, doctors, nurses or members of the paramedical professions, but included a 'girlfriend whose boyfriend is a doctor' and a 'sister with a friend who is a doctor's wife'.

By talking with others, women found out about other people who had had a similar condition and they could then compare their situation with that of another; they no longer felt so isolated and sometimes gained useful information. A little under a third (31 per cent) said in the first interview that they knew, or had heard of another woman or other women who had had the same condition.[1] The reported fate of the other women was, however, not always reassuring. Two interviewees knew of other women who had died of cervical cancer. Several knew women who had had hysterectomies following abnormal smears.[2] Two women had friends who had been treated with radium for cervical cancer in a well-known local cancer hospital. One telephoned her friend who had had a cone biopsy some years previously to ask about the treatment. Her friend replied:

> 'Oh Mary, how absolutely dreadful. I can't talk about it.'

However, there was some comfort to be had from the fact that this friend had subsequently had two children.

By the time they knew what treatment they were to have, a greater proportion of the women knew of other women who had had hysterectomies or cone biopsies, or cauterization or other outpatient treatment to the cervix, but a few had access to someone with experience of exactly the same treatment (particularly cryocautery or laser treatment) whom they could question in detail. However, even to know that a friend of a friend had had the same operation and was 'fine afterwards' was reassuring. At the time of the post-treatment interview 45 per cent of the women interviewed mentioned other women they knew (or knew of) with a similar condition.

It was not only husbands (or partners) but other members of the woman's family and her friends who became involved in practical ways in the medical process following the abnormal smear finding. Half the women came by themselves to the colposcopy clinic, but 31 per cent were accompanied by their husbands or partners and 19 per cent by a friend or relative (Table 26):

> 'You need someone with you – I'd have walked out of the waiting room if I'd come on my own.'

(There were 14 other partners who wanted to come but were unable to, because of work commitments or the difficulty of getting time off work, because they were at home looking after the children, or for some other reason.)[3] Fewer women (32 per cent) came unaccompanied for outpatient treatment; 46 per cent came with their partner; 22 per cent with someone else. Women who were going to have an

Table 26 Who came with the woman to the hospital

	Colposcopy % *(n = 153)*	*Outpatient treatment* % *(n = 44)*
Partner	31	46
Mother	9	9
Friend	4	9
Sister	3	2
Other	3	2
By herself	50	32

operation and who had children were asked how they would manage at home. In 12 cases husbands were mentioned as sources of help, other family members and older children were both mentioned nine times, babysitters twice and, in two cases, friends. In only two cases did women say they would have liked their partners to have come with them when they did not come. It was not clear how often a woman and her partner would have liked the partner to have been in the room when the treatment was being given. Partners were present a few times during cryocautery, but after one partner became faint while watching the treatment, the colposcopist was reluctant to invite others into the room.

The impact of the abnormal smear finding is thus felt by many other people besides the woman herself, and some of these people are involved both emotionally and in practical ways in the subsequent medical process. Those to whom the women turn for support need information in order to help keep the situation in perspective and to support the woman throughout the different stages of the medical process.

7 *INFORMATION*

What the women learned about their condition

Women were told that some abnormality had been found on their smear by letter, by telephone or in person, usually by their GP, but sometimes by a clinic doctor. The immediate reaction to the news was often one of shock and this tended to make it difficult for women to take in the doctor's explanation, or to remember what was said:

> 'After a few words, I didn't listen. I was shocked and it didn't register what he was saying.'

As women often thought of questions they wanted to ask later, it is helpful if doctors invite their patients to come back to see them again, or to telephone with any queries, particularly if there is a long wait before the colposcopy examination.

The doctors varied in how reassuring they were and how well they prepared the women for the likely course of events. It was clear that some GPs were not very knowledgeable themselves about how the smear result should be interpreted, what colposcopy was exactly and what the range of treatment possibilities was.[1] Nearly half (47 per cent) of the women had apparently not had any explanation of colposcopy by the time they came to the colposcopy clinic and very few used the term spontaneously, pronouncing it correctly.[2] Only 26 per cent said that they had been told that outpatient treatment rather than an operation was a possibility.

When the women were asked if the GP had said what was wrong, the explanations given were either in terms of cells, or in more vague terms about the smear being unsatisfactory. They were told they had 'abnormal' (the most frequently used term), 'irregular', 'atypical', 'aplastic', 'dyskaryotic', 'suspicious', 'doubtful', 'funny' or 'odd' cells; 'cancerous', 'foreign', 'infected' or 'inflamed' cells; 'positive cancer' cells; cells which 'weren't quite right', 'didn't look what they should be', 'they weren't happy about', 'were enlarged', 'showed signs of change' or 'harboured something'. Some were told they had a smear which 'they weren't happy about', which was 'a bit abnormal' or 'peculiar', 'not quite right', 'not clear' or 'unsatisfactory'. Occasionally they were told they had 'dyskaryosis', 'dysplasia', 'warts', an infection or inflammation. Sixteen per cent of the women said they were told it was *not* cancer.

After the colposcopy examination, the women were asked if the colposcopist had given the condition a name. Sixty-one per cent said no (56 per cent attending Hospital A and 73 per cent attending Hospital B). Among those who said they had been given a name for their condition, 'abnormal cells' or, at Hospital A, 'wart virus infection', were the most frequently mentioned terms. Other medical terms were used infrequently. One woman saw 'leukoplakia' on her notes, two said they were told they had 'carcinoma-in-situ', three 'dysplasia' and seven 'cervical intraepithelial neoplasia'. Most women knew the term 'abnormal cells' was relevant to their condition, but did not take this to be a name, simply a symptom. The majority of the women thus had no name to attach to the state of their cervix:

> 'I don't know what the problem's called. I haven't got a name for it.'
>
> 'I would have liked a name. It's much easier to deal with a known entity than being left in the dark.'
>
> 'I still don't know what the hell it was. I don't think they realise they leave you in the dark. They involve you with it, but you don't know what you've been involved with.'
>
> 'She was very good. She was sat at the end of the bed. Came straight to the point . . . I would have liked her to have said what was wrong.'

The importance of having a name should not be underestimated.[3] Without a name it was harder for women thinking about their condition or talking about it to other people to fend off the meanings associated with cancer. Since the term cervical intraepithelial neoplasia is now the accepted and accurate medical term for the condition for which most of the women were treated, it is the term which women need in order to have a name. It is too complex a term to be transmitted verbally and needs to be written down, and in normal use to be shortened to CIN.[4]

When asked if the colposcopist had explained what the condition was, women reported being given a considerable variety of explanations. The abnormality of the cells was described in the following terms: 'epithelial changes', 'changed skin formation', 'cells which aren't quite right', 'malfunction of cells', 'odd cells', 'minimal changes', 'a few white cells', 'white patches', 'abnormal bit', 'area of abnormal skin', 'erosion', 'atypical', 'changes in the cells', 'inside of the womb growing outside'. (A few of these explanations refer to conditions other than CIN.) Eighteen women reported after their colposcopy examination that they had been told there were grades of abnormality. Describing the condition in the concrete terms of grades and position on the cervix appeared to be helpful, both because it allowed the women to grasp the idea of a continuum of change from normal cells to cancer cells, and in giving them some way of picturing the condition. It also helped to reassure the women that the doctor knew exactly what and where the abnormality was – that it was confined and treatable.

Most of the women (80) attending Hospital A's colposcopy clinic said they had been shown a diagram of the cervix with the abnormal areas marked on it. About half of the women interviewed at the post-treatment stage who said they had been shown a diagram could still remember it. Fifty-five per cent of the women attending Hospital B's colposcopy clinic were shown a photograph of their cervix (taken through the colposcope on examination). As one woman said, 'They're showing you your body, not hiding it'. There were mixed reactions to seeing the cervix through the teaching aid on the colposcope or a photograph (see page 30). The diagrammatic presentation of the lesion(s) on the cervix seems to have been always acceptable and helpful, although we believe that there was often a lack of knowledge about exactly where the cervix is located and often no clear idea of its size.

In the last interview, the women were asked to say what the condition for which they had been treated was, and given a list to choose from: 'an infection/due to a virus/abnormal cells/cancer/pre-cancerous/possibly pre-cancerous/nothing to do with cancer/do not know', while the interviewer said that it could have been more than one of these conditions. Most women (81 per cent) said they had 'abnormal cells' (Table 27) and 55 per cent said that their condition was *either* 'pre-cancerous' or 'possibly pre-cancerous'. (Four women gave both terms.)

Six women said they had an infection or that the condition was due to a virus, without mentioning 'abnormal cells' or 'pre-cancer'. Four women said (correctly) that their condition had had 'nothing to do with cancer'. No one said they had cancer who had not been

Table 27 Women's choice of terms for their condition (post-treatment)*

	% *(n = 121)*
'Infection'	10
'Due to a virus'	14
'Abnormal cells'	81
'Cancer'	6
'Pre-cancerous'	25
'Possibly pre-cancerous'	33
'Nothing to do with cancer'	3
Did not know	2

*Some women chose more than one answer

diagnosed as having an invasive lesion, but three women said they had 'early cancer cells' and a few of the women choosing the term 'abnormal cells' said that that was what they had been told, one saying:

> 'If you've got some abnormal cells, it's a little bit of cervical cancer.'

Available written information

In the first interview women were asked whether they had read anything about abnormal smears. Nearly two-thirds (62 per cent) replied that they had not. Among those who had, more information had been gained from newspapers and magazine articles than from medical dictionaries or textbooks.

Sixteen per cent said that they had read articles in women's magazines or the 'nursing press'. Some useful information had been gained: that abnormal smears are sometimes caused by inflammation, erosion or age; that cervical cancer can be cured; that the cervical smear can show 'viral changes' and 'pre-cancer'. However, there was some dissatisfaction with the level of information because it was 'washing across the top – didn't go into it'; 'didn't help much – led one astray – all black and white'; mostly 'goes on about cancer . . . what would happen if it were cancer'.

Seven per cent had read newspaper articles in the *Daily Telegraph, The Times* and the *Guardian*, and in a local paper in the northwest. Some of these articles appeared after the publication of the report in the *British Medical Journal* of the association between oral contraceptive use and an increased risk of cervical neoplasia.[5] Women reported that the articles talked of an 'increase in the numbers of young women with abnormal cells, linked with the use of the pill and starting sex early' (*Guardian*); the 'increased number of positives because of promiscuity' (*Daily Telegraph*); 'the contraceptive pill and the increase of cervical cancer' (*The Times*); and the 'epidemic in the northwest' (local paper).

Eleven per cent had tried to look 'it' up in various dictionaries. One woman said:

> '[I'd] no name to go on, otherwise I would have looked it up in the medical dictionary.'

Few were able to find the word 'colposcopy'. Another eleven per cent, many of whom were nurses, looked in medical textbooks and medical guides for women. These tended to cover cervical cancer and its treatment but were seldom up to date enough to cover CIN, colposcopy, laser and cryocautery. Only 8 per cent of the women had found anything at all about forms of treatment. Three per cent mentioned television programmes on colposcopy and on laser treatment. Only one woman mentioned a leaflet (published by the British Medical Association) which she said had a small paragraph about colposcopy.

It is evident that some women will go to considerable trouble to try to find out about their condition, and that there is a great need for readily available information on the investigation and treatment of abnormal cervical cells.*

The women's view of the cervical smear test

Towards the end of the post-treatment interview, four questions were asked about the cervical smear test. The answers form a picture of the women's view of the purpose and benefits of the test after they had been through the medical process following an abnormal smear.

The first of these questions was: 'The cervical smear test is popularly called the "cancer smear" – do you think this is mislead-

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*A pamphlet based on women's experiences, their expressed anxieties and informational needs has been written by the researcher. *An abnormal smear: what does that mean? A woman's guide to the medical investigation and treatment of abnormal cervical cells* is available from the Women's Health Information Centre (WHIC), 52 Featherstone Street, London EC1 (telephone 01-251 6580).

ing?' More than twice as many women (59 per cent) thought it was misleading to call the test the 'cancer smear' as thought it was not (27 per cent). Twelve per cent either felt they did not know, or gave a vague answer. From many women's answers it was evident that though they might have thought at one time in black and white terms (cancer/no cancer) about the test, they now understood that it was not simply a diagnostic test for cancer:

> 'It makes it sound as if anything wrong is necessarily cancer. That's how I used to look at it. Now I understand it's to make sure everything's normal.'
>
> 'That's the thing that's misleading... Most of the women I know call it the cancer smear ... It makes it black and white.'
>
> 'It's not to diagnose cancer. It's only to diagnose pre-cancerous changes.'

It was recognised that the term 'cancer smear' set things up in a way that could be frightening and off-putting and could lead women to jump to the conclusion that they had cancer if the test was not 'clear':

> 'It's pre-empting what's going to come back. Frightens people off.'
>
> 'Yes, I think so. [It is misleading.] If once you get that idea, even if you're told it's not, the thought's there.'

A few women thought that the term underlined the importance of the test:

> 'Yes, perhaps it is [misleading]. But if it wasn't called that it might play down its importance.'

Among those who thought the term was *not* misleading, the most frequent sort of comment was 'that's what they are looking for', 'that's what it's all about':

> 'I would presume every woman when she goes for a smear is going to exclude cancer. All they want to know is whether they've got cancer or not.'

Five women mentioned that the test could find other things besides abnormal cells:

> 'They can test for quite a lot of things. The most serious thing they can find is cancer.'

In a few cases the answers were clearly misinformed:

> 'A lot of people get cancer found on the test.'
>
> 'It's [cancer] the only thing they find really.'
>
> 'Positive means cancer.'

The women's knowledge at this stage in the medical process about the meaning of a 'positive' result was investigated by asking: 'If a friend had a "positive" smear test and asked you what it meant, what would you say to her?' Fifty-six per cent of the women said they would reassure their friend; 47 per cent said they would explain in one way or another that it did not necessarily mean cancer. They would explain to their friend in terms such as:

> 'It's nothing to worry about. It's probably only a few cells wrong and they can cure it.'
>
> 'They've found some cells that may be pre-cancerous – it's better to remove them.'
>
> 'It's not cancer, it's a change in the cells. They've got to check up.'
>
> 'I'd try to tell her all the things that no one told me. It didn't mean she'd got cancer.'

Eighty-two per cent of the women said either that they would be reassuring or that they would have explained the meaning of the result in reassuring terms. This is in contrast to the alarmed reactions of many of the women on first hearing of their own abnormal (positive) smear result some six to nine months earlier. Twelve per cent would have advised their friend to 'go and get it seen to'. Four women said they did not know and five did not answer the actual question, one asking:

> 'Is that what I had?'

The next question about the cervical smear test asked whether the woman would advise other women to have a test. Everyone said they would. Then the women were asked: 'What would you say was the main benefit of the cervical smear test?' The women's answers to this question contained four main components (some women answering in terms of more than one): reassurance, early detection, diagnosis (leading to treatment) and prevention (Table 28). Only three women were uncertain about the test's benefit: two whose smears had been

Table 28 Women's view of the benefit of the test

*Answer component**	% *(n = 122)*
Reassurance	42
Early detection	43
Diagnosis – treatment	20
Prevention	15
Ambiguous	2

*Some women's answers contained more than one component

found to be negative after all and had not required any treatment, and a third who answered vaguely that it was 'for your own health really'.

The reassurance that was seen as a main benefit came from 'knowing that everything's okay', '. . . that you're all clear', 'making sure that everything's all right – nothing's going to go wrong', or more specifically, 'knowing that you haven't got cancer'. The benefit of early detection was talked about in terms such as:

> 'To discover any abnormality early, and to treat it early and efficiently.'
>
> 'Saves you from the possibility of cells which can lead to cancer at a later stage, so why not get rid of them now and not leave it to chance.'
>
> 'Early warning of cancer. I'd much rather have gone through what I did than have cancer.'

The third component of the answers comprised the benefit of finding out if you have cancer or not, 'knowing what's going on in your body':

> '. . . even if perhaps you're not as well off, not as healthy as you think you are – you do know where you are.'

and the benefit of having any problems dealt with:

> 'You get to know one way or the other. If anything's there it can be treated.'
>
> 'They can detect anything and can stop it.'

Prevention or protection was often mentioned in conjunction with another benefit:

> 'Peace of mind. Prevention's much better than cure.'
>
> 'Prevents something that could be serious. Detects at early stages.'

This benefit of the test was seen as preventing a major operation, 'something worse later on', dying of cancer, and 'complications'.

The distribution of the four components of the answers to this question among women who had been previously screened and found to require treatment can be compared with the answers to the same question in a survey of women who had also been previously screened but who had not had an abnormal result. Among the latter group the most frequently mentioned benefit was reassurance (56 per cent); early detection (26 per cent) and prevention (4 per cent) were not so often mentioned.[6] From their experience of investigation and treatment, the women in our sample had gained a better understanding of the purpose of the cervical smear test and the meaning of an abnormal result (and were now in a position to pass on that knowledge). The benefits of early detection and prevention were more prominent in their thinking about the test than was found previously among screened women in the general population.

The women's view of the aetiology of the condition

Altogether four questions relating to the cause of the condition were asked, two in each interview – one reflecting what was known of current theories and one in which the women could present any thoughts they had about the development of their own condition.

Ideas about their own condition

In the post-colposcopy part of the first interview the question was asked: 'Do you try to explain to yourself why you might have got an abnormality on your smear now?' Of the 69 per cent who had any comment to make in answer to the question, a few said it was a 'pointless exercise'. Sixteen per cent said, in effect, that they had no idea or did not understand why they had abnormal cells, many saying that they had 'wondered why me' and would like to know the cause:

> 'Completely took me for six. Absolutely no reason why it should come about . . . I haven't a clue. [It's] something that's happened.'
>
> 'I'd like to know why my cells succumbed and how to stop it happening in the future.'
>
> 'I've come to the conclusion nobody's got an answer.'

Among those who did suggest a possible reason, the largest group (Table 29) associated the abnormality with another bodily condition they had experienced. These conditions included: cervical erosion, sterilisation, poor health, the menopause, a caesarean section, a D and C operation, previous miscarriages, childbirth, the number of births, and 'water infections'.

Five women related their cervical condition to stress and strain they had experienced prior to the abnormal smear finding. One woman, who was a prisoner at the time of the first interview, said that on discussing the abnormal smear with fellow prisoners, they had all been able to relate their abnormal smear to a period of great stress. She had had a normal smear a year earlier. She said she had been 'near to breaking point' in the period before she was 'picked up by the police', and subsequently, in jail, had a routine cervical smear which had been found to be abnormal. Another woman suggested a link between stress in her sex life and the fact that she had 'not got a happy cervix'.

There were those who seemed to be attributing the abnormality to fate (14 women), saying it was 'bad luck', 'just one of those things', 'these things happen' and:

> 'You don't catch it, it just comes.'

Eleven women, some at the suggestion of the doctor, associated the abnormal cells with sexually transmitted infections – seven with wart virus infection. (Three women had been unaware they had had such an infection.) Nine women thought that their method of contraception was related to the development of the abnormal cells: in six cases the IUCD, and in three the pill. One of the women taking the pill, as well as two other women, thought that their smoking 'had something to do with it'. Five women suggested a possible link with changes of sexual partner. One woman, whose husband's first wife had died of cervical cancer, talked of 'high-risk men'. Three women related the condition directly to sexual intercourse, one saying that when she had asked the colposcopist how she had got the cells, the colposcopist had said: 'Well, if you'd gone into a nunnery . . .' One woman thought the use of tampons might be a cause, and another that heredity might be a factor.

The women were asked at the post-treatment stage: 'Do you think you could in any way have avoided getting this condition?' Forty per cent of those who replied said that they did not know of any way they could have avoided getting it, many of them pointing out that if you

Table 29 Women's view of the aetiology of the condition

Suggested factors involved in own condition

	% *(n = 76)*
Associated condition	29
Fate	18
Infection	14
Contraception	12
Change of partner	8
Stress	7
Sex	4
Smoking	4
Other	4

Factors thought to be generally involved

	% *(n = 103)*
'Promiscuity'	31
Contraceptive pill	26
Early first intercourse	17
HPV	16
Associated condition	13
Infection	11
Smoking	11
Semen or sperm	10
Other	15

Suggested ways to avoid

	% *(n = 67)*
No sex	18
Avoid infection	18
Screening	15
Avoid pill	15
Avoid change of partners	15
Avoid smoking	8
Avoid IUCD	5
Use barrier methods	5

do not know the cause, it is difficult to take preventive action. One woman's answer was:

> 'No, because I don't know what it's due to. I did ask myself what could have caused this to happen. I kept coming back to a full stop. It's no good blaming yourself.'

A further 13 per cent thought that it was out of their control – a matter of fate – saying:

> 'If it's going to get you, it's going to get you.'
>
> 'It's something that's either in you or it isn't.'

The suggestions of ways to avoid the condition were (Table 29): not having sexual intercourse, not contracting sexually transmitted infections, not taking the pill, having an earlier cervical smear test, not changing sexual partners, not having an IUCD fitted, and using barrier methods of contraception. A few women suggested smoking might have made it worse.

In the first interview when the women were asked if they had heard any theories about the cause of the condition, over half (56 per cent) said they had not. By the time they were asked about 'factors related to the development of the condition' in the last interview, only 7 per cent said they did not know of any. The most frequently mentioned factor was 'promiscuity', changing partners or 'too much intercourse' (mentioned by 32 women – 31 per cent – see Table 29). Only one woman mentioned that the number of previous partners the male partner had had could be a factor. Twenty-seven (26 per cent) also mentioned the contraceptive pill, a comparatively higher proportion among women attending Hospital B who were interviewed after the publicity about the findings of Vessey *et al.*[5] Starting to have sexual relations at 'an early age' was mentioned by 17 per cent. Sexually transmitted infections were mentioned by 11 per cent and wart virus infection or warts specifically, by 16 per cent. Various conditions, particularly childbirth, were thought to be associated with the development of abnormal cervical cells. Smoking was another suggested factor – mentioned by 11 women (11 per cent). Ten women thought that the development of the condition was something to do with sperm or semen. Personal hygiene (mentioned by four women), the coil (four women), stress (one woman), tampons (one woman) and the male partner's job (two women) were also mentioned.

Those women who tried to explain to themselves initially how the abnormal cells might have developed did so mostly in terms of other conditions they had experienced such as childbirth, or gynaecologically relevant factors such as contraception or infections. For most women, however, the abnormal smear finding came 'out of the blue'. In talking to others or reading about the condition a greater proportion of women became aware of current aetiological theories, particularly as they are presented in the media. The stereotype of the woman who brings cervical cancer (or its precursors) upon herself by her promiscuous sexual behaviour resulted in feelings of victimisation because women felt they did not deserve the condition and embarrassment at the *implied* guilt. The women believed that in realistic terms there was usually little they could have done to avoid developing the condition:

> 'Unless you remain a virgin, or if everybody used barrier methods of contraception.'
>
> 'If I'd never been on the pill or had a boyfriend.'

There was quite a high level of awareness of the contraceptive pill and smoking as relevant factors, very much less knowledge of the protective effect of barrier methods of contraception and almost no mention of the role of the male partner's previous sexual behaviour.

Unasked questions

In their responses to the question (in the second half of the first interview): 'Was there anything you would have liked to ask the doctor(s) but felt you couldn't?', women were, for the most part, complimentary about the colposcopists they saw. Most women answered 'no' and some made comments such as:

> 'I asked everything I wanted to.'
>
> 'You could have asked them anything.'

Other women said that they had not felt the need to ask questions because [they] 'explained everything' or 'explained very well', or because 'she explained and answered before you had to ask'. Other compliments were:

> 'Male doctors always tend to be in a rush. Dr A was very good – an open sort of person – you could ask her anything.'

> 'Normally when you go to hospital it's a case of "We know all about it and you don't. . ." It makes a change when you're treated as a human being and you're not there for their benefit.'

The link between feeling able to ask questions and being reassured about the condition was evident in the answer of one woman to a later question (early in the last interview) asking whether the patient had received any reassurance: She said she had:

> 'They were marvellous from start to finish. Whatever I asked, they answered.'

Fifteen women in each hospital (15 per cent in Hospital A and 29 per cent in Hospital B) said that they had felt unable to ask some question(s). Some recognised that they had had difficulty formulating questions they could have asked. This was either because they felt:

> 'Until you've grasped the facts, how can you begin to ask questions?'
>
> '[I] didn't know that much about it, so you leave it in their hands.'

or, as one woman put it,

> 'I hadn't thought it through and formulated questions.'

On the initial visit, nerves, emotional tension and an over-riding concern about cancer tended to dominate women's minds and all other considerations receded in the wake of the reassurance they usually received after the colposcopy examination. Women explained:

> 'My immediate thoughts were "Is there anything seriously wrong or isn't there?"'
>
> 'Maybe I was in a daze – it had been a long session.'
>
> 'I just wanted to come home.'
>
> 'It wasn't that I felt I couldn't [ask questions], I didn't have my wits together at the time.'

Not surprising then that women said that they forgot to ask some questions or that they thought of them afterwards.

Only two women said that they were frightened to ask questions (one in each hospital); and another woman that she was 'not very good at asking questions'. A woman attending Hospital B explained that she had found the situation in the colposcopy clinic off-putting – she would have liked more time on her own with the doctor, 'because it is easier to talk one to one and difficult to feel that one can ask questions with four or five people standing around'. Two women who were seen in the colposcopy clinic in Hospital A said they were put off asking further questions by an awareness that the doctor's time was limited. They both gave the impression that they had already asked quite a lot of questions, and both said that there was nothing important they had not asked.

Several women said they had questions they wanted to ask the consultants they were seeing. Only one woman complained that the consultant actually discouraged questions. The most uncomplimentary remark was made by a woman who had treatment at a third hospital. She said of the doctors there:

> 'I couldn't talk to them at all. No one really explained right from the start.'

Objections to questions

There were apparently no objections to the questions the women attending the colposcopy clinic in Hospital B were asked. However, many women attending Hospital A commented in answer to this question. The colposcopists in this hospital routinely asked women at what age they first had sexual intercourse, and it is clear that concern and comment was provoked by this one question in particular. Many women doubted the relevance of the question, some none the less expressing a faith that all the questions must be justified:

> 'They've got to know...'

> 'Everything they have a reason for...'

One woman said that after she had thought and read about it, she realised it was relevant to research.

The question caused embarrassment and heightening of the sense of the invasion of 'privacy', felt acutely by one patient in her early twenties:

> 'Walking into the outpatient clinic is tantamount to saying "I am sexually active" – everything has already been said.'

The patient thought the questions justifiable but resented having to give 'such private information'. Two women made remarks which reflected acceptance of an invasion of privacy, one saying that she was 'immune' after her pregnancies, and the other that if she were younger, she might have had objections. There were one or two complaints about questions asked outside the colposcopy clinic. One woman was asked by a male doctor in the outpatient gynaecological clinic if she had had a lot of partners since her divorce. She said she had not and that she rather objected to this question because of the implication, if she had said 'yes', that she was 'not a good woman'. Another woman, who was middle-aged and about to undergo a diagnostic cone biopsy operation, suffered much distress after being questioned by a doctor about when she first had intercourse and how many partners she had had, admitting that she had had one other partner prior to her present husband. In questioning women about their sexual history, doctors are using their authority to gain access to privileged information, and may be extracting a 'confession' without giving 'absolution'. If the information is not clinically necessary – will not alter treatment – then it is suggested that no good will come of collecting it. If the information is for research purposes, then the woman should be given an explanation of the purpose of the research and a chance to opt out.

8 CONCLUSION AND RECOMMENDATIONS

This report has shown that considerable upset may result from the discovery of a few aberrant cervical cells – cells which might have come and gone without causing any problems if they had not been noticed! The problem arises because they might equally well *not* have quietly disappeared. It is worth a great deal of trouble to avoid the possibility that the aberrant cells might develop into cancer which, if left undiscovered long enough, would result in a death which need not have occurred. A basic rational criterion for acceptability of a screening procedure is that it does more good than harm, and therefore it is essential to find ways of reducing the negative aspects of the impact of the medical process on women discovered to have abnormal cervical cells.

As our findings have demonstrated, much distress arises from lack of sufficient *information* about the nature of CIN, so that there is much unnecessary anxiety and stress. Whenever cancer is a possible threat, lack of information will allow the patient to assume the worst. In the absence of a fuller understanding, the framework of lay interpretation is the curative rather than the preventive medical mode, and the meaning attached to the condition is strongly influenced by a cultural image of cancer which presents the disease as inevitably destructive.[1] The merest hint of cancer can be overlaid with the same negative metaphorical image as the fully developed disease and this may affect the way a woman with abnormal cervical cells thinks about her body, her health status and her future prospects. Well women, who may be symptomless, can be rendered passive patients, feeling helpless in the face of a threat to their well-being, and fearful of their body's 'contamination'.

The challenge to *health education* in this field is to make the black and white convincingly grey, the invisible and threatening, visible and less threatening, the unbeatable clearly vanquished. There is a chance to make inroads into the doom-laden image of cancer, because this is an area where malignant disease can be prevented or cured, where the outlook is essentially optimistic, and where hints of the possibility of cancer do not mean an inevitable progression towards eventual bodily disintegration. The idea of CIN as a stage between normality and disease, and the acknowledgment that abnormal cells may not necessarily progress to become a cancer, are keys to changing the black and white conception of the cervical smear test, and to providing an understanding of the meaning of a 'positive' result and the rationale for treatment.

If the image of cancer which at present fills the conceptual gap and dominates the experience of investigation and treatment of abnormal cells, causing women to have morbid feelings about themselves and their bodies, is to be replaced, women need to be fully informed as early as possible. Accurate information is needed not only to make sense of what is happening, to provide some framework of interpretation, but also to prepare women for the different stages of the medical process.[2] Only if the woman is properly informed can she play her full part in the preservation of her own health, by her involvement in any decision to eradicate the abnormal cells, after discussion of the risks of treatment or non-treatment.

The side effects of the cone biopsy operation have been previously documented,[3] and our study has also found that there may be a significant complication rate (see Chapter 4). Outpatient treatment has been presented as without untoward effects. However, our study found that some women suffer considerable distress as a result of outpatient treatment, and it is likely that the sensitivity of the cervix and the stressfulness of the procedure have been underestimated. Our findings suggest that nulliparous women are particularly vulnerable. Further distress is caused by lack of awareness of the meaning for women of medical intervention which involves a transmutation of private space. The hurtfulness of it may not be confined simply to physical pain. In the cause of preserving the physical integrity of her cervix, a woman may feel that her personal integrity is violated and her moral integrity impugned. We hope our documentation of women's views will increase sensitivity to this aspect of women's experience. Healing requires attention to the personal and social meaning of medical intervention as much as to the physical state of the cervix. Reassurance, warmth and understanding from doctors and nurses and the patient's family and friends have all been shown to be important in providing support for women as they go through the medical process. There is a possible role for self-help groups for women with abnormal cervical smears. In such a group, women could share their feelings about their experiences with others in a similar position and could provide mutual support.

Recommendations

Investigation and treatment

1 An early appointment for colposcopy will reduce the time when anxiety is most likely.

2 The longer the examination takes, the more uncomfortable the woman is likely to become in the lithotomy position. Sometimes insufficient care is taken in making quite sure that the woman's legs are resting comfortably in the stirrups. These points need attention.

3 The clinic door should be locked during examination or treatment, so that no one can intrude.

4 It is important not to leave the patient with nothing to do but stare up at the ceiling during the examination. Having a nurse who can devote her attention to talking with the patient can be helpful, particularly when the colposcopist is busy talking with an observer. Where there is a closed circuit television facility, this can allow the patient to feel that nothing is being hidden from her. However it should not be assumed that everyone will welcome the opportunity of viewing a picture of the lesion; for some, the vague notion of 'a few cells on the surface of the cervix' may be preferable to a magnified and undeniably real image.

5 Observers should not be allowed in the clinic unless it is absolutely necessary and then only with the patient's consent. Additional people in the clinic make it less likely that the patient will feel able to discuss her concerns fully and more likely that she will feel embarrassment and exposure.

6 Wherever possible, the same doctor and nurse(s) should see the patient on every visit to the clinic. This allows a personal relationship to develop which will help to counterbalance the depersonalising aspects of assessment and treatment.

7 The first colposcopy examination presents an important opportunity to resolve the uncertainty about what treatment, if any, is necessary. It is recommended that the likely treatment option is discussed with the patient unless there is a more than usual degree of doubt about the extent and nature of the cervical lesion. An opportunity is needed for explanation of what is involved in the treatment and for the patient to ask questions.

8 The woman should be brought as far as possible into a decision to eradicate the abnormal cervical cells, so that she can feel she is continuing to take responsibility for the care of her own body, and has chosen the treatment as a well woman to protect her future

health. If the treatment is uncomfortable for her, she then need not feel the distress of suffering as a passive, helpless 'victim'.

9 When coming for treatment, the patient should be encouraged to bring someone with her who can provide comfort and support. If the patient's companion may be allowed in the clinic during treatment, this option should be put to the patient at an earlier visit so that there has been time for consideration of feelings about this possibility.

10 Women receiving outpatient treatment should be given nursing care and attention for half an hour at least after treatment, and not be expected to get up and walk out shortly afterwards as if nothing had happened. Treatment for shock should rarely be necessary, but acknowledgment of the stressfulness of the experience and the possibility of a subsequent state of feeling 'battered', by allowing the woman to rest and to have a hot drink, can begin the process of healing and recovery. Women should be encouraged to take the day off work, and be warned that they may be feeling off-balance and vulnerable for a time afterwards. Particular care should be taken with women coming for treatment on their own.

11 Cone biopsy patients should be strongly advised, in view of the risk of haemorrhage, to 'take things easy' for a week, however well they feel (additional help being arranged for mothers of young children if necessary), and not to resume work for at least two weeks.

Sexual relations

1 GPs need to be aware that women learning that they have an abnormal smear may be unsure whether to continue to have sexual intercourse; in particular, whether to do so might make the cervical condition worse, and whether their condition might, in some way, be transmissible to their partner. Since there may be a wait of some weeks, if not months, before the woman sees a colposcopist, it is important that she has an opportunity to discuss anxieties and concerns of this nature in the hope of avoiding psychosexual disturbance which could add to the weight of anxiety.

2 Changes in contraceptive method at this time may exacerbate psychosexual anxieties, particularly if the new method is felt to be less protective against pregnancy. On the other hand, barrier methods may allow an increased sense of protection and may, in fact, reduce the risk of transmission of HPV. The use of condoms has also been linked with the possible regression of CIN.[4]

3 Women should not be asked routinely about the age at which they

first had sexual intercourse or any other question about their sexual history. In asking such questions, doctors are using their authority to gain access to privileged information; this may add to the sense of invaded privacy, and may be extracting a 'confession' without giving 'absolution'. If the information is not clinically necessary and will not alter treatment, then it is suggested that no good will come of collecting it. If the information is for research purposes, then the woman should be given an explanation of the purpose of the research and a chance to opt out.

4 Advice about the resumption of sexual intercourse after treatment should always be offered to the patient either verbally or in written form.

5 There should be greater awareness of a possible need for psychosexual counselling, particularly for women who are not in stable relationships, and for women who are treated by hysterectomy. The offer of such counselling needs to be made sensitively in order not to intrude further on a private sphere in a way which is unwelcome.

Information

1 The GP or sometimes the family planning clinic doctor is the most likely person to inform the woman of the abnormal smear finding. The way the doctor explains the meaning of the finding and the medical process following it, can be all-important in reducing anxiety levels because s/he is likely to be the first person to discuss it with the patient who may then wait some weeks before the condition is investigated and she has any further explanation. When asked if they had received any reassurance about their condition at any stage, over a quarter of the women in our sample said that they had found what the GP (or family planning doctor) had said reassuring. The GP is in a difficult position, however, and cannot be categorically reassuring until s/he has seen the reports of the colposcopy and histology investigations. It is unlikely that the patient will be able to formulate all the questions she might wish to ask about the condition and its treatment shortly after she first learns that she has an abnormal smear finding, and it is therefore helpful if the doctor invites her to visit again or to telephone to discuss it further if she wishes.

2 It is important that women having a colposcopy examination have some prior explanation of the procedure. This was lacking for nearly half of our sample of women.

3 It is insufficient to reassure patients that they do not have cancer; in

order to fill the 'conceptual gap', patients need a name for their condition and some way of locating it, both in terms of the degree of abnormality and in terms of its size and position.

4 An older woman having an hysterectomy for reasons other than or in addition to the abnormal cervical cells, may be particularly vulnerable to continuing fears of a diagnosis of cancer which she cannot bring herself to ask about directly, and may need careful reassurance.

5 The pictorial representation of the cervix and the CIN lesion is important but not easy. We believe that women often have a lack of knowledge about exactly where the cervix is and have no clear idea of its size. If the patient is shown her cervix during the colposcopy examination or a photograph afterwards, it is important to explain the magnification involved. Women having cone biopsy operations invariably over-estimate the size of the cone to be excised, and an indication of the actual size can be reassuring.

6 Among the women in our sample, there was almost no awareness of the possible role of the male partner's sexual history in the development of CIN and very few mentioned the use of barrier methods of contraception as a possible protection. Health education literature could usefully put greater emphasis on these factors, particularly in relation to the spread of HPV.

7 Written information is recommended as a way of reinforcing and supplementing any verbal explanation of the meaning of the abnormal smear result and the subsequent medical process given by medical personnel involved. A leaflet or leaflets would help to familiarise women with words they might not have heard before such as 'colposcopy'. (It was found that very few of the women interviewed could say the word 'colposcopy' correctly.) Written information can be shared with family and friends, and their understanding can reinforce the patient's own grasp of new concepts.

The investigation and treatment of abnormal cervical cells is an optimistic area of modern medical care in which it is possible, because of medical expertise, to be aware of what is happening in the body and to prevent unhealthy developments. Collaboration between patients and doctors can preserve women's health. However, the medical and lay interpretations of this field, as demonstrated by our research, are currently very different. Bringing the two closer together by increasing mutual understanding can help to reduce the unintended negative effects and allow medical intervention to be more clearly preventive.

APPENDIX THE INTERVIEWS

Altogether, 357 interviews were carried out involving 153 women. Nineteen women were interviewed once only, 67 twice, 64 three times and 3 four times. There were two interview schedules to be completed by the researcher with questions relevant to different stages of the medical process: pre-colposcopy, post-consultant/post-colposcopy and pre-treatment/post-treatment. Where possible women were interviewed for the first time while they were waiting for their colposcopy examination, although it was not always possible to fit in an interview at this time without interfering with the running of the clinic. In such cases the woman was interviewed immediately she came out of the colposcopy clinic or as soon as possible thereafter at home. Those who were seen prior to colposcopy were re-interviewed about the colposcopy examination so that the pre-treatment interview schedule could be completed when they next attended the hospital (and were thus interviewed three times altogether). Sometimes women called in to the interviewing room in the outpatient department to keep the researcher informed of 'developments'. Three of these unscheduled visits resulted in the women being interviewed four times. Women found to be unsuitable for outpatient treatment would be given an appointment to see the consultant who would arrange for their admission for cone biopsy operation. Where they had not seen the consultant before, page 3 of the first interview schedule could be completed only after this visit.

Refusals

Women quickly understood that the focus of the enquiry was on their own experiences and enthusiastically endorsed the aim of the investigation. The researcher was impressed and encouraged by the interviewees, and grateful for their cooperation. Only in one case did a woman refuse to take part at all: she was an eighteen-year-old, whose mother came in the room with her, and who might have been apprehensive in case she was asked personal questions in front of her mother.

Four women, all of whom had to be contacted by telephone, refused a further interview at the post-treatment stage. One woman who had appeared rather impatient and reluctant during the first interview was antagonistic to the whole idea. Of the other three, two were apologetic but 'had had enough of the whole business' and clearly wanted to put it out of their minds. There had been a more than usual amount of uncertainty for both of them. One had in the end not had treatment; with the other it was not clear whether the treatment had been successful. It had taken some time to contact two of these women because they were seldom at home. It seems likely that if contact had been possible face-to-face and sooner, they would have agreed to a further interview.

When the researcher had to turn up at the door in order to make contact again, the women were surprisingly welcoming in view of the degree of intrusion. (The researcher always offered to come back at a more convenient time.) In one instance a woman was just about to get in a bath, but none the less invited the researcher into the house. The women often seemed pleased about the continuing interest in their 'story'. However, a few appointments made for interviews were not kept, and this could have been another form of refusal. It is as likely though, given the circumstances of the women, that it was simply a reflection of a degree of disorganisation in their lives, or a difficulty in contacting the researcher to re-arrange the appointment. (Messages could be left at the hospital – the telephone number and an extension number were given on the compliments slip with the researcher's name on it, but her home telephone number was not given.)

Women unavailable for re-interview

For one reason or another, 26 women were unavailable for re-interview. (In three of these cases some details of reactions to and symptoms from treatment were given at the post-colposcopy interview which had to be carried out shortly after treatment as it could not be arranged before.) Eleven women (7 per cent of the sample) had moved (Table 30). Ten of them had attended Hospital A. They had either moved too far away for re-interview or had failed to give their new address either to the hospital or to leave it at their previous address. Of the other 15 (10 per cent of the sample), 14 were not on the telephone. Seven women were subsquently excluded from follow-up for the following reasons: one address proved to be non-existent; one woman was being treated in hospital for (pre-existing) depression; one woman who had needed no treatment died of liver failure; three women lived too far away for calling on the off-chance that they would be in, and it was either not possible to coordinate hospital appointments with re-interviews or they failed to keep hospital appointments; and one woman's treatment was delayed for over a year. Calls were made to the homes of the other eight women at different times of the day in the hope of finding them in so that an interview could be arranged or carried out then and there. In some cases half a dozen calls were made. In three cases (where the women were attending Hospital B) appointments were made for the researcher to come back which were then not kept. Eventually these attempts to re-interview had to be abandoned because of the need to end the data-gathering stage of the project in order to complete the analysis, the lapse of time since treatment affecting recall, and the cost in terms of time and money.

Table 30 Reasons last interview not carried out

Refused			4
Unavailable	Moved	11	26
	Excluded	7	
	Repeated calls	8	

Interview schedules

First interview

1 Is this the first time you've been to the colposcopy clinic?/Have you been to the colposcopy clinic just the once?
2 How did you first hear that they'd found something wrong on the smear?
3 Did s/he say what was wrong?
4 Did s/he say what might be done about it?
5 How did you feel about it when you knew they'd found something wrong on your smear?
6 Do you know anyone else who's had the same thing?
7 Have you talked to anyone else about it? (If yes:) Who?
8 Have you read anything about it? (If yes:) What? Where?
9 Have you heard any theories about what causes it? (If yes:) What were they? What do you believe?
10 How long did you have to wait to come/go to the hospital?

If has seen consultant:

11 Which doctor did you see today? Which doctor did you see at the hospital?
12 How long did you have to wait to see him/her?
13 Did s/he examine you?
14 Did s/he say what the treatment might involve?
15 Did s/he explain what colposcopy was?
16 Did s/he explain at all what was found on the smear?
17 Did s/he give it a name?
18 Did you have the colposcopy the same day, or did you have to go back to the hospital?
19 Did the doctor who did the colposcopy tell you what s/he was doing?
20 Did you find the examination painful? (If yes:) How painful? (If mentions biopsies:) Would you like to have been told just before the biopsies were taken, or would that have made it worse?
21 How did you feel about the colposcopy examination?
22 Did the doctor who did the colposcopy explain to you what the condition was?
23 Did s/he give it a name?
24 Did s/he draw any diagrams?

After colposcopy:

25 How did(/do) you feel about things after you'd(/now you've) been to the colposcopy clinic?
26 How do you feel about the prospect of treatment(/an operation)?
27 Do you know anyone who's had the same treatment(/operation)?
28 Was the treatment(/operation) explained to you? (What they were going to do? What to expect)?

If for operation:

29 Have you had any previous operations?
30 How will you manage at home?

Second interview

31 Did you read anything about it anywhere? (If yes:) What? Where?
32 Have you had any symptoms at all? (If yes:) What?
33 Was there anything you would have liked to ask the doctor(s) but felt you couldn't?
34 Did you have any objections to any of the questions you were asked by the doctor(s)? (If yes:) Which?
35 Do you try to explain to yourself why you might have got an abnormality on your smear now?
36 Have you had any symptoms at all since your smear was found to be abnormal? (If yes:) What?
37 Did you go for your original smear because you were worried about anything? (If yes:) What?
38 Had you had a smear before? (If yes:) How many? Where?
39 Have you ever been referred to a gynaecologist before? (If yes:) Did you have treatment? Were you happy with it?
40 Have you had any children? (If yes:) How many? How old are they?
41 Were any of their births particularly difficult?
42 Has it made you feel any differently about your body knowing you had an abnormal smear?
43 Has it made you feel any differently about sexual relations?
44 Are you married/separated/divorced/cohabiting/or single?

If has partner:

45 What has your husband's(/partner's) attitude been?
46 Did he come/go to the hospital with you?
47 Would you have liked him to have been there with you in the colposcopy clinic?
48 Have you had much ill health, or are you generally fit?
49 Have you ever suffered from much depression?
50 Have you been worrying about things recently? (If yes, without amplification:) What in particular has been worrying you?

51 Have you talked to anyone else about it? (If yes:) Who?
52 You mentioned your worry about the possibility of cancer. Has anyone you know, or anyone in your family had cancer?
53 Has anything anyone's said reassured you?
54 Do you mind telling me your age?
55 Did you stay on at school or have any further education or training? (If yes:) How many years? What?
56 Do you go out to work? (If yes:) What do you do?
57 May I ask what your husband does?
58 Is there anything I haven't asked about that you'd like to comment on?

Post-treatment interview

1 First may I check on what's happened about your abnormal smear in the last six months? You've had treatment/laser treatment/a cone biopsy/a hysterectomy/no treatment/further smears?
2 Have you talked about it at all with your GP during that time? (If yes:) When?
3 How many times altogether have you been to the colposcopy clinic?
4 Do you know how many more check-ups you'll have?
5 How often will you have a smear in the future?
6 Have you attended the gynaecology, infertility, or ante-natal clinics during that time? (If yes:) Number of times?
7 When was the most anxious time for you?
8 When you first heard anything was wrong, what were your worst fears?
9 Were you reassured at any time by anything anyone said or anything that happened?
10 How long was it on your mind a lot of the time?
11 Has it helped you to talk to anyone about it? (If yes:) Who?
12 Is there anything (about the condition or its treatment) that you wish you'd known earlier? (If yes:) What?

If had cryocautery or laser treatment:

13 Was there anything that particularly worried you about having the freezing(/laser) treatment?
14 Was your husband/partner with you? (If yes:) Did it help?
15 Did the treatment hurt?
16 How did you feel afterwards?
17 Did you carry on as usual afterwards?
18 Did you have any symptoms afterwards? (If yes:) How long did they last? How severe were they? Did you have any treatment?
19 Did the treatment upset you more or less than you thought it would?

If had cone biopsy or hysterectomy:

20 Was there anything that particularly worried you about having the operation?
21 Did you feel the operation was explained to you enough beforehand? (If no:) What was not explained sufficiently?
22 Did anyone draw you a diagram of what they do? (If yes:) Can you show me?
23 Did anyone say what size the cone – the piece they remove – is?
24 Was the operation and staying in hospital worse or not as bad as you had thought it would be?
25 How long did it take you to recover from the operation?

If no treatment:

26 When you were told you did not need treatment, did you worry any more about your condition?

All:

27 Did it cause you any concern that you had to come back for check-ups?
28 Did you tell any friends, relations or work-mates about the abnormal smear or the treatment? (If yes:) Who? What was the reaction?
29 Did you ever feel at all embarrassed or guilty about having an abnormal smear? (If yes:) Why?
30 Did the abnormal smear finding, in any way, disturb your sexual relations?
31 Did your GP or the clinic doctor ever say anything about sexual relations?
32 How much of a disruption of your normal life was it to be told not to have sex for two to three weeks after treatment? Did you comply?
33 Is your sex life back to normal now? (If not:) Why do you think this is?
34 What do you feel that you have learnt about the condition they found on the smear test?
35 Where did you learn it from?
36 Would you say that the condition was: an infection; abnormal cells; due to a virus; cancer; nothing to do with cancer; pre-cancerous; possibly pre-cancerous? (More than one answer is possible)
37 Did the doctor in the colposcopy clinic show you a diagram? (If yes:) Do you remember it? (If yes:) Can you show me what it was like?
38 Do you think the condition is likely to recur? Don't know/Yes/No/Not likely but possible.
39 Do you think that you could in any way have avoided getting this condition?
40 Do you know of any factors related to the development of the condition?
41 The cervical smear is popularly called the 'cancer smear' – do you think this is misleading?

42 Do you feel at all threatened by the possiblity of cancer now?
43 How would you describe cancer?
44 Would you say that cervical cancer is: curable if caught early; usually curable; sometimes; seldom curable; not curable?
45 If a friend had a 'positive' smear test and asked you what it meant, what would you say to her?
46 If she needed freezing (or laser) treatment/an operation, how would you explain what is done?
47 Would you say that the investigation and treatment you've needed after the abnormal smear finding has been: a bit of a nuisance but not much more/a big upset and disruption in your life/something you haven't really got over/something you've already largely forgotten about?
48 Do you feel that you are back to normal in all respects now?
49 Have you ever wished you hadn't had the test?
50 Would you advise women you know to have a smear test? (If not:) Why not?
51 What would you say was the main benefit of the cervical smear test?
52 Has having an abnormal smear made you think differently about things in any way?

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Chapter 1 Introduction

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24 The definition of a 'positive' result has varied. In general terms, it means that the cytopathologist considers the abnormality significant enough to warrant further investigation. In practice, it usually means that the smear shows evidence of cervical intraepithelial neoplasia (CIN) or of carcinoma of the cervix. There are three grades of CIN: CIN1 (mild dysplasia); CIN2 (moderate dysplasia); CIN3 (severe dysplasia or carcinoma-in-situ). There are five stages of carcinoma of the cervix (invasive cancer): micro-invasive (cancer cells dip below the basement membrane of the epithelium of the cervix); stage I (the tumour has spread but is confined to the cervix); stage II (the tumour has spread to the vagina and neighbouring tissue); stage III (the tumour extends to the pelvic wall); stage IV (the tumour extends beyond the true pelvis).
25 In Hospital A's colposcopy clinic the cytology, colposcopy and histopathology results and the resultant diagnosis in terms of CIN grades 1, 2 or 3, or type and grade of carcinoma, were recorded on the patient's record card to which the researcher had access. In Hospital B the results of the different investigations were not all recorded on the most accessible record file (the cytology record file in the pathology laboratory) and the diagnosis was less evident. In both hospitals a patient with clinically evident carcinoma of the cervix would not routinely have been sent for colposcopy investigation pre-operatively.
26 The distribution of women in the different age groups was similar in the samples from the two hospitals, except in the older age groups. There were nine women 45 years or older from Hospital A but only one from Hospital B (Table 1, page 15). There were differences in the parity distributions, however: over half the sample (55 per cent) in Hospital B having no children and a considerably lower proportion having two (18 per cent in Hospital B, 31 per cent in Hospital A – Table 2, page 15). There was also a different pattern of distribution of women according to marital status: the sample from Hospital A (as with the distribution of children) resembling the expected pattern while there were as many married as single women in the sample from Hospital B (Table 3, page 16). This situation seems to be accounted for by the number of older (25 years and above) single women with no children (12) in the sample

attending Hospital B. The two samples also differed to some extent in the educational levels of the women, fewer women having stayed on at school or obtained university degrees or teaching qualifications, and more having trained as nurses in the sample from Hospital B (Table 4, page 16).

27 Seventy-four per cent of 25 to 29-year-olds had an educational qualification in 1985, 11 per cent having a degree or equivalent qualification, according to the Central Statistical Office. (See Social Trends 18, London, HMSO, 1988, p 61.)

28 The social class distributions in the two relevant areas (for adults of all ages) were compared with the findings of the 1981 Census, published in Chief Statistics for Urban Areas, London, HMSO, 1984.

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> The psychobiological state of the organism represented by the experiencing and reporting of hopelessness may in some as yet undetermined way provide a permissive atmosphere or a facilitating role which allows those who are already biologically predisposed to cancer to develop the clinical manifestations of the disease. The experiencing of the feeling of hopelessness, in and of itself, does *not* predispose to cancer.

30 Among women attending Hospital A the proportion of tests reported as having been taken by the GP approached nearly twice as many as those taken at a clinic. Among women attending Hospital B the proportions taken by a GP and at a clinic were roughly equal.

31 Of the other first tests, five were taken on asymptomatic women; two were taken in association with infertility investigations, three in association with symptoms, and two were ante-natal tests.

Chapter 3 The colposcopy examination

1 In Hospital B one of the colposcopists regularly explained to women before they got on the couch for examination that 'none of this machinery goes inside . . .'

2 Quotes taken from recordings of pilot study interviews.

3 In Hospital B there was always a technician in the colposcopy clinic. This meant that the nurse was not required to assist the colposcopist (by passing her instruments or fixing the slides) as she was in Hospital A, and could devote all her attention to the patient. However, the technician's role was not as clear to the patient as the doctor's or the nurse's, and there were some queries about her presence. Since she seldom spoke to the patient, she was to some extent a depersonalising element in the situation.

4 Emerson J. Behaviour in private places: sustaining definitions of reality in gynaecological examinations. In: Dreitzel H P (ed). Recent sociology. 2. Patterns of communicative behaviour. London, Collier-Macmillan, 1970, p 90.

5 *ibid*, p 79.

6 *ibid*, p 85.

7 This percentage can be only an approximation. It is not clear exactly how many women had biopsies taken, though it was a standard procedure in both clinics. The percentage was calculated on the basis of the number answering the question minus those who were sure that they did not have a biopsy taken (for example, if they were pregnant).

8 A woman interviewed in the pilot study gave the most elaborate description of her discomfort during colposcopy, saying it 'seemed ages' and was 'ever so uncomfortable'. Her legs trembled and she clung to the edge of the table. She cried because the biopsies hurt and she found it hard to bear, and 'they were poking and shoving things in', she said. The nurse tried to calm her and take her mind off it, but was 'busy getting the swabs and other things'. They were concerned she was in pain and said they would try not to be too long. She described the colposcopist's difficulty securing biopsies:

> 'They were snipping bits off. The first bit – it was a bit grisly – they couldn't get it. They said it was a bit rubbery and they couldn't get it. Of course I couldn't even walk then. When she tried to snip it, it was like scraping a bone. It was horrible really.'

9 The colposcopists here were not cytopathologists and may have been concerned to make quite sure that they provided enough 'good' material for pathology laboratory examination.

10 A 'biopsy' is thought of as a test for cancer, particularly associated with breast cancer, and involving a surgical procedure. The term 'punch biopsy' sounds rather traumatic.

11 In Hospital A, most of those who said they were told at all were told beforehand (53 per cent). In Hospital B, 39 per cent said they were told before and 25 per cent after. Whichever was done was wrong as far as the women were concerned, in a more or less equal proportion of cases: 13 per cent who were told before in Hospital A and 14 per cent who were told after (except in one case) in Hospital B.

12 Women sometimes misinterpreted the photographs assuming that the darker rather than the lighter area was the abnormal part, so a large part of the cervix would seem to them to be affected.

Chapter 4 Treatment

1 A number of patients knew women who had had cone biopsy operations and subsequently a hysterectomy. They concluded that the first operation must have been unsuccessful; in fact, the hysterectomies may have been performed for reasons other than the continued presence of abnormal cells.
2 Thirty-six per cent altogether (46 per cent of those having hysterectomies).
3 See Zola I K. Culture and symptoms: an analysis of patients presenting complaints. American Sociological Review, 1966, 31, 615–30. Objective assessments based on expressions of pain at the time are unreliable, since some people are habitually more expressive than others, expressiveness being encouraged in some cultures more than others. Involuntary movements are indicators of sensitivity – a few women reported that they could not help 'jumping'.
4 This was frequently given as a reason for pain being an unlikely experience. It has been a standard assumption in gynaecology. In the experience of colposcopists, the sensitivity of the cervix varies greatly from one woman to another. Even when the cervix is relatively insensitive, treatment may produce contractions in the cervical canal which can be observed, and which the woman will feel as cramps or 'period pains' (Dr Jane Johnson, personal communication).
5 Two other patients spoke in similar terms, using the word 'violated' and saying they felt they knew what it was like to have been 'raped'.
6 Estimates of the number of sanitary towels used went over the 100 mark with some women using eight to ten pads a day when the discharge was at its heaviest. One went on holiday with a suitcase full of sanitary towels because she would be staying in an out-of-the-way place and wanted to be sure she had a sufficient supply.
7 Ward E. Psychological and physiological factors related to discomfort during laser vaporisation of the cone of the cervix and the influence of psychological preparation or local anaesthetic upon the discomfort. MSc thesis submitted to Leicester University, 1983.
8 Obvious influences on the degree of pain experienced were women's expectations and the availability of analgesics on request. It is possible that women expected more post-operative pain than was generally felt, and that the relative lack of discomfort was a pleasant surprise. This specific expectation was not investigated.
9 See Luesley D M *et al.* Complications of cone biopsy related to the dimensions of the cone and the influence of prior colposcopic assessment.

British Journal of Obstetrics and Gynaecology, 1985, 92, 158–64. Luesley *et al* found complication rates of 13 per cent for haemorrhage and 17 per cent for cervical stenosis.

10 This myth is reiterated in lay literature too: 'As the cervix has very few nerves, treatment is not painful and no anaesthetic is needed.' (Taken from TUBE Women and Health Booklet, Trade Union and Basic Education Project, Manchester.)

11 See Illich I. Limits to medicine. London, Marion Boyars, 1976; and Melzack R. The puzzle of pain. Harmondsworth, Penguin, 1973.

Chapter 5 Reactions to the medical process

1 In the post-colposcopy interview, the women were asked how they felt about the prospect of treatment, but it was in general too early to ask that question. Having just got over the first hurdle of the medical process, they had not started to think about the next, and sometimes did not know what treatment they would have at that stage. (See 'Anxieties about treatment', page 32.)

2 Posner T R. Cancer: metaphor and morality. Unpublished paper presented to the British Sociological Association Medical Society Annual Meeting, 1980. Discusses a content analysis of the answers of women taking part in a health education programme to the question 'How would you describe cancer?' and includes a critical discussion of the work of Susan Sontag.

3 See 'Changes in women's body image' (page 61) for a discussion of the image of leprosy as a disease and its parallels with the modern image of cancer *cf* 'Let her not be as one dead, of whom the flesh is half-consumed . . .' (Numbers 12:12).

4 These percentages are similar to those found on two population surveys carried out in 1979 and 1982 and reported in Posner T R. Women's view of cervical cancer. Unpublished paper presented to the British Sociological Association Medical Sociology Annual Meeting, 1982. These surveys were carried out as part of a Cancer Research Campaign project – 'The evaluation of education and persuasion related to screening for cervical cancer in high-risk popuations'. (Director Dr P Hobbs, University of Manchester Department of Epidemiology and Social Research. Report in preparation.)

5 The condition of CIN cannot be passed on to a sexual partner; however, human papilloma virus (HPV) can be. If there are clear signs of recent infection with the virus, a patient could be advised, if it seems appropriate, to use barrier methods of contraception to protect herself and her partner and to wait until the abnormal cervical cells and any genital warts have been treated before having sexual intercourse with a new partner.

6 On occasions, because of additional factors, the total length of abstention could be considerably longer; for example, for a woman who had a cone

biopsy following the birth of her baby, it was ten weeks; and for another woman who had discontinued six months on in her pregnancy and had not resumed while she waited for outpatient treatment (carried out three months after the birth), it was still continuing when the researcher interviewed her a week after her treatment.

7 This advice may well have been motivated by a concern to protect, but in view of current findings about the male partner's sexual history as a risk factor for women, it is clear that female monogamy would not in itself be protective. (See Buckley J D *et al.* Case-control study of the husbands of women with dysplasia or carcinoma of the cervix uteri. The Lancet, 1981 II, 8254, 1010–14.)

8 Goffman E. Stigma: notes on the management of spoiled identity. Harmondsworth, Penguin, 1964.

9 The use of the word 'needed' may have discouraged questioning of the treatment.

10 There appeared to be no distinction between women according to the treatment they had had, in their readiness to present the treatment to others in a positive light.

Chapter 6 The role of others

1 At the time when we first asked if they had talked to anyone else, most of the women knew only that they had an abnormal (positive) smear. They had not yet been to the colposcopy clinic and learnt more about the condition.

2 These hysterectomies may or may not have been performed because of a condition indicated by the abnormal smear.

3 In six cases the women preferred to come on their own; and in five cases they discouraged their partners from coming, saying it was not necessary or that they would only be waiting around a lot. Where the partner did not come the woman might be accompanied by a friend or by a member of her family: her mother (or mother-in-law in two cases), her sister, in one case her grandmother, in another both parents, and in two cases her father. In only one case did a woman say that her partner did not come with her when she would have liked him to do so, without giving a reason.

Chapter 7 Information

1 Mcpherson A. Cervical screening: a practical guide. Oxford, Oxford University Press, 1985. It is hoped that this pamphlet written for GPs will help to remedy this situation.

2 The women's recall may of course have been partial – we know only what they remembered and told the researcher.

3 See Fuller-Torrey E. A shared world-view: the principle of Rumpelstiltskin. In: The Mind Game. New York, Emerson Hall, 1972. Fuller-Torrey suggests that according to the 'principle of Rumpelstiltskin', naming the condition is a basic step in any therapeutic intervention.

4 The pronunciation of 'CIN' with a soft 'c' as 'sin' rather than naming the letters separately as 'C-I-N', is unfortunate as it may cause unnecessary distress.

5 Vessey M P *et al.* Neoplasia of the cervix uteri and oral contraception: a possible adverse effect of the pill. The Lancet, 1983, II, 930–34.

6 See Posner T *et al.* Women's view of the benefits of the cervical smear test. Unpublished paper presented to the Society for Social Medicine 1981 Annual Scientific Meeting containing results of a similar contents analysis.

Chapter 8 Conclusions

1 Davison R L. Overcoming fear and pessimism. In: Burn I and Meyrick R L. Cancer – a guide for the caring professions. London, HMSO, 1977.

2 Johnson J E. Preparing patients to cope with stress while hospitalized. In: Wilson-Barnett J (ed). Patient teaching. Edinburgh, Churchill-Livingstone, 1983, pp 19–33.

3 Luesley D M *et al.* Complications of cone biopsy related to the dimensions of the cone and the influence of prior colposcopic assessment. British Journal of Obstetrics and Gynaecology, 1985, 92, 158–64.

4 Richardson A C and Lyon J B. The effect of condom use on squamous cell cervical intraepithelial neoplasia. American Journal of Obstetrics and Gynecology, 1981, 140, 8, 909–13.

INDEX

PREVENTION OF CERVICAL CANCER

The Patient's View

TINA POSNER
MARTIN VESSEY

The investigation and treatment of abnormal cervical cells is an optimistic area of modern preventive medicine – but how does medical intervention affect the women involved? Are there any unwanted effects?

This book is based on the first research study to look at the impact on women of a positive cervical smear and subsequent investigation and treatment. It follows their experiences from the initial discovery of abnormal cells through the waiting period for colposcopy, the colposcopy examination itself, and finally outpatient treatment or inpatient surgery. The authors describe the thoughts and feelings women have at different stages about their bodies, sexual relationships, medical treatment and future health prospects. They document the symptoms resulting from medical intervention, the causes of anxiety and how a woman's understanding evolves, and make recommendations for meeting the need for information and support throughout the medical process. The medical and lay interpretations of this process can be very different, as this study shows. By presenting 'the patient's view' the authors hope this book will increase mutual understanding and collaboration in preserving women's health.

Prevention of cervical cancer: the patient's view will interest gynaecologists, colposcopists, nurses in gynaecology outpatient clinics, GPs, practice nurses, staff in family planning clinics and well woman centres, and everyone concerned with women's health care.

Tina Posner is currently Research Fellow at the Policy Studies Institute. She carried out the research on which this book is based while a Research Associate at the University of Oxford Department of Community Medicine and General Practice.

Martin Vessey is Professor of Social and Community Medicine at the University of Oxford. He is also Chairman of the DHSS Advisory Committee on Breast Cancer Screening, Adviser to the WHO Special Programme on Human Reproduction and a member of the Committee on Safety of Medicines.

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