Accounts of abnormal Pap smears

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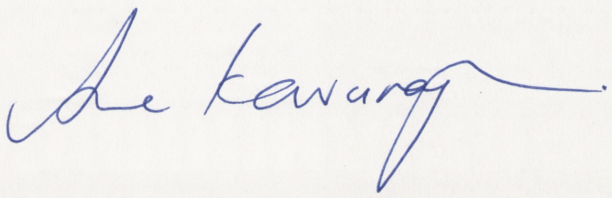
Unless otherwise stated the research reported in this thesis is my own.



Anne Marie Kavanagh

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Abstract

This thesis addresses abnormal Pap smears and clinical practice from three perspectives: a population perspective, the perspective of women who have abnormal Pap smears and from a health economic perspective. Exploring these perspectives reveals contradictions between them that inhibit the implementation of public health policy and amplify women's distress.

If a woman is found to have an abnormal Pap smear she may be referred for colposcopy or a repeat Pap smear may be recommended. This thesis considers the consequences of referring women who have an abnormal Pap smear for a colposcopy. The research was conducted in the Australian Capital Territory (ACT).

In 1989/90, in the ACT, an estimated one in forty women between ages 15 and 74, had a colposcopy. On a lifetable simulation of a hypothetical cohort, it is estimated that if current patterns of referral for colposcopy continue three quarters of women will have a colposcopy by age 75. There is a mismatch between current clinical practice and population derived risks of cervical cancer.

To explore women's perspectives, 29 detailed individual interviews with women who had abnormal Pap smears were conducted. Following diagnosis, women experienced their risk of cervical cancer as part of themselves. They felt vulnerable and sought to manage their newly defined state of risk. Women felt that their risk required ongoing medical surveillance. This defined their cervix as an ongoing site of potential disorder.

Some women made sense of their state of risk by linking it to various life pressures. For example, several women associated their abnormality with stress or diet which offered avenues for reasserting control over their own health. They often found their gynaecological care unsatisfactory as their gynaecologists failed to engage with the meanings their abnormality held for them. Often clinicians did not explain their approach and hence women lacked a conceptual framework within which to make sense of their treatment and its after-effects. There were conflicts between the way

clinicians approached women's abnormalities and the women's own accounts.

To explore abnormal Pap smears from a health economic perspective, I conducted a case note audit of 502 women who attended a Canberra colposcopy service because of an abnormal Pap smear between January 1 1989 and April 30 1990. Women who had minor cytological abnormalities (CIN 1 or less) constituted the majority of the financial costs to government and women. In multiple linear regression analyses the severity of cytology was associated with costs to government and women however, other variables such as a woman's age also influenced costs. If implemented, new policy recommendations for the clinical care of women who have abnormal Pap smears would be less costly than the current approach. However, the new policy recommendations may not be effective because they do not recognise the complexity of clinical decision-making.

Twenty per cent of the clinic sample did not complete the follow-up recommended by their clinicians. In a multivariate analysis, women who had had treatment were more likely to discontinue attending than women who had not had treatment. Women younger than 25 were also less likely to continue attending. For women who had no past history of abnormal Pap smears, attendance was less likely if they did not have private health insurance. Out-of-pocket expenses may be a barrier to attendance for some women. Conflicts between the way women conceive their abnormality and the way gynaecological care is delivered may discourage some women from continuing to attend.

The thesis concludes with a discussion of how the research findings can contribute to public health policy and clinical practice. Directions for future research are also indicated.

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Acronyms

ACT	Australian Capital Territory
CCSEC	Cervical Cancer Screening Evaluation Committee
CIN	Cervical intraepithelial neoplasia
CLC	Canberra Laser Clinic
DHSH	Department of Human Services and Health
DRG	Diagnostic Related Group
ICD 9	International Classification of Diseases, 9th revision
ICD 9-CM	International Classification of Diseases, 9th revision, Clinical Modification
FPC	Finite population correction
HIC	Health Insurance Commission
HGSIL	High-grade squamous intraepithelial lesion
HPV	Human papillomavirus
JJH	John James Hospital
IARC	International Agency for Research on Cancer
LGSIL	Low-grade squamous intraepithelial lesion
LLETZ	Large loop excision of the transformation zone
NHMRC	National Health and Medical Research Council
TAH	Total abdominal hysterectomy
WVH	Woden Valley Hospital

Part A

Opening the accounts

Chapter One

Introduction

This thesis considers current clinical practice and abnormal Papanicolaou (Pap) smears from a population perspective, from the perspective of women who have abnormal Pap smears and from a health economic perspective. I believe that each perspective should contribute to shaping public health policy and clinical practice.

Each perspective provides an account of abnormal Pap smears. The accounts may be descriptive, narrative or financial. To gather the accounts I have used methods from different disciplines. The population account employs demographic and epidemiological methods; women's accounts draw on the disciplines of sociology and anthropology; and the economic account uses health-economic and epidemiological methods.

Throughout the thesis 'abnormal Pap smear' refers to any cytological abnormality except invasive cancer. 'Abnormal', rather than 'positive', is used because cytological findings such as inflammation, mild atypia, human papillomavirus (HPV) infection and cervical intraepithelial neoplasia (CIN) are clinically conceptualised, understood and treated as deviations from normal.

For women's accounts I use the term cervical abnormality. All the women I interviewed had had a colposcopy and biopsy. Their 'abnormal' Pap smear had been investigated and defined in colposcopic and histological terms. The term 'cervical abnormality' better encapsulates the characteristics of a condition defined using these different tests.

This thesis:

- describes age-specific patterns of Pap smear and colposcopy use
- considers the cumulative risk of colposcopy if current patterns of referral for colposcopy continued

- describes the consequences for women of cervical abnormalities
- explores how women understand their cervical abnormality and the consequences they identify
- documents women's experiences of current clinical practice
- compares the costs of current gynaecological care on the basis of the level of presenting smear[1]
- documents the contribution of different levels of presenting smear to the total cost of the gynaecological care of women who have abnormal Pap smears
- computes the likely cost savings of alternative approaches to the treatment of abnormal Pap smears
- identifies the socio-demographic and clinical factors which predict economic costs
- identifies the socio-demographic and clinical factors which predict whether women complete the follow-up recommended by their clinicians.

Two economic costs are examined: costs to government and costs to women. Costs to government tend to drive policy while costs to women are of social, political and personal importance. The out-of-pocket expense of a service influences whether an individual can access that service. If costs are high some women may be unable to afford a particular service, such as colposcopy. Such a service would be inequitable and hence politically, socially and personally unfavourable. Clinicians are also concerned about costs to the users of their services. Hence costs to government and women are presented separately rather than as a total cost to society because they have different implications for policy and clinical practice.

The research for this thesis was conducted in Canberra in the Australian Capital Territory (ACT). In June 1992 the ACT had 295,700 residents, 1.7 per cent of Australia's population. The ACT has a higher than average per capita wage, lower unemployment rate, higher workforce participation rate and

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[1] By 'presenting smear' I mean the cervical cytological report that resulted in women's referral to a gynaecologist for colposcopy.

higher levels of education, than the rest of Australia. (Australian Bureau of Statistics 1993a).

The Commonwealth government funds a national universal system of health care financing called Medicare. The Health Insurance Commission manages the Medicare scheme. The Health Insurance Commission (HIC) provides benefits (under the Medicare scheme) for private inpatient and outpatient medical services. Individuals may also purchase private health insurance which covers some of the costs of inpatient services. Other ancillary health services may also be covered by private health insurance. Private health insurance also enables the choice of inpatient service provider. Public hospitals are managed by state and territory governments and are partially funded by grants to the states from the Commonwealth. Individuals admitted as public patients to public hospitals have no out-of-pocket expense but have no choice of doctor. Most public hospitals have outpatient services. There are no out-of-pocket costs to individuals attending public outpatient services.

The ACT has two public hospitals but no public colposcopy service. All colposcopy services are provided on a private outpatient basis. Most cervical cancer screening is performed by private general practitioners. Medical and nurse practitioners also provide cervical cancer screening services at community health centres, a women's health service and a family planning service.

Structure

The thesis is comprised of eleven chapters. In Chapter Two, I review the epidemiological and social science literature on abnormal Pap smears. I also describe Australian public health policy relevant to abnormal Pap smears.

Chapter Three details the population account of abnormal Pap smears. Using Medicare and laboratory statistics I describe current patterns of Pap smear and colposcopy use and simulate the population effects of current patterns of use.

In Chapter Four, I describe the methods used for the research on women's accounts of cervical abnormalities. Chapters Five through Seven describe the results of this inquiry. Chapter Five examines how women experienced their cervical abnormality as neither a state of health nor illness — rather it

was a state that defined them as being at ongoing risk of cervical cancer and death. In Chapter Six, I explore how women sought to manage this newly defined state of risk. Women's accounts of their interactions with the health system are detailed in Chapter Seven.

Chapters Eight through Ten present a clinical and economic account of abnormal Pap smears. The methods of this inquiry, sample characteristics and concordance between cytology, colposcopy and histology are described in Chapter Eight. The economic costs, for government and women, of current practice and new policy recommendations, are considered in Chapter Nine. In this chapter, I also examine how cost is influenced by various socio-demographic and clinical variables. As 20 per cent of the clinic sample did not complete the recommended follow-up I use survival models to estimate how socio-demographic and clinical factors might be associated with non-attendance. The results of this analysis are reported in Chapter Ten.

Finally, in Chapter Eleven I overview the research findings and consider how they might reshape clinical practice and public health policy. I also recommend directions for future research.

Chapter Two

Setting the scene

This chapter describes the scientific and policy context in which the research conducted for this thesis was located.

The chapter examines the following questions: what is the historical context of cervical cancer screening; is cervical cancer a significant public health problem in Australia; are Pap smears efficacious; how should a screening program be organised; how are Pap smears reported; what is the natural history of cervical cancer; and, what is the appropriate clinical approach to abnormal Pap smears? Epidemiological literature is the main source of information. The chapter concludes with an overview of current Australian policy and abnormal Pap smears and a description of the relevant health economic and social science literature that address the economic and non-economic costs of abnormal Pap smears.

Historical context

Although the Pap smear is well accepted as an efficacious screening test, previous uses of both the speculum and Pap smear have been harmful for some women.

Dr J Marion Sims 'invented' the speculum in the mid 1800s. When he inserted it into the vagina of a woman positioned 'all fours', he is purported to have said:

> Introducing the bent handle of a spoon, I saw everything as no man had ever seen before...The speculum made it perfectly clear from the beginning... I felt like an explorer in medicine who first views a new and important territory. (Barker-Benfield 1976). p95

Sims, who had a self-declared hatred of the female pelvis, developed the speculum to perform operations on women who had fistulas between their bladder and vagina. These were initially performed on black slaves whom he housed in a building in his backyard. (Barker-Benfield 1976).

The vaginal speculum has been an instrument of women's oppression and a tool of women's resistance to that oppression. The speculum was used to examine Parisian prostitutes for signs of venereal disease in the 1830s. Any identified lesions were then treated with caustic solutions. When British gynaecologists tried to introduce the speculum to their practice in the mid nineteenth century they met with resistance because such examinations were regarded as inappropriate for 'virtuous' women. Such treatment was believed to change a woman's 'purity' and 'delicacy'. Further, it was thought that some women became addicted to these examinations and were 'uterine hypochondriacs'. (Walkowitz 1980).

In 1864 the British Parliament passed the first Contagious Diseases Act which enabled plain-clothes policemen to identify women who were 'common prostitutes' and require them to undergo fortnightly internal examinations. The Ladies' National Association, which formed with the leadership of Josephine Butler, fought the introduction of the Act on the basis that it constituted class and sex discrimination. (Walkowitz 1980).

George Papanicolaou originally collected vaginal cytology specimens from guinea pigs. Later he discovered that cervical carcinoma cells could be found on scrapings from the human female cervix and vagina. He first presented a paper on his findings at a 'race betterment conference' in Michigan in 1928. His work was initially poorly received and he did not publish his research until 1941. (Papanicolaou and Traut 1941; Barter 1992).

Since the 1960s the Pap smear (named after George Papanicolaou) has been widely used in the secondary prevention of cervical cancer through screening women who do not have symptoms of cervical cancer. The advent of cervical screening, the use of the speculum in routine gynaecological examinations and in pregnancy and childbirth means that most Australian women are now familiar with the vaginal speculum.

In the 1970s the speculum became part of the feminist self-help groups. It became a symbol of women seizing technology from medicine and gaining greater control over their own bodies. (Ehrenreich and English 1973). Some women's health books contain accounts of how to perform self-examination with a vaginal speculum.[1]

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[1] For example, for an account of vaginal self examination see The Boston Women's Health Collective 1971. p270

In the 1980s the work of Professor Herb Green, at the Royal Hospital for Women in Auckland, was exposed as unethical. It became a subject of international controversy. Professor Green believed that carcinoma *in situ* was not a precursor to cervical cancer. Women who had persistent carcinoma *in situ* after treatment were followed without any further treatment and without their consent for withholding treatment. Twenty-two per cent developed cervical cancer and five died. Colleagues, who were concerned about his practice, published the results of his clinical practice in a medical journal in 1984. (McIndoe, McLean et al. 1984). The work was first brought to public attention by two feminists — Sandra Coney and Phillida Bunkle (a journalist and an academic) (Coney and Bunkle 1987). A national inquiry was subsequently held (Committee of Inquiry into Allegations Concerning Treatment of Cervical Cancer at the National Women's Hospital and into Related Matters 1988).

Our current understanding of cervical cancer screening has been made at considerable cost to women in the past two centuries.

Cervical cancer incidence and mortality

In 1988, 1061 women in Australia developed cervical cancer and 345 women died from it. Cervical cancer was the seventh most frequent cause of cancer death for Australian women. The highest incidence of cervical cancer was among those aged 65 to 69 years. The incidence rates were similar for women aged between 35 and 84. Based on 1987 incidence rates, a woman's lifetime risk of developing cervical cancer was one in 90. (Australian Institute of Health and Welfare and the Australasian Association of Cancer Registries 1994). In New South Wales in 1991 there were 361 new cases of cancer of the cervix and 105 cancer deaths. (Coates, McCredie et al. 1994).

In Australia, between 1950-1954 and 1975-1979 the age-standardised mortality rate from cancer of the cervix fell from 12.5 to 7.5 per 100,000 person years. These rates were adjusted for the number of women who had undergone hysterectomy in each age group (and hence are no longer at risk of dying from cervical cancer). However, women born after 1940 seem to have experienced increased rates of cervical cancer mortality at ages 30-34, 35-39 and 40-44. Mortality rates may be decreasing for women born after 1955. (Holman and Armstrong 1987).

Between 1973 and 1982 in New South Wales the incidence and mortality rate from cancer of the cervix fell by 1.3 and 3.6 per cent per year respectively (McCredie, Coates et al. 1989). Thirty-five per cent of women who had cervical cancer in a series of 237 cases referred to a Sydney hospital had never had a smear (Wain, Farnsworth et al. 1992). Of 100 women referred to a Perth based hospital 61 had not had a smear prior to the diagnosis of their cancer (Holman, McCartney et al. 1981).

Overview of screening

Morrison (1992) describes screening as:

> ...the examination of asymptomatic people to classify them as likely, or unlikely, to have the disease that is the object of screening.

In the case of cervical cancer, screening should identify individuals who are likely to develop cervical cancer. The Pap smear test detects cervical cytological abnormalities that may develop into cervical cancer during a woman's lifetime. Morrison calls abnormalities that would not progress to cancer 'pseudodisease'. (Morrison 1992). The purpose of the Pap smear is to prevent invasive cervical cancer. It does not prevent preclinical disease. This distinction must be borne in mind when considering the natural history of cervical cancer discussed later in this chapter. (Morrison 1992).

Morrison (1992) provides a framework for considering screening. He identifies the characteristics of a disease suitable for screening and the characteristics of a suitable screening test. Diseases which pass through a preclinical phase, which do not produce symptoms, are suited to screening techniques. Screening identifies asymptomatic individuals in the preclinical phase of the disease. The preclinical phase begins when the pathological process first occurs. This is often indistinct. The preclinical phase finishes when a person develops symptoms that would lead to identifying the disease. A long preclinical phase makes a disease even more suitable for screening.

Another precondition for a screening test is that a diagnostic procedure is available to investigate people who have a positive result. For screening to be effective, treatment in the preclinical phase must confer an advantage over treatment at a later stage. That is, early treatment must reduce morbidity and mortality from the screened disease. (Morrison 1992).

A suitable test must distinguish between those with and those without preclinical disease. This distinction is often difficult to make because there may be considerable overlap in test measurements. For example, atypical cells on a cervical cytology specimen may occur in both women who do and do not have preclinical stages of cervical cancer. Whether a woman who has atypical cervical cells is considered screen-test positive depends on the *criterion of positivity*. This criterion is somewhere between clearly normal and clearly abnormal. If the criterion of positivity is low the test will have high sensitivity for preclinical disease, as most people with the disease will be detected. However, a lot of people without preclinical disease will be labelled screen test-positive and the test will have low specificity. On the other hand, a high criterion of positivity will result in low sensitivity and high specificity. A screening test should also be reliable. That is, it should produce similar results when repeated on the same person at a similar time. Once a possible screening test has been identified it should be evaluated.

Evidence for the efficacy of cervical cancer screening

Ideally a screening test should be evaluated in a randomised controlled trial in which a group is randomly invited to participate in a particular screening schedule. This schedule includes screening at specified intervals, protocols for the assessment of people who screen positive and treatment of those identified with preclinical disease. Another group is also randomly assigned to a control group, which receives no intervention or an alternative intervention with which one wants to compare the screening schedule. This alternative is usually the previously accepted best practice schedule. Groups are followed over many years to ascertain whether the screening program reduces morbidity or mortality from the screened disease. There have been no randomised controlled trials of the Pap smear in which the cervical cancer incidence and mortality of women who are offered screening is compared with women who are not screened. This is because Pap smears were introduced before such evaluation was considered necessary and it is now considered unethical not to offer screening to all women.

Other evidence for the efficacy of screening tests comes from non-experimental studies. Correlational and analytical studies provide the evidence for the efficacy of cervical cancer screening.

Time trend and geographical correlational studies from Canada and British Columbia (Miller, Lindsay et al. 1976; Anderson, Boyes et al. 1988) , the United States (Cramer 1974), Norway (Magnus, Langmark et al. 1987), Denmark (Lynge 1983; Lynge, Madsen et al. 1989), Sweden (Pettersson, Bjorkholm et al. 1985), Iceland (Sigurdsson, Adalsteinsson et al. 1989) and Finland (Timonen, Nieminen et al. 1974) have demonstrated that cervical cancer screening can reduce the incidence of and mortality from cervical cancer. In contrast, cervical screening in the United Kingdom has been less effective in reducing incidence and mortality from cervical cancer (Murphy, Campbell et al. 1987). A comparison of cervical cancer mortality rates in the Nordic countries showed reductions in mortality between 1965 to 1982 of between 40 and 80 per cent for Sweden, Iceland and Finland. Denmark and Norway, who had less extensive 'organised' programs, did not experience as large a reduction in mortality. (Laara, Day et al. 1987).

Various case-control studies have demonstrated the preventive effect of cervical cancer screening. They have shown that women who participate in cervical screening have a reduced incidence of cervical cancer. Protective effects of between 40 and 90 per cent have been reported. (Clarke and Anderson 1979; Aristizabal, Cuello et al. 1984; La Vecchia, Franceschi et al. 1984; Berrino, Gatta et al. 1986; Wangsuphachart, Thomas et al. 1987; Celentano, Klassen et al. 1988; Olsen 1988; Palli, Carli et al. 1990; Herrero, Brinton et al. 1992).

About 85 per cent of all cervical carcinomas are of the squamous cell type. The remainder are adenocarcinoma, adenosquamous and a mixture of other types. Most epidemiological studies have only demonstrated a protective effect of cervical cancer screening for squamous cell cancers.

An international collaborative study based on ten screening programs related the risk of invasive cancer to time elapsed since the last negative smear and the number of previous negative results. They concluded that smears performed up to three years previously provided 90 per cent protection against invasive cancer. They recommended that screening programs should be aimed at women between 35 and 60 years of age and the smears should be taken at least every three years. Annual or biennial smears did not offer much greater protection than triennial smears. (IARC Working Party on the Evaluation of Cervical Cancer Screening Programmes 1986). There were various methodological problems associated with that study, however. Individual studies used different definitions for a negative smear from that

initially agreed upon by the collaborating group. Some women without symptoms, who were detected as a consequence of screening, were included as cases. Inclusion of these women as cases will underestimate the beneficial effect of screening. Analytical studies may also be subject to bias because women who are screened are less likely to have cervical cancer. This is because women screened more frequently are less likely to have preclinical disease or a false negative test. To be screened frequently means one cannot have the disease the screen is designed to detect. Someone who has been screened frequently is also more likely to have been screened more recently. Therefore, case-control studies may overestimate the benefit of recent smears. (Morrison 1992).[2]

A screening program

A 'screening program' is the application of a screening test in a population and the diagnosis and treatment of the early disease. The Nordic countries, which have introduced organised screening programs for cervical cancer, have experienced the greatest reductions in incidence and mortality. Based on the Nordic experience, the International Agency for Research on Cancer (IARC) outlined the essential elements of an organised cervical cancer screening program. These are:

- the target population is identified
- individual women are identifiable
- measures are available to guarantee high coverage and attendance, such as a personal letter of invitation
- there are adequate facilities for taking Pap smears and adequate laboratory facilities to examine them
- there is an organised program for quality control of the taking of Pap smears and their interpretation
- adequate facilities exist for the diagnosis and appropriate treatment and follow-up of women who have confirmed neoplastic lesions

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[2] For a review of the methodological difficulties associated with case-control studies of screening see: Morrison 1982; Weiss 1983; Morrison 1992.

- there is a carefully designed and agreed upon referral system, an agreed link between the women, the laboratory and the clinical facility for diagnosis of the abnormal screening test, for the management of the abnormality found and for providing information about normal screening tests

- there is evaluation and monitoring of the total program; that is, incidence and mortality rates among those attending and not attending are described and there is quality control of epidemiological data. (Hakama, Miller et al. 1986), p289

Thus there are numerous steps involved in a population-based cervical cancer screening program. This thesis focuses on the final steps in a cervical screening program — what happens when women have an abnormal Pap smear result. In the remainder of this chapter I concentrate on issues directly relevant to abnormal Pap smears.

Cervical cytology, colposcopy and histology

The reporting of cervical cytology

Since the introduction of the Pap smear in the 1960s, several systems for reporting cytology have been used. These are presented in Table 2.1.

Initially Pap smears were divided into classes. (McKay, Terjanian et al. 1959). Govan et al. (1969) described the histological criteria for defining dysplasia (Govan, Haines et al. 1969). Because of the difficulty in differentiating between severe dysplasia and carcinoma *in situ*, Richart (1966) introduced a system in which precancerous smears were classified as cervical intraepithelial neoplasia (CIN) grades 1 to 3. CIN 3 corresponded with severe dysplasia and carcinoma *in situ*. Classification into grades of CIN depended on the proportion of the epithelium that had atypical nuclear changes. CIN 1 corresponded with one third of epithelial involvement and CIN 2 and 3 with two thirds and full thickness respectively. Previously dysplastic lesions and *in situ* lesions had been classified by the degree of cellular atypia or the proportion of the epithelium occupied by atypical cells. The CIN system of classification also accommodated a conceptual shift in thinking about the natural history of cervical cancer. At the time Richart introduced the CIN classification, the progression of precancer to cancer was thought to be a continuous process rather than occurring in discrete stages.

(Richart 1966; Buckley, Butler et al. 1982). Buckley (1982) also argued that the CIN classification made clinical sense because the distinction between benign atypical lesions and CIN provided a guide to clinicians. All CIN lesions should be considered as having similar prognoses and hence the approach to clinical care of women who had any grade of CIN should be similar. CIN should be considered as signifying a significant future risk of cervical cancer. (Buckley, Butler et al. 1982).

Table 2.1 Reporting systems for cervical cytological specimens

Class system (McKay, Terjanian et al. 1959).	(Richart 1966).	Bethesda (National Cancer Institute Workshop 1989).	(Commonwealth Department of Human Services and Health 1994).
Class 1 - Normal	Normal	1. Specimen adequacy 2. General category 3. Descriptive diagnosis (i) Infection (ii) Reactive or reparative changes	1. Report category *Normal* Includes smears with no abnormalities and those with minor reactive changes only) *Low grade epithelial abnormalities* (Includes changes of HPV and CIN 1. Also includes endocervical cells demonstrating minor glandular changes)
Class 2 - Suspicious Class 3A - Very mild dysplasia Class 3B - Mild dysplasia	CIN 1 (equivalent to mild dysplasia)	(iii) Low grade epithelial cell abnormalities: *Squamous* (equivalent to CIN 1 and HPV and mild dysplasia) *Glandular*	
Class 3C - Moderate dysplasia Class 3D - Severe dysplasia	CIN 2 (equivalent to moderate dysplasia) CIN 3 (equivalent to severe dysplasia/carcinoma *in situ*)	(iv) High grade epithelial abnormalities: *Squamous* (equivalent to CIN2/CIN3 and moderate/severe dysplasia/carcinoma *in situ*) *Glandular*	*Inconclusive* *High grade non-epithelial lesions* eg sarcomas *High grade epithelial abnormalities* (i) Intraepithelial lesions (this includes squamous and glandular cells changes equivalent to CIN 2 or 3)
Class 4 - Carcinoma *in situ* Class 5 - Invasive carcinoma		(v) Invasive carcinoma *Squamous* *Glandular* (vi) Non-epithelial malignant neoplasm	(ii) Invasive lesions

Recently the Bethesda system has been introduced. In this system precancerous changes are divided into two distinct groups: low and high grade squamous intraepithelial lesions (LGSIL and HGSIL). Low grade abnormalities are equivalent to CIN 1 and HPV infection (koilocytosis); high grade abnormalities correspond with CIN 2 and 3. (National Cancer Institute Workshop 1989; Broder 1992). The amalgamation of HPV change and CIN 1

into one reporting category is logical because they have a similar natural history and in practice it has been difficult to differentiate HPV and CIN 1. In contrast, CIN 2 and 3 are associated with different HPV types than CIN 1 and are more likely to progress to cancer. (Richart 1990; Kurman, Malkasian et al. 1991). Low grade squamous intraepithelial lesions (LGSIL) appear to be associated with HPV types that are not associated with invasive cancer whereas high grade squamous intraepithelial lesions (HGSIL) are more commonly associated with virus types that have been related to cervical cancer (Kiviat, Critchlow et al. 1992). It is suggested that LGSILs are transient HPV infections which confer women with a higher risk of developing a HGSIL. LGSIL and HGSIL are considered to be distinct entities rather than part of a disease continuum. (Kiviat, Critchlow et al. 1992).

The Bethesda system was introduced to improve reproducibility; achieve better concordance between cytological, colposcopic and histologic findings; to represent more accurately current understandings of the natural history of cervical cancer; and, to improve communication between clinician and pathologist (Kurman, Malkasian et al. 1991). The Papanicolaou and CIN reporting systems have poor inter- and intra-observer reliability. In contrast, the Bethesda system appears to have better reproducibility (Sherman, Schiffman et al. 1992).

Until recently there were no uniform guidelines for the reporting of cytology in Australia. Both the Papanicolaou and CIN systems were used. The frequency of minor abnormalities reported by laboratories has varied. In Victoria, in 1992 the frequency of abnormalities showing minor reactive or inflammatory changes ranged from one to 44 per cent (Mitchell and Higgins 1993). Guidelines have recently been released for the reporting of cervical abnormalities in Australia. These guidelines follow a similar format to the Bethesda system. (Commonwealth Department of Human Services and Health 1994).

Concordance between cytology, colposcopy and histology

Inter- and intra-observer reliability for cervical cytology, colposcopy and histology is poor. Concordance between cytology and colposcopy and histology is also low.

In 1992 in Victoria 86 per cent of women who received a cytology report of CIN had a subsequent histologic or colposcopic report that was the same or

within one grade of their cytology report. (The colposcopic findings were used if no biopsy was taken.) Fifty-seven per cent of women had cytology and histology or colposcopy reports of equivalent grade. (Mitchell and Higgins 1993).

Usually, cytology results are compared with the histology report (and occasionally the colposcopy findings) to determine the accuracy of cervical cytology. Colposcopy and histology can also be inaccurate, however. For example, colposcopy and direct punch biopsies may miss significant lesions found on cone biopsy (Skehan, Soutter et al. 1990). Inter-observer reliability for histology is often poor, particularly for low grade CIN. CIN 1 is not easily distinguished from reactive squamous proliferations of the epithelium. (Ismail, Colclough et al. 1989; Robertson, Anderson et al. 1989).

A major concern is that women with low grade cytology reports may have more significant disease when a biopsy is taken. For example, a small proportion of women with cytology reports of inflammatory or squamous atypia may have histologic reports of CIN. Another concern is that women with CIN 1 on Pap smear may have a higher grade lesion on biopsy. Studies examining the proportion of women with minor cytological abnormalities who have histological evidence of a higher grade lesion are reviewed later in the chapter.

In clinical practice, the reliability of cytology and histology might be even poorer. Studies of reliability of particular measures use agreed-upon classification systems. Most studies involve experienced pathologists. Until recently there has not been uniform criteria for the reporting of pathology in Australia. Pathologists and cytotechnicians with a range of experience report on specimens.

The accuracy of cervical cytology

The reported inaccuracies of cervical cytology have been of concern. Recent court cases have brought this to public attention.[3]

Of most concern is the frequency of false negative reports. That is, the sensitivity of cervical cytology is poor. False negative reports can be a consequence of reporting or sampling error. Although the concept of sensitivity (the probability that someone with the disease will have it detected on a screening test) appears to be straightforward, dilemmas arise when one attempts to define what constitutes a positive screening test and disease. In theory, in order to calculate the sensitivity of a test in a particular setting all participants should have a diagnostic test which establishes whether or not the disease is present; then, those with falsely negative screening tests can be identified. In the context of an ongoing program this is impractical. Measures of sensitivity are also likely to be falsely elevated in these circumstances since women with symptoms may be screened and are more likely to be followed up regardless of their screening test result and cytotechnicians may pay more attention to smears from a woman where symptoms are reported (Mitchell 1989).

A positive screening test might be defined as one that results in referral of the woman for further investigation. Practice has varied in this regard. Some clinicians and their clients might chose to seek further investigation for minor levels of abnormalities; others might consider referral only if the smears report is of CIN 2 or greater.

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[3] Two actions have recently been taken against a private and a public laboratory. One court case involved a woman with invasive disease who had symptoms of intermenstrual and postcoital bleeding. Pap smears were reported as normal. The woman, who lived in Sydney, sued the pathology laboratory for missing significant pathology on her smear and her general practitioner for failing to refer her when she had symptoms. She was awarded over $400,000. She died soon after the court case.

Action was recently taken against a public laboratory by a woman who received a false negative report and subsequently developed cervical cancer. There was an out of court settlement for an amount similar to the Sydney case.

In cervical cancer screening emphasis is on detecting precursor lesions. In this situation, precursor lesions might be conceived as disease. The definition of precursor lesions is unclear, however. The sensitivity of the Pap smear varies for different grades of abnormality and large lesions are more readily detected than smaller lesions (Giles, Hudson et al. 1988; Barton, Jenkins et al. 1989).

Later in the chapter I discuss how many women with CIN or HPV would never develop cervical cancer. The lower the grade of CIN, the less likely the lesion will progress to invasive cancer. Those women who have lesions that will not progress have what Morrison refers to as 'pseudodisease'. Can these women be considered 'true positives' even though they have precursor lesions that would not develop into invasive disease?

The aim of a cervical cancer screening program is to reduce morbidity and mortality from cervical cancer in the population. It is not to prevent precursor lesions. Therefore, sensitivity may be better considered in the context of the program itself. Program sensitivity is 'the proportion of cases found as a result of screening among cases that arise during the screening program' (Morrison 1992). Does the screening test detect disease in those participating in the screening program or does it prevent disease amongst the population to whom it is offered? In Australia, it is estimated that screening prevents 46 per cent of cervical cancers (Australian Health Ministers' Advisory Council. Cervical Cancer Screening Evaluation Committee 1991). One might consider, therefore, the sensitivity of Australia's cervical cancer screening program to be 46 per cent. Uptake of the screening tests, the interval for screening and screening test sensitivity all affect the above calculation.

The interval cancer rate is related to program sensitivity. Interval cancers are those cases of cancer detected in women who have negative results within a specified time period after a screening test, for example, three years. These women might be considered to be false negatives of the screening program. They include women who have a false negative test (reporting or sampling error) or those who develop rapidly growing new cancers. For established screening programs, the interval cancer rate also gives an indication of a screening test's accuracy (Mitchell 1989). Between 1982 and 1986 in Victoria, the interval cancer rate for women younger than 35 and between 35 and 69 years was 10 per 100,000 women years and 16 per 100,000 women years, respectively (Mitchell, Medley and Giles 1990).

Specificity is another measure of a screening test's validity. Specificity refers to the probability that someone who does not have the screened disease has a negative screening test. The false positive rate is one minus the specificity. Pap smears may be specific for preclinical disease. They may accurately discern those who do not have precursor lesions. However, because most women would not develop cervical cancer in their lifetime, the specificity of the program for cervical cancer may not be high enough. That is, a large proportion of women who would not develop the disease will be referred for further investigation (screen-test positive with 'pseudodisease'). These women could be considered to have false positive results because they would never develop cervical cancer.

The quality of cervical cytology

A satisfactory smear should sample sufficient cellular material from the transformation zone, be maintained in a good state of preservation and have clearly visualised cellular material unobscured by blood or inflammatory material. (Commonwealth Department of Human Services and Health 1993).

Endocervical cells are used to judge whether cells have been sampled from the transformation zone or above. Because neoplastic changes occur in the transformation zone it is imperative that adequate cells are sampled from this area. It is also suggested that smears with endocervical cells are more likely to detect precursors of adenocarcinoma.

Smears lacking an endocervical component are often judged suboptimal and re-screening earlier than the regular interval is recommended. The concern is that if smears lack an endocervical component then precursors of cervical cancer may be missed. However, this concern may not be substantiated empirically. Mitchell and Medley (1991) performed a longitudinal study comparing the rate of subsequent abnormalities amongst women whose smears lacked an endocervical component with a control group of women who had negative smears and endocervical cells. They hypothesised that if smears lacking an endocervical component were more likely to miss important abnormalities, then this group of women should have a higher rate of CIN on subsequent smears than the control group. No significant difference in the rate of CIN was found between the two groups. (Mitchell and Medley 1991).

Rates of abnormal Pap smears

Between 1970 and 1988 the crude rate of CIN reported on cytology in Victoria increased almost sevenfold, from 4.6 per 1000 to 17.7 per 1000. The age-adjusted increase was 390 per cent. The rate of CIN 3 decreased. CIN became more prevalent in younger age groups in the later years of the study. (Mitchell and Medley 1990). Mitchell and Medley (1990) estimated that the ratio of women receiving a report of CIN in their lifetime to women who would develop cervical cancer is 148: 1. Proposed explanations for the change in the rates of CIN were that the natural history of CIN had changed and that there had been a shift in reporting practices towards more frequent reporting of CIN. A South Australian hospital-based laboratory study also reported increases in CIN between 1977 and 1981, particularly in the younger age groups. (MacCormack, Lew et al. 1988). Until recently Victoria was the only state in which there were population-based figures on cervical cytology. However, it is likely that the trends in CIN reported in Victoria also occurred in other parts of Australia.

In 1992, 12.9 per cent of smears registered with the Victorian Cervical Cytology Registry were abnormal; 9.6 per cent showed minor reactive, inflammatory or mildly atypical changes only. CIN 1 and CIN 2/3 were each reported on one per cent of smears. Large variations (of orders of magnitude) between the rate of reporting of abnormalities was found between laboratories. The rate of abnormal smears reported by laboratories ranged from 4.4 to 47.3 per cent. The reporting of minor abnormalities with no evidence of CIN ranged from 1.4 to 43.9 per cent. There was less variation in the reporting of CIN. (Mitchell and Higgins 1993). Clearly these differences cannot only be explained by different populations of women. Such differences would not explain the forty fold difference in the reporting of minor abnormalities. Differences in reporting practice probably affect the varying rates of abnormal Pap smears found in laboratories.

Syrjanen et al. (1990) modelled the lifetime risk of receiving a cytology report indicating HPV infection based on current incidence rates. He estimated that 79 per cent of women would receive a cytology report indicating wart virus infection based on current reporting practices and incidence rates for 22-year-old women in Finland. (Syrjanen, Hakama et al. 1990). Even if this were inflated by a factor of ten, many more women will receive a cytology report of HPV than will ever develop cervical cancer.

Richart and Wright (1993) suggests that the increase in the reporting of abnormalities of uncertain significance may have occurred because pathologists are increasingly concerned about missing an abnormality in women who later develop cervical cancer. In contrast, they believe clinicians would prefer fewer reports of minor abnormalities so that they increase the probability that women they refer have significant disease and hence are likely to benefit from further treatment. (Richart and Wright 1993).

The role of human papillomavirus

Cervical cancer has been related to smoking, age of first sexual intercourse, number of sexual partners (both the woman and her male partner/s), socio-economic status, HPV infection, herpes simplex virus infection and the oral contraceptive pill. Recently, intake of vitamins A, C and E have received research attention. I do not review the literature for all the risk factors for cervical cancer and its precursors. Instead, I provide a brief overview of the current state of knowledge about wart virus infection since this condition presents clinical dilemmas regarding appropriate care.

Wart virus infection (HPV) has different morphological manifestations. It can present as frank warts resulting in condyloma acuminatum or flat condyloma (clinical infection) or it may only be evident on cervical cytology or colposcopy (subclinical infection). It may also be latent. Latent infection can only be identified virologically, using techniques that detect viral DNA. Someone with HPV infection may move between the clinical, subclinical and latent phases of infection.

Human papillomavirus is a DNA virus that inserts into the nucleus of human cells. About 70 types of HPV have been identified, some of these have been related to anogenital cancers (penile, vulval, anal and cervical cancer).

Early epidemiological studies of cervical cancer concentrated on the link between sexual activity and cervical cancer. Studies that compared the rates of cervical cancer of nuns with other women (Rigoni-Stern 1842 reprinted 1987; Gagnon 1950; Fraumeni, Lloyd et al. 1969) have become folklore. In fact, Rigoni-Stern, the earliest of the researchers, compared the ratios of uterine to breast cancer in 'nubile' women (nuns included) and married women. The ratio was 1 to 4 for women who had never married and 1 to 2 for married women. Cancer of the breast was much more common in nuns. He did not separate cancer of the body of the uterus from the cervix. (Rigoni-

Stern 1842 reprinted 1987). The misquoted lower rate of cervical cancer (or uterus) amongst nuns has been taken to suggest that sexual activity was related to cervical cancer because nuns were, presumably, celibate.

Griffiths (1991) reviewed the evidence relating to cervical cancer among nuns. He found that many of the studies had been misquoted. Some had even concluded that nuns had rates of cervical cancer similar to other women but had been quoted as supplying evidence in support of the low risk of cervical cancer among nuns. Most studies had serious methodological flaws. He concludes:

> there is no substantial objective evidence for the dogma that cervical cancer is rare among nuns. (Griffiths 1991). p802

Yet the studies on nuns still influence practice. New regulations in Britain require general practitioners (GPs) to achieve 80 per cent participation of the women registered in their practice in cervical cancer screening. Payments are linked to them achieving this target. A conservative MP raised the issue in the House of Commons, concerned that GPs may be unable to reach their target because they had nuns, virgins and spinsters on their books: a GP with a convent on the books stood to lose £1000 or more. The conservative party supported a motion to exclude nuns and spinsters from the group of women targeted for cervical screening. (Warden 1990).

Recent studies have found that sexual activity is associated with cervical cancer and CIN (Cuzick, De Stavola et al. 1989; Slattery, Overall et al. 1989; Cuzick, Singer et al. 1990; Herrero, Brinton et al. 1990; Jones, Brinton et al. 1990; Parazzini, Hildescheim et al. 1990; Parazzini, LaVecchia et al. 1992; de Vet, Knipschild et al. 1993). The most popular explanation for the consistent relationship between sexual activity and cervical cancer or CIN has been that cervical cancer is related to a sexually transmitted agent. Lately HPV infection has been identified as the probable link between sexual activity and cervical cancer.

Measuring HPV

The greatest barrier to assessing the relationships between HPV infection, sexual activity and cervical cancer has been with problems in accurately measuring HPV infection. Recent advances in molecular biology have contributed to this field; it is now possible to detect HPV DNA in human tissue.

A variety of techniques have been used, most popular of which have been the Southern blot, dot blot, filter in-situ hybridisation (FISH) and, most recently, PCR-based techniques. Serological tests are also being developed but have not yet been used in large-scale epidemiological studies. The different techniques have variable validity and reliability. Often, the sensitivity and specificity of the techniques are tested against clean model systems such as purified DNA which do not reflect the clinical conditions or field conditions under which they are used (Lorincz 1992). Alternatively the validity of the techniques is tested against Southern blot which has been used as the 'gold standard'. The Southern blot requires biopsy specimens. This is not possible in epidemiological studies where control subjects do not have any evidence of disease. Schiffman (1992) reviewed the validation of different hybridisation assays. In his review he cites unpublished work which illustrates the relatively poor reliability of all methods. Between laboratory and within laboratory comparisons demonstrate poor reproducibility. Slight differences in the use of the same techniques in different settings make it difficult to compare the results. He concludes that Southern blot is superior to all but the polymerase chain reaction (PCR) based methods which are capable of detecting one HPV DNA molecule in 10^5 cells (Young, Bevan et al. 1989). Schiffmann concludes that while a Southern blot requires a large sample to be sufficiently sensitive, both the PCR and dot blot methods are useful techniques for epidemiological studies. In contrast, the sensitivity and specificity of FISH too low. However, he maintains that there is a critical need for a reference centre to develop standards to enable comparisons between laboratories. Another study which compared Southern blot, dot blot and PCR found that the intra- and inter-test reliability was reasonable. They found that Southern blot and dot blot were less sensitive for women without neoplasia than women with invasive cervical cancer. (PCR was the gold standard used to assess the sensitivity of these tests.) (Guerroro, Daniel et al. 1992).

It is important to have a valid and reliable technique to measure HPV because misclassification of HPV status can significantly bias the results of epidemiologic investigations (Munoz, Bosch et al. 1988; Franco 1991; Franco 1992; Schiffman and Schatzkin 1994). Poor specificity is likely to overestimate the prevalence of HPV in the general population. In case-control studies of cervical cancer and HPV, poor specificity and sensitivity of HPV hybridisation techniques, which result in non-differential misclassification of exposure status for case and controls, will underestimate the strength of the

relationship between HPV and cervical cancer. (Franco 1991). This form of misclassification error was postulated as a reason why early analytic studies failed to demonstrate a consistent relationship between HPV infection and cervical cancer (Munoz, Bosch et al. 1988). Franco (1992) suggests, however, that misclassification of HPV status may not have been random between cases and controls. Instead, the techniques may be more sensitive for HPV in cases than controls partly because different specimens are collected from cases and controls. Schiffman and Schatzkin (1994) show how two similar case-control studies designed to assess the relationship between HPV and CIN found odds ratios of different orders of magnitude because of the different techniques used to assess HPV exposure.

Studies that investigated the relationships between HPV infection and cervical cancer, CIN and sexual activity in the 1980s, were hampered by the difficulties in measuring HPV infection. Hence the findings of these studies are now questioned.

The nature of the association between HPV and cervical cancer

An international workshop, organised by the International Agency for Research on Cancer, considered that the association between HPV and cervical cancer was causal. (Munoz, Bosch, Shah et al. 1992). In a review of the evidence, Munoz and Bosch drew this conclusion for five reasons: the relationship between HPV and cervical cancer was strong and consistent across several case-control studies; risk appeared to be related to a limited number of viral types; the viral load risk was related to cervical cancer risk implying a dose-response relationship; indirect evidence suggested that the presence of HPV DNA in neoplastic cells pointed to prior infection with HPV, indicating the temporality of the relationship (which cannot be established in case-control studies); and, the risk of progression to cervical cancer is higher for HPV types 16 and 18, both associated with cervical cancer in the case-control studies (Munoz and Bosch 1992). Since 1992 further evidence has emerged to support this conclusion. This is reviewed below.

A recent case-control study demonstrated that HPV infection was strongly related to the number of the woman's sexual partners (Kataja, Syrjanen et al. 1993). Another study has failed to demonstrate such a clear link (Villa, Franco et al. 1989). Case-control studies of HPV and sexual activity have used cytology or the less sensitive HPV DNA hybridisation methods to define

HPV status. These methods may have resulted in some misclassification of cases and controls.

In a case-control study of women who reported only one lifetime male sexual partner, their male partner's sexual history was associated with a much higher risk of cervical neoplasia. A history of male genital wart virus infection and non-use of condoms was also associated with a higher risk of cervical cancer. The association between women's male partners' sexual history and risk of cervical cancer was not statistically significant when male genital wart virus infection, condom use and age were controlled for in a multivariate analysis. This finding suggests that the association between a male partner's sexual history and women's risk of cervical cancer is likely to be due to a sexually transmitted agent, probably of wart virus infection. This was a small case-control study, however. (Kjaer, de Villiers et al. 1991).

Recent case-control studies using more sensitive PCR-based techniques for detecting HPV DNA consistently demonstrate a very strong relationship between cervical neoplasia (both cervical cancer and CIN 3) and HPV infection. (Munoz, Bosch, de Sanjose et al. 1992; Bosch, Munoz et al. 1993; Morrison, Ho et al. 1991; Schiffman, Bauer et al. 1993; Eluf-Neto, Booth et al. 1994; Peng, Liu et al. 1991). Odds ratios of between ten and 70 are reported. Such high odds ratios are rare in cancer epidemiology and suggest a causal relationship between HPV infection and cervical cancer. These findings are consistent with biological evidence that shows that particular proteins produced by HPV deactivate human tumour suppressor genes (Scheffner, Munger et al. 1991; Crook, Wrede et al. 1992).

HPV 16 has been most commonly implicated. Other types such as 18, 31, 33, 35 are also associated with higher risk of cervical cancer. After controlling for HPV status, the number of a woman's sexual partners became insignificant, suggesting that HPV infection explained the relationship between sexual activity and cervical cancer (Bosch, Munoz, de Sanjose et al. 1992; Schiffman, Bauer et al. 1993; Eluf-Neto, Booth et al. 1994). There also appears to be a relationship between risk of cervical neoplasia and viral load, implying a dose-response relationship (Reeves, Brinton et al. 1989; Morrison, Ho et al. 1991; Munoz, Bosch, de Sanjose et al. 1992). Two methods were used to assess viral load: an assessment of intensity of the HPV signal and the number of different HPV DNA hybridisation assays (PCR, Southern blot and ViraPap) which were positive. If the specimens were positive on all of the tests it was assumed that the viral load was high, whereas if the specimens were positive

only on PCR-based tests then the viral load was assumed to be low. None of the studies discusses the reliability and validity of the techniques used to assess viral load. The association between viral load and risk of cervical cancer needs further exploration. Previous use of oral contraceptives was associated with increased risk of cervical neoplasia in the IARC case-control studies. This was specific to women who had evidence of HPV infection on PCR-based detection techniques. A possible explanation for this finding is that oral contraceptives promote the oncogenic potential of HPV. (Munoz, Bosch et al. 1994).

Thus far I have reported evidence from retrospective case-control studies demonstrating a link between HPV infection, CIN and cervical cancer. One possible explanation for this association is that cervices with neoplastic change are more liable to HPV infection or that HPV DNA detection techniques are more sensitive to HPV infection in neoplastic tissue.

Longitudinal studies that follow women with HPV infection will give further insight into the natural history of HPV infections. A recent study followed a cohort who had negative cytology. Women who were HPV DNA positive on dot blot hybridisation had a cumulative incidence of CIN 2 or 3 of 28 per cent at two years compared with a cumulative incidence at two years of 3 per cent amongst HPV negative women. Women testing positive for HPV types 16 and 18 had the highest risk of progression. (Koutsky, Holmes et al. 1992). Other prospective studies using HPV DNA hybridisation methods are in progress. In a cohort of Finnish women with evidence of HPV infection on biopsy but with no CIN, 5.8 per cent developed CIN 1 or greater in a mean follow-up time of 45 months (Kataja, Syrjanen et al. 1989). In an Australian study, 13 per cent of women with cytological evidence of HPV infection in 1979 developed cytological or histological evidence of CIN over a six year follow-up period. Their risk of developing carcinoma *in situ* was 16 times greater than that expected on population incidence figures. (Mitchell, Drake et al. 1986). These studies use cervical intraepithelial neoplasia as an endpoint because following women until they develop cervical cancer is unethical. They do not, therefore, give us information about risk of cervical cancer associated with HPV infection. Such information is extrapolated from information we already have regarding the natural history of CIN.

Prevalence of HPV infection

With the advent of new HPV detection techniques several studies have examined the prevalence of different HPV types in women with normal cytology, mild atypia, CIN and cervical cancer. An increasing prevalence of HPV is apparent as the severity of the Pap smear abnormality increases (Zhang, Coppleson et al. 1988; van den Brule, Walboomers et al. 1991; de Roda Husman, Walboomers et al. 1994). Low grade lesions demonstrate a greater degree of heterogeneity of HPV types than higher grade lesions (Lungu, Sun et al. 1992; de Roda Husman, Walboomers et al. 1994). Several studies have shown that CIN 2 and 3 and cervical carcinoma are most commonly associated with HPV types 16 and 18 (Fuchs, Girardi et al. 1988; van den Brule, Walboomers et al. 1991; Lungu, Sun et al. 1992; Cusick, Terry et al. 1994; de Roda Husman, Walboomers et al. 1994). In contrast, CIN 1 and HPV atypia are most commonly associated with types 6 and 11 (Fuchs, Girardi et al. 1988; de Roda Husman, Walboomers et al. 1994). A considerable proportion of low grade lesions also have a HPV 16 and 18 infection (van den Brule, Walboomers et al. 1991; Lungu, Sun et al. 1992; Schiffman, Bauer et al. 1993; de Roda Husman, Walboomers et al. 1994). The proportion of women with CIN or cervical cancer who are HPV positive depends on the assay used to assess HPV DNA and the number of HPV types that are tested for. Studies using PCR-based analyses to detect HPV have reported prevalences of HPV for CIN 3 and invasive cancer from 63 to 100 per cent (van den Brule, Walboomers et al. 1991; Cusick, Terry et al. 1994; de Roda Husman, Walboomers et al. 1994; Eluf-Neto, Booth et al. 1994; Munoz, Bosch et al. 1994).

Table 2.2 shows the point prevalence of HPV infection among groups of women who have normal cytology. The table includes subjects included as controls in the case-control studies described earlier. A wide range of prevalence rates has been reported. The variation can partly be attributed to differences in the techniques used, samples collected and the number and types of HPV virus that were tested. The populations from which the samples are drawn also vary. For example, in the Spanish and Columbian case-control study of invasive cancer and HPV infection the prevalence of HPV positivity amongst control subjects was 4.6 per cent in Spain and 13.3 per cent in Columbia. Identical methods were used to determine HPV positivity amongst these control subjects. The authors suggest that the higher prevalence of HPV infection in Columbia may explain why Columbia has a

much higher incidence of cervical cancer than Spain. (Munoz, Bosch et al. 1994).

The samples in the studies shown in Table 2.2 vary with regard to age and other risk factors for HPV infection. Nonetheless it is evident that an appreciable proportion of the population may have infection with one or more HPV types. The prevalence of the high risk types 16 and 18 in women without cervical cancer has been reported as between zero and 75 per cent (see Table 2.2). Even if one takes the high estimates (32 and 75 per cent) to be falsely elevated (perhaps due to problems with hybridisation such as contamination or non-specific techniques) prevalence rates of 5 and 6 per cent are still reasonable. These are point prevalence estimates; the cumulative lifetime risk of a woman developing HPV DNA positivity for a high risk type is probably much higher. Most of these women would not develop cervical cancer. Although the relative risk of infection with high risk HPV types is extremely high the absolute risk of developing cervical cancer in the presence of these infections may be low.

HPV infection appears to be dynamic and often transient in nature. Using Southern blot hybridisation, Rosenfeld et al. (1991) found that 57 per cent of adolescents (n=51) had at least one HPV infection, on two tests taken six to 36 months apart. Only one young woman had infection with the same HPV virus on both occasions. Eight per cent of young women were HPV positive on both occasions. The authors conclude that self-limiting transient infection may be part of the natural history of cervicovaginal HPV infection in young women. (Rosenfeld, Rose et al. 1991).

Clearly, HPV infection can only be considered part of a multifactorial causation for cervical cancer. Other factors such the oral contraceptive pill or herpes simplex virus infection may also play a role.

Table 2.2 Point prevalence of HPV infection in women with normal cytology

Authors	Description of sample	HPV detection method and types tested for*	Prevalence of HPV positivity (positive for high risk types 16 and 18)
(van den Brule, Walboomers et al. 1991).	1346 asymptomatic women with normal cytology	PCR. Types 6, 11, 16, 18, 31, 33 and unspecified types	3.5% (0.9%)
(Fuchs, Girardi et al. 1988).	102 women with normal epithelial changes (includes 71 women with metaplastic changes)	Southern blot of cervical biopsies. Types 6, 10, 11, 16, 18	14.7%
(Eluf-Neto, Booth et al. 1994).	225 age matched controls in the Brazilian hospital-based case-control study	PCR of cervical cytology. Types 6, 11, 16, 18, 31, 33 and unspecified types	16.8% (6.4%)
(Bosch, Munoz et al. 1992).	A random sample of 130 women selected as controls for the Spanish case-control study	PCR, Virapap and Southern hybridisation. Types 6, 11, 16, 18, 31, 33, and 35.	4.6%
	98 women randomly selected as controls for the Columbian case-control study	PCR, Virapap and Southern hybridisation. Types 6, 11, 16, 18, 31, 33, and 35.	3.3%
(Reeves, Brinton et al. 1989).	1467 randomly selected hospital controls	Filter *in situ* hybridisation. Types 6, 11, 16 and 18.	(32.0%
(Schiffman, Bauer et al. 1993).	500 controls selected from within a cohort of women who are part of a Kaiser-Permante HMO study on the natural history of cervical cancer.	PCR. Types 6, 11, 42, 31, 33, 35, 39, 45, 51, 52, 16, 18 or unspecified types.	17.7% (2.9%)
(Peng, Liu et al. 1991).	146 hospital-based controls	PCR. Types 16 and 33.	1.4%
(de Villiers, Schneider et al. 1987).	8755 women attending gynaecology outpatients with normal cytology	Filter *in situ* hybridisation. Types 6, 11, 16, 18.	9%
(Fischer, Rosenfield et al. 1991).	107 women undergoing pelvic examinations at an adolescent health centre	Southern Blot. Types 6, 11, 16, 18, 31, 33, 35, 39, 42, 45, 56 and unspecified types.	32.1% (18% HPV 18, 3 % HPV 16)
(Borg, Medley et al. 1993).	318 women with normal cytology attending a Melbourne STD clinic population	Dot blot hybridisation. Types 6, 11, 18, 31, 35.	9% (5.2 %)
(Rakoczy, Sterrett et al. 1990).	510 normal smears in a Western Australian laboratory in 1987	Dot blot hybridisation and PCR. Type 16.	(74.8% HPV 16)
(Martinez, Smith et al. 1988).	68 adolescent women with normal cytology who had pelvic examinations at an adolescent clinic	Southern hybridisation. Types 6, 11, 16, 18, 31 and 45.	2.9% (0%)

* Unless otherwise specified the cytology or cervicovaginal lavage specimens were used for the HPV DNA hybridisation.

HPV DNA typing and screening

In light of new molecular biological and epidemiological evidence linking infection with particular HPV types with cervical cancer, some authors have suggested that HPV typing be included in screening (Ritter, Kadish et al. 1988; Meijer, van den Brule et al. 1992). Ritter et al. (1988) found that the sensitivity of both HPV typing and cytology for histological evidence of dysplasia was 89 per cent. Cytology and HPV typing alone yielded sensitivities of 74 and 68 per cent respectively. The authors concluded that the two tests combined were a better screening test than either technique alone. However, the false positive rate was 41 per cent with the two screening tests combined compared with 27 per cent for cytology alone. Therefore, although the combined tests may improve the sensitivity of screening, the increase in the false positive rate would increase drastically the number of women referred for biopsy. It would be premature to include HPV typing in cervical screening. It has not yet been formally evaluated as a screening technique. Such an evaluation would require a randomised controlled trial in different populations. Some HPV typing techniques have poor reproducibility in field studies and are likely to be even worse in a clinical setting. There is also a reasonable prevalence of high risk HPV types among women with normal cytology and some women with HGSIL or cervical cancer may not be positive for high risk types. HPV typing would also increase the cost of cervical screening.

Others have suggested that HPV typing be used to assess women who have LGSIL (Beral and Day 1992). Testing in this proposal might enable the identification of those women who have lesions at high risk of progressing, since it is postulated these women who have infection with high risk types are more likely to develop cervical cancer. Not enough is known about the natural history of LGSIL with certain HPV types to establish whether HPV typing would be useful in such situations.

As discussed earlier, a major concern is that women who have benign atypical or CIN 1 changes on cytology may have a more severe lesion on biopsy. Borst et al. (1991) investigated the possibility of performing HPV typing on the cytological specimens of women who have mildly atypical smears. In their small sample (n=51) HPV 16 positivity (by Southern blot) was a poor predictor of whether someone had histologic evidence of CIN. (Borst, Butterworth et al. 1991). In a sample of 133 women with abnormal smears of various grades referred for colposcopy in Britain, high levels of

HPV 16 had a positive predictive value for CIN 3 of 93 per cent. The sensitivity was only 59 per cent, however. Using high levels of HPV 16 or high levels of either HPV types 18 or 31 improved the sensitivity of the test for detecting women who had histological evidence of CIN 3. However, the positive predictive value fell due to a reduction in specificity. They conclude that HPV typing may be a helpful adjunct to cytology for women who have CIN 1. If high risk types are detected in this group of women, they should be referred for colposcopy. (Cuzick, Terry et al. 1994).

Summary

Human papillomavirus infection is presently considered to be causally related to cervical cancer. Several case-control studies have demonstrated a strong consistent relationship between HPV infection and cervical cancer. Risk of cervical cancer appears to increase with viral load and epidemiological evidence is consistent with molecular biological knowledge about HPV. Retrospective studies cannot establish the temporal nature of the relationship between HPV and cervical cancer and it is possible that HPV DNA is more readily detected or incorporated into neoplastic tissue. One study suggests that some HPV DNA detection methods may be more sensitive to the presence of HPV DNA in neoplastic tissue (Guerroro, Daniel et al. 1992). Finally, although there appears to be a very strong relationship between HPV infection and cervical cancer, the prevalence of HPV infection (even with high risk types) among healthy women may be reasonable. Not all women with cervical cancer have infections with high risk HPV types. HPV infection is neither a necessary nor sufficient cause of cervical cancer. Other factors may be important in the causation of cervical cancer. Also, although HPV infection may explain most of cervical cancer incidence (high attributable risk per cent) the absolute risk of cervical cancer associated with HPV types may be low. Prospective cohort studies will enable the temporal nature of HPV infection and cervical neoplasia to be established and will provide evidence regarding the risk of CIN associated with HPV infection.

The natural history of cervical cancer

Several methods have been used to determine the proportion of precursor lesions that progress and regress. These include longitudinal studies (summarised in Table 2.3) and modelling the disease using population rates of different stages of the disease. I consider each of these approaches in turn.

Longitudinal Studies

Longitudinal studies provide the most reliable data about the natural history of cervical cancer precursor lesions. Table 2.3 summarises studies that have examined the natural history of cervical precursor lesions. They are presented from most recent to earlier studies.

Comparison between the studies is difficult. Below I list some of the problems with the longitudinal studies listed in Table 2.3.

1. They use different criteria for entry into the study. For example, some studies use one abnormal smear to define disease status on study entry, others three consecutive abnormal smears and others biopsy-proven disease. These different criteria will affect progression and regression rates. If one abnormal smear is taken as a criterion for entry it is more likely that this smear is misclassified. It may be a higher or lower grade lesion on follow-up, and therefore progression and regression rates may be higher than if three abnormal smears or biopsy-proven disease is used. The studies that use several consecutively abnormal smears to define disease status are likely to report higher rates of persistent disease.

2. Different criteria are used to define disease progression or regression. Some studies use cytology and others histology. Like (1) these different criteria will affect the reported progression and regression rates.

3. There is some evidence that biopsy may occasionally completely remove the neoplastic tissue and interrupt the disease process (Koss, Stewart et al. 1963). Therefore, if biopsy is used to define disease status at entry into the study, progression rates may be underestimated and regression rates overestimated.

4. There is no uniformity in the disease classification systems used in natural history studies. Most of the studies were conducted some time ago. It is

likely that reporting practices have changed and therefore the generalisability of the findings of these early studies is limited.

5. Most studies did not have a control group, so risk of progression and regression among those women with neoplastic disease could not be compared with a group of women who had no evidence of disease.

6. Few studies have followed women in a consistent manner. Even in studies with protocols for follow-up, women with less severe levels of disease were not followed as intensely as other women in the study. More frequent contact means that it is more likely that transient states of progression and regression may be detected which will affect the rates reported.

7. Most studies (particularly the earlier studies) do not account for time in the denominator of their calculations. They present the proportion of women with disease that has progressed or regressed over an average or range of follow-up periods. Recent studies have used lifetables which account for the differing periods of time in the study.

8. There is poor intra- and inter-test reliability for the classification of cervical cytological and histological specimens. Misclassification errors may affect rates of progression and regression.

9. The natural history of cervical cancer is likely to be different for women of different ages. Studies do not take account of the age distribution of their sample. Overall rates of progression and regression are reported, rather than age-specific rates.

These studies were often conducted under stringent research conditions. They frequently involved experienced pathologists and gynaecologists. Therefore, findings from these studies may not be directly transferable to clinical practice where conditions and levels of experience are more variable.

Table 2.3 The natural history of cervical abnormalities

Author	Study design and analysis	Findings
(Kirby, Spiegelhalter et al. 1992).	Retrospective cohort study of 500 women with cytological evidence of mild or moderate dysplasia and 500 women with normal cytology, matched for age. All cytology and biopsy results were recorded. Lifetables were used for analysis.	29-30% of women up to 35 years of age progressed to CIN 3 or worse in ten years. Women older than 35 had a progression rate to CIN 3 at ten years of between 3 and 15%.
(Montz, Monk et al. 1992).	Prospective study of 91 women with cytological evidence of atypical squamous cells and 203 women with cytological evidence of low grade squamous intraepithelial changes (ie HPV or CIN 1). Followed three monthly with cytology and colposcopy for nine months and then six monthly. Simple proportions are calculated.	*Atypical squamous cells* At nine months 46.2% had persistent changes, none had progressed and 53.8% had regression to normal. (Women who were lost to follow-up were excluded from the analysis.) *Low grade squamous intraepithelial abnormality* At nine months 18.2% had persistent changes, 3.4% had progressed and 78.3% had regression to normal. (Women who were lost to follow-up were excluded from the analysis.)
(Narod, Thompson et al. 1991).	Retrospective cohort study of 70236 women constructed from pathology records. (20461 were randomly selected and 49775 were added because of a cytological diagnosis of dysplasia.) Cytology and histology results were available. Lifetable techniques were used for the analysis.	*Minimal dysplasia*: Progression to carcinoma in situ or invasive cancer was 38.5 women per 100,000 women years (n=20742) *Mild dysplasia*: Progression to carcinoma in situ or invasive cancer was 84.1 women per 100,000 women years (n=21396) *Moderate dysplasia*: Progression to carcinoma in situ or invasive cancer was 462.3 women per 100,000 women years (n=10165) *Severe dysplasia*: Progression to carcinoma in situ or invasive cancer was 1301 women per 100,000 women years (n=2460) (The results excluded women who had evidence of carcinoma in situ within 3 months of their abnormal smear.) (When compared with the entire cohort, the relative risks of developing carcinoma in situ for women with minimal, mild, moderate and severe dysplasia were 1.48, 3.42, 20.9 and 71.5 respectively.)
(Fletcher, Metaxas et al. 1990).	A prospective study of 666 women with cytological evidence of minimal, mild or moderate dysplasia. Follow-up according to protocols at 3, 6 and 18 months with cytology +/- histology. Lifetable analysis was used.	14% probability of progression to severe dysplasia/carcinoma in situ over a 4.5 year period 24% probability of regression to normal over a 4.5 year period
(Murthy, Sehgal et al. 1990).	Prospective cohort study of 1107 women with cytological evidence of mild, moderate or severe dysplasia followed at 3 to 6 month intervals with cytology, colposcopy +/- histology. Life-table analysis was used.	*Mild dysplasia:* 4.9% progressed to carcinoma in situ at 78 months. The mean transition time from mild dysplasia to carcinoma in situ was 26.6 months. *Moderate dysplasia:* 24.4% progressed to carcinoma in situ at 78 months. The mean transition time from moderate dysplasia to carcinoma in situ was 21.7 months. *Severe dysplasia:* 42.0% progressed to carcinoma in situ at 78 months. The mean transition time from severe dysplasia to carcinoma in situ was 12.1 months.

Table 2.3 (continued) The natural history of cervical abnormalities

Author	Study design and analysis	Findings
(Carmichael and Maskens 1989).	Prospective study of 192 women with mild or moderate dysplasia associated with HPV Infection on cytology. Followed at six month intervals and evaluated with cytology and colposcopy. Followed for up to 24 months. Results are presented as proportions.	At six months 2.1% had progressed to severe dysplasia or carcinoma in situ, 53.6% were persistent and 44.3% had regressed to normal. (Data on later follow-up periods are presented but are liable to biases because many women were not followed and were sent back to their referring physician.)
(Kataja, Syrjanen et al. 1989).	Prospective study of 149 women with biopsy proven CIN 1, 2 and 3 associated with HPV infection. Followed at 6 month intervals with cytology, colposcopy +/- histology. Lifetables were used. (However the results are presented in graphical form so that estimates of cumulative progression cannot be calculated.)	*HPV CIN1:* 12.3% of lesions progressed to higher grade lesion in a mean follow-up time of 45 months. 31.1% of HPV-CIN 1 lesions regressed to a lower grade lesion in a mean follow-up time of 45 months. *HPV CIN 2:* 20% of lesions progressed to higher grade lesion in a mean follow-up time of 45 months. 34.2% of HPV-CIN 2 lesions regressed to a lower grade lesion in a mean follow-up time of 45 months. *HPV CIN 3:* 55.2% of lesions progressed to higher grade lesion in a mean follow-up time of 45 months. 20.7% of HPV-CIN 3 lesions regressed to a lower grade lesion in a mean follow-up time of 45 months.
(Paavonen, Kiviat et al. 1989).	Prospective study of 124 women with mild atypia (not severe enough to signify CIN). Four monthly follow-up of with cytology, colposcopy +/- histology. Life-table methods to calculate the cumulative proportion developing biopsy-proven CIN 2 or 3.	At 30 months of follow-up 13.5% had evidence of CIN 2 or 3.
(Robertson, Woodend et al. 1988).	Cohort study of 1781 women with mild dysplasia on cytology between 1965 and 1984 followed until mid 1987. Only 1347 followed for two years or more. Followed by cytology +/- histology as per clinical protocol. Analysis include lifetable techniques and simple proportions.	15.2% developed carcinoma in situ or invasive cancer after two years. 46% regressed to normal within two years. Of these 75 per cent would have no evidence of disease at 14 years.
(Luthra, Prabhakar et al. 1987).	Prospective study of a cohort 650 women with mild, moderate and severe dysplasia followed with cytology +/- histology at 3 to 6 month intervals. Analysis using lifetables.	*Mild dysplasia:* The cumulative risk of progression was 2.2% at 84 months. *Moderate dysplasia:* The cumulative risk of progression was 28.2% at 84 months. *Severe dysplasia:* The cumulative risk of progression was 31.5% at 24 months. (Based on small numbers due to losses to follow-up.)
(Campion, McCance et al. 1986).	Prospective study of 100 women with CIN 1. Followed four monthly with cytology, colposcopy +/- histology. Results are presented as proportions.	26% progressed to CIN 3 over 19-30 months 67% had persistent disease over 19-30 months 7% regressed over 19-30 months

Table 2.3 (continued) The natural history of cervical abnormalities

Author	Study design and analysis	Findings
(Nasiell, Roger et al. 1986).	Prospective cohort study of 555 women with cytological evidence of mild dysplasia followed with cytology +/- histology at 3 to 12 month intervals. Results include proportions and lifetable analysis.	16% progressed to severe dysplasia/carcinoma in situ in an average follow-up time of 39 months 22% persisted over an average follow-up time of 39 months 62% regressed over an average follow-up time of 39 months 250-800/100,000 women year progressed to severe dysplasia/carcinoma in situ (560 times the rate of controls with normal cytology). Over 12 years the cumulative risk of progression to severe dysplasia/carcinoma in situ was 23%.
(Syrjanen, Mantyjarvi et al. 1985).	Prospective cohort study of 118 women with cytological evidence of HPV infection with CIN. Followed at six-monthly intervals with cytology, colposcopy +/- histology. Results are presented as proportions.	*CIN 1-HPV:* 22.8% progressed to CIS over an average follow-up time of 20 months; 49.1% persisted over an average follow-up time of 20 months; 28.1% regressed over an average follow-up time of 20 months *CIN 2-HPV:* 18.7% progressed to CIS over an average follow-up time of 20 months; 62.5% persisted over an average follow-up time of 20 months; 18.7% regressed over an average follow-up time of 20 months *CIN 3-HPV:* 72.4% progressed to CIS over an average follow-up time of 20 months; 17.2% persisted over an average follow-up time of 20 months; 10.3% regressed over an average follow-up time of 20 months
(Nasiell, Nasiell et al. 1983).	Prospective study of 894 women with cytological evidence of moderate dysplasia. Followed every 3 to 12 months (depending on severity of the lesion) with cytology, colposcopy +/- histology. Data presented as proportions.	54% regressed to normal over an average follow-up time of 78 months. 16% had persistent evidence of dysplasia. 30% regressed to severe dysplasia or greater.
(Luthra 1970).	Prospective study of 351 women with dysplasia followed with cytology +/- histology for 1 to 9 years.	11.1% progressed to higher grade of abnormality, 1.7% developed invasive cancer, 23.0% had persistent disease and 64.4% regressed to normal.
(Richart and Barron 1969).	257 women with cytological evidence of minimal, mild, moderate and severe dysplasia followed at one to four monthly intervals with cytology and colposcopy. Transition probabilities were calculated at different follow-up examinations.	At the ninth follow-up examination 40.6% of women with minimal dysplasia had cytological evidence of carcinoma in situ. The corresponding probabilities for mild, moderate and severe dysplasia were 62.5%, 79.6% and 98.6% respectively.
(Hall and Walton 1968).	Prospective study of 206 women with mild, moderate and severe dysplasia on cytology or histology followed for up to 14 years. Follow-up was with cytology and histology. Data are presented as proportions.	*Mild dysplasia:* 6.2% progressed to carcinoma in situ. 13.4% progressed to a higher grade lesion, 24.4% persisted and 62.2% regressed. *Moderate dysplasia:* 12.9% progressed to carcinoma in situ. 18.4% progressed to a higher grade lesion, 48.7% persisted and 32.9 regressed. *Severe dysplasia:* 29.1% progressed to carcinoma in situ. 33.3% progressed to a higher grade lesion, 47.6% persisted and 19.1% regressed.

Table 2.3 (continued) The natural history of cervical abnormalities

Author	Study design and analysis	Findings
(Johnson, Nickerson et al. 1968).	349 women with cytological or histological evidence of mild, moderate or severe dysplasia followed for 1 to 9 years every 3 to 12 months with cytology +/- histology. The incidence rate of carcinoma in situ is calculated. This accounts for the different periods over which individual women were followed.	All dysplasias: in an eight year period 4.4 women per 1000 women years developed carcinoma in situ. (This compares with a rate of carcinoma in situ of 0.2 per 1000 women years among the cohort of women who had normal cytology on entry into the study.)
(Fox 1967).	Prospective study of 278 women with cytological evidence of mild or moderate dysplasia followed with cytology. Data presented as proportions.	*Mild or moderate dysplasia:* 60.1% progressed to carcinoma in situ or worse in a follow-up period from 15-19 months 8.9% persisted in a follow-up period from 15-19 months 31% regressed in a follow-up period from 15-19 months
(Figge, Alvarez et al. 1962).	Prospective study of 46 women with atypical hyperplasia followed at 6-monthly intervals for 3 years and yearly for 3 years. (30 completed the entire follow-up schedule.) At each visit subjects had a punch biopsy and cytology.	8.6% progressed to carcinoma in situ, 65% had persistent evidence of atypical hyperplasia and 26% regressed.
(Scott and Ballard 1962).	Prospective study of 223 women with evidence of dysplasia on biopsy followed for 10 years. Follow-up with cytology +/- histology.	In 9 years of follow-up 7.2% developed changes suspicious of carcinoma in situ or worse, 43.9% had persistent evidence of dysplasia and 48.9% regressed to normal.
(Petersen and Wiklund 1959).	Prospective study of 84 women with epithelial hyperplasia with nuclear abnormalities and 43 women classified as borderline (histological sections suggested the possibility of invasion) . Followed up for between 8 and 26 years. (Atypical epithelial hyperplasia is almost equivalent to what would have been classified as carcinoma in situ.)	*Epithelial hyperplasia with nuclear abnormalities:* Progression to cancer at a rate of 40 women per 1000 women years in the first 5 years. Progression to cancer at a rate of 23 per 1000 women year between years 5 and 10. (Women with no evidence of invasion at 5 years.) Progression to cancer at a rate of 38 per 1000 women years between years 10 and 15. (Women with no evidence of invasion at 10 years.)

Despite the above reservations, it is clear that CIN/dysplasia/SIL is a dynamic condition and that the probability of developing carcinoma *in situ* or worse increases with more severe levels of abnormality. In a recent review of the natural history of CIN based on the published literature, Ostor (1993) concluded that 57 per cent of CIN 1 lesions regress, 32 per cent persist, 11 per cent progress to CIN 3 and one per cent progress to invasive cancer. In contrast, he estimated that 43 per cent and 32 per cent of CIN 2 and 3 lesions regress respectively; five per cent and 12 per cent of CIN 2 and 3 lesions progress to invasive cervical cancer respectively. Ostor's approach is seriously flawed, however. To calculate these proportions he merely tabulated the proportion of cases with a particular diagnosis that experienced a particular endpoint. As well as the methodological differences between the studies in defining the various disease states and endpoints, his approach takes no account of the different follow-up periods in the different studies and for individuals within each study. As stated earlier, those followed for longer periods have a greater chance of experiencing a particular endpoint.

Progression also appears to be more likely when CIN lesions are associated with infection with HPV types 16 and 18. Several studies have found that CIN is more likely to progress if women are also infected by high risk types of HPV. (Campion, McCance et al. 1986; Kataja, Syrjanen et al. 1990; Murthy, Sehgal et al. 1990; Kataja, Syrjanen et al. 1992). Some consider lesion size might be important, hypothesising that women with larger CIN lesions may be more likely to develop cervical cancer than those with smaller lesions of the same severity. (Tidbury, Singer et al. 1992).

The new classification systems combine HPV and CIN 1. They also combine CIN 2 and CIN 3. Future studies of natural history will use these systems which have been developed to accommodate contemporary thinking about natural history. To what extent will this system of classification for cytology shape the findings and interpretation of future epidemiologic investigations?

Scientific writing on CIN assumes a natural history. Rates of progression, regression or persistence are discussed. Yet one does not know whether the area of the cervix which has LGSIL changes is the same area that would later develop a higher grade lesion. Should we conceive of CIN as a marker of risk rather than a precursor of cervical cancer? Is it important to make this distinction?

One further point should be emphasised. The natural history of cervical cancer became a subject of public debate following Professor Herb Green's study of the natural history of carcinoma *in situ* (McIndoe, McLean et al. 1984). [4] This was first publicly exposed in 1987 (Coney and Bunkle 1987) and was later subject to a national enquiry (Committee of Inquiry into Allegations Concerning Treatment of Cervical Cancer at the National Women's Hospital and into Related Matters 1988). Review of the literature on the natural history of cervical cancer reveals that this unethical experiment was not an isolated incident, however. Several earlier studies have followed women with carcinoma *in situ* until they developed invasive cancer and even died. One study followed women with evidence of invasive cancer (Petersen and Wiklund 1959). There is much debate today about ethical endpoints for studies of the natural history of cervical cancer precursor lesions, but most would accept that invasive cancer is ethically an unacceptable endpoint. CIN 3 is the most severe endpoint that is accepted.

Modelling the natural history of cervical cancer

Modelling the disease using observed rates of dysplasia, carcinoma *in situ* and invasive cervical cancer begins with the assumption that cervical cancer passes through a series of transition stages, which can be distinguished morphologically, before invasive disease develops.

The simplest way to model the natural history of cervical cancer is to use population incidence and prevalence figures. For example, Boyes et al. (1982) proposed that should all preclinical lesions progress, the ratio of the cumulative incidence of the preclinical cancer (dysplasia and carcinoma *in situ*) to the prevalence of preclinical cancer plus the cumulative incidence of cervical cancer should be one. To test this, incidence rates from the British Columbia cohort study were used. They examined the results of two birth cohorts of women. Boyes et al. (1982) demonstrated that the ratios were less than one for both dysplasia and carcinoma *in situ* at all ages. Regression was found to be more frequent in the younger age groups and for less severe degrees of dysplasia (Boyes, Morrison et al. 1982). The modal age for

[4] This study is not included in Table 2.3 because it followed women who had been treated. All but 25 of the 948 women in the study received some form of treatment for histologically proven carcinoma *in situ*. 131 women had persisting cytological evidence of cervical neoplasia following treatment. 22 percent of these women developed invasive cancer. Using survival analysis the authors estimated that risk of developing invasive cancer if a woman has cytological evidence of neoplasia following treatment was 18% and 36% at ten and twenty years respectively.

carcinoma *in situ* in the British Columbia Cohort study was 25 to 29. This was 35 years earlier than the modal age for invasive carcinoma implying a long natural history. (The Walton Report 1976). These data have subsequently been used by numerous researchers to model the disease.

The ratio of the point prevalence to the incidence of the disease has been used to estimate the sojourn time (period during which the state is detectable by screening but not clinically apparent) of the preclinical states. Albert (1981) extended this formula by summing the age-specific prevalence and dividing it by the age-specific incidence of disease to determine the sojourn time using British Columbia data. Using this method, the mean duration of carcinoma *in situ* was 7.6 years. However, the mean sojourn time may not represent the experience of most women who develop carcinoma *in situ*. If the distribution of sojourn times is positively skewed, most women will have sojourn times shorter than the mean.

A number of mathematically-based computer models have been used to estimate the course of cervical cancer. Such models have informed cervical cancer screening policies. Prorok (1986) provides a comprehensive review of these models.

Several models have been used to simulate the natural history of cervical cancer. Models are restricted by their structure and assumptions about the disease process. The output of the model can be compared with real data to test the validity of the estimations and assumptions made in the model. By far the most common model is the Markov chain model in which the probability of an individual with a particular disease status moving into another disease status, over a specified period of time, is assigned a transition probability. These are constant regardless of previous disease status and duration in state, a limitation of the model.

For example, Barron et al. (1968) developed a Markovian model to describe transition probabilities. These probabilities were based on their earlier study with 557 women. (Barron and Richart 1968). These data were compared with cross-sectional data derived from Barbados, West Indies. (Barron and Richart 1970). They predicted that progression of carcinoma *in situ* to invasive disease was a function of time. They assumed that carcinoma *in situ* eventually progressed to cervical cancer. This is not consistent with recent evidence. The Barbados data were then used with the British Columbia data to derive estimates of disease duration. The upper time limit for progression

of carcinoma *in situ* was estimated to be ten years and the lower limit three years. (Barron, Cahill et al. 1978).

Coppleson et al. (1975) used the published results of a 1971 study by Bibbo et al. (1971) to develop a Markovian model. The model that best fitted the data had high rates of regression of dysplasia and carcinoma *in situ*, especially in the younger age group, and an increasing rate of conversion to carcinoma *in situ* to invasive cancer with increasing age. (Coppleson and Brown 1975).

Micro-simulation models have also been used to model natural history. Habbema et al. (1985) developed MISCAN, a computer simulation model designed to examine the cost-effectiveness of different screening situations. In this model life histories of individual women are simulated generating a hypothetical cohort. The data were fitted to the Dutch pilot data and British Columbia data. Based on the Dutch data it was estimated that the mean duration of the preclinical phase of cervical cancer is between 14 and 19 years and that 45 to 65 per cent of preinvasive disease regresses. (Habbema, van Oortmarssen et al. 1985).

A probabilistic model using four disease states was constructed by Albert (1981) to examine the natural history of cervical cancer. The British Columbia data were once again used as the basis for the model. The rate of transition of carcinoma *in situ* to invasive cervical cancer was 3.7 per cent per year; 98.6 per cent of carcinoma *in situ* lesions were estimated to progress to cervical cancer; and between 1.7 and 9.7 per cent of new cases of cervical cancer were estimated to be of the rapid onset variety. (Albert 1981).

Based on empirical data on Swedish population incidence and mortality rates of carcinoma *in situ* and cervical cancer Gustafsson et al. (1989) estimated the progression of carcinoma in *situ* to cancer by solving differential equations. They estimated that 12 per cent of all new cases of carcinoma *in situ* would progress to cervical cancer. The proportion of prevalent cases that progress was estimated to be 15 to 23 per cent. The mean duration of the *in situ* phase was estimated to be 13.3 years. (Gustafsson and Adami 1989).

By applying a similar method to that used by Gustafsson et al. (1989) to the British Columbia cohort study data, van Oortmarssen et al. (1991) found a good fit between model and data with the following assumptions: 84 and 40 per cent regression rate for women less than 34 years of age and over 35 years

of age respectively and an average duration of carcinoma *in situ* of 11.8 years. (van Oortmarssen and Habbema 1991).

The assumptions upon which a model are based produce different estimates about the natural history of cervical cancer. Different modelling approaches, but the same data set (eg British Columbia Cohort study), have produced different estimates for the progression of preinvasive disease. Some models have many unknown parameters (eg the sensitivity of the Pap smear and the natural history of preinvasive disease). When many parameters are unknown, several different natural history scenarios may fit the population figures used to model the disease. As stated earlier the models begin with a premise that CIN/dysplasia and carcinoma *in situ* are preclinical states that precede cervical cancer. The models provide parameter estimates for the premise. Another feature of models is that they are based on populations rather than a sample of individual women followed longitudinally. In these studies the women with invasive cancer and preclinical disease are not the same. Finally, the proportion of women who experience preclinical phases that are shorter or longer than the preclinical phase depends on the distribution of transit times. Knowledge of the distribution of transit times is important for policy recommendations about appropriate screening intervals. Longer screening intervals mean that a greater proportion of women may develop a preclinical lesion which progresses to invasive cancer between screens.

Conclusion

The natural history of cervical cancer is uncertain. More severe levels of CIN appear to confer on women a higher risk of developing cervical cancer. Most women with CIN will not develop cervical cancer. Risk may be a function of age. Infection with particular HPV DNA types is also associated with a greater risk of cervical cancer and CIN. There is no way of identifying which individual women with CIN will develop cervical cancer in the future.

The relationship between CIN and cervical cancer has usually been conceived as a morphological continuum; cervical cancer is considered to pass through a series of stages from CIN 1 to invasive disease. Based on this model, treatment of CIN at any stage will interrupt the disease process.

Some have shifted their thinking regarding the natural history of cervical cancer. New perspectives have been incorporated into the Bethesda system

and the Commonwealth recommendations for the classification of cervical cytology. Within this model, treatment is recommended for HGSIL only.

The research conducted for this PhD was carried out when the CIN classification system was in use. This classification system provides a framework for the status of knowledge and thinking about cervical cancer at the time my research was conducted. Even at the time of writing it is the main system of classification for clinicians and researchers in Australia. Throughout the remainder of the thesis I therefore use the term CIN to describe precancerous lesions of the cervix.

The assessment and treatment of women who have abnormal Pap smears

In this section I outline usual gynaecological assessment and treatment practices for women who have abnormal Pap smears. I conclude with a discussion about clinical protocols and public health policies.

Assessment of women who have abnormal Pap smears

When an abnormality is detected the woman may be advised to have a repeat Pap smear within a defined period of time, or alternatively she may be referred for gynaecological assessment usually with colposcopy.

Colposcopy was introduced into Australia in the late 1950s (Chanen 1990). It is currently widely used for the assessment of women who have abnormal Pap smears. Prior to the introduction of colposcopy women were admitted to hospital and a cold-knife cone biopsy was performed. The cone biopsy was diagnostic, and usually therapeutic. The introduction of colposcopy has meant that it is now possible to assess on an outpatient basis women who have abnormal Pap smears.

Colposcopy magnifies the cervix so that abnormal areas are more readily visualised. Acetic acid is applied to the cervix to identify abnormal areas. It is generally recommended that biopsies be taken and a histological diagnosis is made before any treatment is performed. Otherwise a woman with invasive disease may be inadvertently treated with an ablative treatment and women who do not have significant disease may have unnecessary treatment.

Two recent Australian studies have shown that the assessment and treatment of women with abnormal Pap smears is inconsistent. In a study following women with a cytological report of CIN 2 or 3, it was found that most had colposcopy and treatment. According to a protocol defined by experts, less than one third of women who should have had treatment follow-up colposcopy had it. (Towler, Irwig et al. 1993). Women with mild squamous atypia or CIN 1 had more heterogeneous follow-up. Fifty-one per cent of women with CIN 1 for the first time had treatment. Nineteen per cent of women with mild squamous atypia had a colposcopy to further investigate the lesion and eight per cent had treatment. (Hunt, Irwig et al. 1994). Both studies relied on general practitioners to obtain information regarding whether a woman had a colposcopy, treatment and follow-up. General practitioners may not always have complete information on their patients' assessment and treatment. Nonetheless these studies illustrate that a significant proportion of women with CIN 2 and 3 may not have appropriate assessment and treatment and that there is no consistent approach to the assessment and treatment of women who have minor abnormalities.

This is not a uniquely Australian problem. A survey of 72 gynaecologists performing colposcopy in Britain revealed that there was an inconsistent approach to the referral, treatment and follow-up of women who have abnormal Pap smears (Woodman and Jordan 1989).

There is international consensus that women with CIN 3 should have further assessment with colposcopy. Most would recommend that women with CIN 2 have further assessment. The appropriate follow-up for women with minor abnormalities such as mild atypia, HPV atypia only and CIN 1 is far more controversial.

The call for referral of all women who have minor abnormalities on Pap smear is fuelled by concerns over the accuracy of cervical cytology. Many cross-sectional analyses based in hospital clinics have shown that women with minor cytological abnormalities may have more significant disease on colposcopy or biopsy.

Between three and 37 per cent of women with smears showing atypia have evidence of CIN on histology. On careful examination it is found the proportion of cases with CIN 2 or 3 ranges from two to ten per cent, however. (Soutter, Wisdom et al. 1986; Walker, Dodgson et al. 1986; Jones, Creasman et al. 1987; Spitzer, Krumholz et al. 1987; Morrison, Erickson et al. 1988;

Kaminski, Sorosky et al. 1989; Kaminski, Stevens et al. 1989; Cecchini, Iossa et al. 1990; Busseniers and Sidawy 1991). On the basis of these findings many authors recommend that women with mild atypical smears should have a colposcopic assessment in the first instance. (Jones, Creasman et al. 1987; Spitzer, Krumholz et al. 1987; Morrison, Erickson et al. 1988; Kaminski, Stevens et al. 1989; Busseniers and Sidawy 1991). Women who have cytological atypia on two or more smears have a higher prevalence of CIN 2 or 3 than women who have only one smear showing atypia. (Soutter, Wisdom et al. 1986; Spitzer, Krumholz et al. 1987; Morrison, Erickson et al. 1988; Kaminski, Stevens et al. 1989). Older women were found to have a lower level of CIN on histology (Kaminski, Sorosky et al. 1989; Kaminski, Stevens et al. 1989).

A hospital based study found that 13.6 per cent of women who had smears showing HPV atypia had histologic evidence of CIN. Only 4.1 per cent with histologically proven CIN had normal repeat cytology. 11.6 per cent were CIN 2 or 3 and 6.1 per cent had CIN 3. On the basis of these findings the authors recommended colposcopic assessment for all women who receive a cytology report showing HPV only. (Pagano, Chanen et al. 1987). Mitchell (1992) found only one per cent of women who had a cytology report showing HPV were found to have CIN 3 on biopsy; 9.6 per cent had evidence of CIN 2 or 3. On the basis of these findings she concludes that women with HPV on cytology have a low risk of undiagnosed CIN 3 and that repeat cytology in six to 12 months is a reasonable alternative to immediate colposcopy. (Mitchell 1992).

Studies of women who have a cytology report indicating CIN 1 have reported rates of CIN 3 on histology of between 6.2 and 45 per cent. (Soutter, Wisdom et al. 1986; Maggi, Zannoni et al. 1989; Anderson, Flannelly et al. 1992). Soutter et al. (1986) found that 5.9 per cent of women who had only one smear showing CIN 1 had CIN 3 on biopsy. On the basis of these studies the authors conclude that all women with CIN 1 should be referred for colposcopic assessment. One study found that 33 per cent of women with CIN 1 on cytology had CIN 2 or 3 on biopsy. Repeat cytology confirmed CIN 1 or greater in 93 per cent of women histologic CIN 2 or 3. Eighty-three per cent of these women had a CIN 2 or 3 on repeat cytology. (Giles, Deery et al. 1989). Similarly 26 per cent of women with CIN 1 referred to a British hospital had CIN 2 or 3 on biopsy (Campion, McCance et al. 1986).

A recent longitudinal study found that women with cytological evidence of CIN 1 or 2 under the age of 35 (who have no previous history of an abnormality) had a 30 per cent risk of developing CIN 3 or worse over a ten year period. Women older than 35 had a lower risk of developing CIN 3. Follow-up with regular Pap smears identified most women with progressive disease. (Kirby, Spiegelhalter et al. 1992).

Because of the wide variation in reporting practices in Australia it is difficult to extrapolate from these studies to clinical practice in Australia. With the shift towards more frequent reporting of minor abnormalities it is likely that the prevalence of high grade CIN in women who have reports of minor abnormalities will be lower than the studies reported above. Most of the studies are based in hospital clinics and hence may represent a biased sample of women with cytological reports of minor abnormalities. Women may have been referred because of symptoms or other risk factors for cervical cancer. Even if these women make up only a small proportion of the sample the findings are likely to be biased because the prevalence of disease in these women will be much higher. Another problem is that the studies are cross-sectional. Although they show that a reasonable proportion of women with minor cytological abnormalities may have a high grade lesion on histology, the significance of these lesions is unknown.

Of all women with HPV and CIN nearly six per cent of women screened at any time would be referred for colposcopy. If women with any evidence of CIN were referred almost three per cent of women would require colposcopy. (Commonwealth Department of Human Services and Health 1994). A British study showed that a shift in guidelines from recommending follow-up for women with CIN 3 only to recommending follow-up for women with CIN 2 and women with persistent evidence of CIN 1 would result in half the workload of a cytology laboratory being devoted to the follow-up of abnormal smears. The authors felt that the increased laboratory workload would undermine the effectiveness of the screening program because resources would be transferred away from evaluating cytology specimens from women participating in the screening program. (Raffle, Alden et al. 1990).

The treatment of histologically confirmed cervical abnormalities

Cervical intraepithelial neoplasia can be treated with ablative or excisional methods. Ablative methods destroy the area of the cervix that shows CIN changes. Excisional treatments involve removing the affected area. An advantage of the excisional method is that the removed tissue can be examined and examined histologically to see whether the entire CIN lesion has been removed. However, because excisional methods remove more tissue than is destroyed by ablative methods, ablative methods are preferred by clinicians. It is thought they are less likely to result in infertility or pregnancy complications.

Ablative methods include cryotherapy, CO_2 laser, cold coagulation and diathermy. Cryotherapy and laser are most commonly performed using local anaesthetic in gynaecologists' rooms. Excisional methods include cone biopsy with cold knife, laser cone biopsy and more recently large loop excision of the transformation zone (LLETZ). Both LLETZ and laser cone biopsy can be performed on an outpatient basis using local anaesthetic. Some maintain that the advantage of this approach is that a biopsy can be taken at initial consultation that is both diagnostic and therapeutic. However, about a quarter of the patients in one series had no evidence of CIN, indicating that this approach may mean that many women have excisional treatment with no indication. (Luesley 1990). Both of these methods may result in heat artefact in the specimen making interpretation difficult. A recent study showed that laser cone biopsy was an unsuitable treatment technique if a reliable histological specimen was necessary (Howell, Hammond et al. 1991). An advantage of LLETZ is that the cost of the equipment is much less than a CO_2 laser. A concern with ablative methods is that women with invasive disease may be missed and inadequately treated. Occasionally hysterectomy is used to treat CIN.

It is recommended that women with suspicion of early invasive disease, cytological evidence of precursors of adenocarcinoma or an unsatisfactory colposcopy should have a cone biopsy. For all other women ablative treatment is sufficient. (Giles and Gafar 1991).

The reported success rates for various treatments appears to be similar but there have been few properly conducted comparative trials. Instead rates of success and failure are reported in series of patients exposed to one particular treatment. At one and five years following treatment of CIN with

cryotherapy, 95 and 92 per cent of women respectively showed no evidence of CIN (Gordon and Duncan 1991). After a single CO_2 laser treatment, 5.6 to 14 per cent of women have persistent abnormalities. (Puttmemans, van Belle et al. 1968; Caglar, Ayhan et al. 1985; Ali, Evans et al. 1986; Pearson et al. 1989; Paraskevaidis, Jandial et al. 1991). One study found that women had a one per cent risk of invasive disease six years after laser treatment for CIN (Pearson et al. 1989). Chanen et al. (1983) found that 2.7 per cent of women had residual cervical abnormalities in the first twelve months of follow-up after treatment with electrocoagulation diathermy; a further 0.8 per cent of women developed CIN after one year of follow-up. (Chanen and Rome 1983).

Tabor et al. (1990) compared the rates of recurrent or persistent disease for women who had CIN treated with cold-knife cone biopsy and laser cone biopsy. Cold-knife cone biopsy was the treatment of choice early in the study period. Later the unit performed mainly laser cone biopsy. In three to 21 months of follow-up, evidence of persistent or recurrent disease was found in eight and five per cent of women with cold-knife and laser cone biopsy respectively. (Tabor and Berget 1990).

One commonly held concern is that excisional procedures are more likely to result in more frequent short term and long term complications than ablative treatments. A randomised controlled trial compared the laser excisional cone with laser vaporisation in a group of patients suitable for ablative treatment. There were no differences in the rate of treatment failure and short term complications such as bleeding. (Partington, Turner et al. 1989). However, the study was based on small numbers and lacked statistical power.

Most studies examining treatment failures (evidence of recurrent or residual (persistent) disease following treatment) are methodologically flawed. Women are followed for varying periods of time. Many are lost to follow-up. Yet the results are presented as simple proportions and no consideration is given to the length of time a woman contributes to the denominator. Future studies should employ survival models to analyse treatment failures.

An Australian study found that women who had a history of histologically confirmed CIN were twenty times more likely to develop squamous cell carcinoma in the future than women who had negative smears. Women in the CIN cohort were twice as likely to develop CIN as women in the control

group. (Mitchell, Medleyand Carlin 1990). This study illustrates the need to follow carefully women who have CIN after they have had treatment.

Given the reported rates of residual and recurrent abnormalities after treatment careful follow-up after treatment is necessary. One study reported that 95 per cent of women who had residual abnormalities were found at the first post-treatment visit (three to four months following treatment). The remaining five per cent of women with residual disease were detected at the second post-treatment visit (six to eight months following treatment). Three and nine per cent of women with residual abnormalities detected by histology had negative cytology and colposcopy respectively. Cytology and colposcopy combined detected 98.5 per cent of all residual abnormalities detected by histology. On the basis of these findings the authors conclude that one follow-up visit with cytology and colposcopy following treatment is necessary, after which follow-up with cytology alone is appropriate. (Falcone and Ferenczy 1986).

In the last twenty years there has been a shift from recommending hysterectomy for the treatment of CIN towards more conservative treatments. The term 'conservative' is used in many ways. Anything other than hysterectomy is sometimes considered conservative. Sometimes conservative is anything other than hysterectomy or cold knife cone biopsy. Alternatively conservative may mean ablative treatments only. Goodwin et al. (1990) documented that there was a steady increase in the percentage of women having conservative treatments (anything other than hysterectomy) in New Mexico. The proportions of women having treatments other than hysterectomy for their abnormal Pap smears was 11.8 and 50.3 per cent in 1969 and 1985 respectively. They state that this shift occurred in the absence of any controlled trials comparing the two treatments. They compare the adoption of more conservative treatments for CIN with breast cancer treatment. In the case of breast cancer, evidence from controlled trials comparing radical mastectomy and local treatments was not incorporated into clinical practice. (Goodwin, Hunt et al. 1990). A common reason cited for the change in the treatment of CIN is that conservative treatments do not prevent future pregnancy in women treated for CIN. For example Sagot et al. (1990) say:

> The increasing number of very young women with low parity presenting with cervical intraepithelial neoplasia has led to the development of conservative treatments to provide reliable oncological results.

To my knowledge there has never been an analysis of changes in treatments used for CIN in Australia over the last two decades, partly because there would be no suitable population data base that could be used for such an analysis. However, it is likely that there has been a similar, if not larger, shift in Australia towards the use of more conservative treatments. This shift has almost certainly been accompanied by other changes in clinical practice. Women with minor abnormalities are being treated more actively than previously. In the past hysterectomy or even cone biopsy required hospitalisation. With the advent of outpatient procedures more women with minor abnormalities are treated. Women with cytological and histological evidence of HPV are also treated with ablative treatments. A recent study found women who had ablative treatment for histologically confirmed HPV had similar rates of CIN in the following two years as women who had no treatment (Ward and Thomas 1994). Indeed laser vaporisation may disperse viral DNA onto adjacent normal epithelium (Ferenczy, Bergeron et al. 1990).

Protocols for the assessment and treatment of women who have abnormal Pap smears

The Commonwealth Department of Human Services and Health has recently released guidelines outlining approaches to clinical care for women who have screen-detected abnormalities. (Commonwealth Department of Human Services and Health 1994). This is the first time in Australia there has been a consistent set of recommendations regarding an appropriate approach to the assessment and treatment of women with abnormal Pap smears. On the working party formulating the guidelines were gynaecological oncologists, an epidemiologist, a cytopathologist, a medical educator, a consumer representative and a general practitioner. Consultation with interested individuals and organisations was sought. (In addition to formulating guidelines, the working party also developed the new reporting system for cervical cytology discussed earlier in this chapter.)

These guidelines suggest that any woman who has HGSIL should be referred for assessment with cytology, colposcopy and colposcopically directed biopsy. Decisions regarding treatment should be determined on the basis of the colposcopic and histologic findings in consultation with individual women. Ablative treatment can be recommended if the cervix has been evaluated by a competent colposcopist, there is no evidence of invasive disease, the abnormal transformation zone is fully seen, and there are no cells

indicative of the precursors of adenocarcinoma. (Commonwealth Department of Human Services and Health 1994).

Recommendations for LGSIL were less clear-cut. For HPV infection alone it is recommended that if HPV only is confirmed at colposcopy then Pap smears should be repeated six-monthly until two consecutive smears are reported as normal. Then annual smears are recommended. When two annual smears are negative, cervical screening at two year intervals is recommended.

It is suggested that all women with CIN be referred for colposcopy. If CIN 1 is confirmed with colposcopy and directed biopsy, two approaches to the care of the woman are proposed. The 'observational' option involves six-monthly follow-up with Pap smears until the lesion either regresses or progresses. Further colposcopy may also be recommended. If two consecutive smears are normal, annual smears are then recommended. Biennial smears are recommended after two normal annual smears. Alternatively a woman may elect to have treatment. (Commonwealth Department of Human Services and Health 1994).

After treatment, follow-up with colposcopy and cytology (using a cytobrush and spatula) should be carried out within two to six months. Follow-up with colposcopy or cytology within twelve months of treatment and annual cytology thereafter are also recommended.

The Australian recommendations contrast with overseas approaches. In Canada, only women with CIN 2 or 3 are referred for colposcopic assessment. For women with CIN 1 with or without HPV effects, six-monthly Pap smears for two years are recommended. If there is evidence of progression or the abnormalities are persistent over that two year period then referral for colposcopy is considered appropriate. (Miller, Anderson et al. 1990). In Britain referral of women with CIN 2 and 3 for colposcopy is recommended. It is suggested that women with minor abnormalities (CIN 1 or less) should have a repeat Pap smear in six months and if that is abnormal referral for colposcopy should occur. (Shafi and Luesley 1992).

Clearly there is no agreement on the appropriate approach to the assessment and treatment of women with minor abnormalities detected on Pap smears. Women with these abnormalities are at risk of developing invasive disease. Several overseas trials which compare different approaches to the

gynaecological care of women with minor cytological abnormalities are currently underway. These trials will provide some guidance in the future. However, it is unlikely that any approach will offer unambiguous benefits over another. Immediate referral might reduce one's risk of future cancer by a small amount. Yet, whether immediate referral is justified in the light of the consequent economic, personal and social costs borne by the women affected and society is a crucial question.

Studies of the economic and non-economic costs of abnormal Pap smears

In this section I review the literature in relation to the costs of abnormal Pap smears for society and for individual women.

Economic costs

Few studies have been undertaken on the cost-effectiveness of cervical screening in Australia. Most Australian studies have concentrated on the costs and effects of screening at particular intervals.

Between 1988 and 1990 the Cervical Cancer Screening Evaluation Committee (CCSEC) directed the Screening Co-ordination Unit at the Australian Institute of Health to undertake an evaluation of current cervical cancer screening practice and consider various policy options. (Australian Health Ministers' Advisory Council. Cervical Cancer Screening Evaluation Committee 1991). The CCSEC report explored the cost-effectiveness of cervical cancer screening in three ways: by comparing the cost-effectiveness of the current approach with an organised approach; estimating the cost-effectiveness and marginal cost-effectiveness of different screening intervals under an organised approach; and, estimating the cost-effectiveness and marginal cost-effectiveness of screening different age groups with varying participation rates. (Australian Health Ministers' Advisory Council. Cervical Cancer Screening Evaluation Committee 1991). Following this evaluation the National Policy on Screening for the Prevention of Cervical Cancer was developed. Biennial screening is now recommended. It is suggested that screening commence between 18 and 20 years of age and cease at age 70, provided that the past two Pap smears taken in the last five years have been normal (Commonwealth Department of Health, Housing and Community Services 1991).

The Knox microsimulation model was used to estimate life-years saved under various screening scenarios (Knox and Woodman 1988). The cost of screening was determined from the pilot project data. Data included the costs of recruitment and education, taking and reporting of Pap smears and the notification of results and counselling. The costs of follow-up, which included general practitioner and specialist visits, claims for pathology tests, and procedures performed, were taken as 85 per cent of the scheduled Medicare fee. This was the cost to government if women were admitted to hospital as private patients or attended a private outpatient service. There is no Medicare rebate for women admitted to public hospitals as public patients or women attending a public hospital outpatient service. In addition, the limitations of the simplified treatment regimen reduce the accuracy of this cost analysis. For example, it was assumed that of the women referred for colposcopy, 60 per cent had treatment. It was also assumed that the treatment was either laser conisation or diathermy and was undertaken under general anaesthetic as a day patient. The follow-up after treatment or initial colposcopy included one further specialist visit and one general practitioner visit. CCSEC estimated that cervical cancer screening activities cost $125 million per year. The follow-up of women who had abnormalities detected on screening comprised over half ($64.4 million) of the total costs of the cervical cancer screening. (Australian Health Ministers' Advisory Council. Cervical Cancer Screening Evaluation Committee 1991). This contrasts with overseas models which have concluded that the follow-up of abnormalities comprises only a small part of a total cost of a cervical cancer screening program. (Koopmanschap, Lubbe et al. 1990).

A Dutch study modelled the effect of screening intervals on the number of diagnostic and treatment procedures performed as a consequence of the detection of abnormal Pap smears. More frequent screening resulted in a higher incidence of diagnostic and treatment procedures because women with abnormalities that might otherwise regress were more likely to have their abnormality detected, diagnosed and treated. (van Ballegooijen, Koopmanschap et al. 1990). The study assumed that all women with CIN 3 or worse were referred for colposcopic follow-up and 60 per cent of women with CIN 2 were referred. Current Australian practice is to refer women with any level of CIN. Often women with HPV or mild atypical changes are also referred. The rate of diagnostic and treatment procedures that result from more frequent screening in Australia are therefore likely to be much greater than estimated by the Dutch model.

The most comprehensive study of the costs of abnormal Pap smears in Australia was conducted by Bragget et al. (1993). They used the following data to model the costs of different approaches to the follow-up of women with abnormal Pap smears: screening participation rates from the Victorian Cytology Service and Medicare; unpublished data on rates of progression, regression and persistence of minor abnormalities from studies conducted by the New South Wales Family Planning Service; age-specific rates of detection of different levels of abnormal Pap smears from the Victorian Cytology Service; and other information collected by CCSEC as part of the national evaluation from 1988-90. A series of flow charts were constructed that simulated what might happen if a woman had a particular level of abnormality detected on her Pap smear. The different treatments on the flow charts were derived from the recommendations from the recently released report by the National Health and Medical Research Council Working Party (Commonwealth Department of Human Services and Health 1994). They compared the different approaches to the evaluation of women who have CIN 1. Several approaches were compared:

1. colposcopic assessment of all women with cytological evidence of CIN 1 and ablative treatment if CIN 1 is confirmed histologically;

2. colposcopic assessment of all women with cytological evidence of CIN and continued follow-up with cytology if CIN 1 is confirmed histologically;

3. cytological follow-up of all women with CIN 1.

They estimated that the costs of options 1, 2 and 3 in 1993 would be $136.7 million, $130.2 million and $129.5 million, respectively. The cost of further assessment alone was $61.6 million, $55.2 million, $54.4 million for options 1, 2 and 3, respectively. Thus, no matter what approach to the follow-up of women with CIN was adopted, the cost of follow-up of women with abnormal Pap smears comprised a substantial proportion of the total budget for a cervical screening program. Women younger than 35 accounted for twice the costs of further assessment than women older than 35. (Braggett, Lea et al. 1993). Costing was based on Medicare statistics even though a significant proportion of women may have treatment in the public sector. Assumptions regarding assessment and treatment practices were often based on information from experts (eg length of hospital stay, item numbers billed for particular procedures, occurrence of residual disease after treatment). These may be inaccurate. There is also no discussion of the validity of the

rates of progression and regression that are used for the cost simulation. The report provides a useful benchmark on the economic costs of the various protocols recommended by the working party.

Non-economic costs

Very different techniques are required to consider the personal costs to women of an abnormal Pap smear. The most comprehensive account of the costs to women of the diagnosis and subsequent assessment and treatment has been provided by Posner and Vessey (1988). I therefore provide a brief synopsis of this research. The research involved structured interviews with 153 women interviewed on one to four occasions (131 were interviewed on two or three occasions) during the course of their colposcopic assessment and treatment of their abnormal Pap smear. The first interview was conducted immediately prior to the first visit for colposcopic assessment. The research was based in two hospitals in the United Kingdom that provided outpatient colposcopy services.

Most women found the colposcopic examination distressing. Often nurses were important sources of support during the examination process because they discussed personal matters. Many found the procedure painful or uncomfortable. Many women felt 'weaker' or 'delicate' following colposcopy or treatment. Minor outpatient procedures were often associated with distress. The authors suggested that this may be because outpatient treatment is regarded as a minor procedure, both by doctors and others, while inpatient treatment is considered a life event of some significance. Many women feared cancer and initially felt their abnormal Pap smear signified cancer. Cancer was described in metaphorical terms as unstoppable and as destructive of human body and spirit. As a consequence of their abnormal Pap smear some women felt alienated and out of control; others felt dirty. Sexual relations were frequently affected. As a consequence of their abnormality many women 'took stock of their lives' and considered their own mortality. The abnormal Pap smear frequently affected women's moral and personal integrity. (Posner and Vessey 1988).

Susan Quillam's book "Positive Smear" is a resource book for women who have abnormal Pap smears. In producing this book, Quillam interviewed women who had had abnormal Pap smear results. She found that women had a wide range of experiences. Some women felt powerless, were concerned about death, felt guilty and violated. Women reported that their

sexual relationships often suffered as a consequence of their abnormal Pap smear. (Quillam 1989).

Another study, which involved open-ended interviews with women who had been referred to a colposcopy service because of an abnormal smear, found that women most commonly described fear in relation to the following: cancer, loss of reproductive and sexual function, medical procedures and concern about 'bodily betrayal'. Bodily betrayal was described as the concern that they could no longer directly control their bodies and were no longer able to be directly controlled by them. (Beresford and Gervaize 1986).

Other studies have used various psychological instruments to examine the consequences of an abnormal Pap smear result for women. Women experience anxiety and distress as a consequence of an abnormal Pap smear (McDonald, Neuten et al. 1989; Lerman, Miller et al. 1991). Two studies have demonstrated that women are less anxious if provided with an informational brochure at the time they are informed of their abnormality (Wilkinson, Jones et al. 1990; Stewart, Lickrish et al. 1993). These studies have also demonstrated that women who had abnormal Pap smears feared cancer (Wilkinson, Jones et al. 1990; Stewart, Lickrish et al. 1993), experienced changes in their sexual relationships (Campion, Brown et al. 1988; Lerman, Miller et al. 1991) and sleep disturbances (Lerman, Miller et al. 1991). The studies examined women's experiences through a series of psychological instruments which organised their responses. For example, the widely quoted study by Campion et al. (1988) examined female sexual experience in terms of their interest in sex, frequency of intercourse, vaginal lubrication and sexual arousal, frequency of orgasm with intercourse and negative feeling towards intercourse. The final item was taken to signify feelings towards one's partner. The questionnaire was administered before and after treatment. The study compared the experiences of women in three categories: women who had CIN and CO_2 laser treatment; women who were partners of men with HPV; and, women who were partners of men who had been seen at the STD clinic with non-specific urethritis. After treatment, women with CIN reported a reduction in sexual interest, vaginal lubrication, frequency of intercourse and frequency of orgasm with sexual intercourse. Women with CIN also experienced pain with intercourse and reported negative feelings towards sexual intercourse following treatment. (Campion, Brown et al. 1988). Even though the results demonstrate psychosexual sequelae for women with CIN, these may not be experienced as 'personal

costs' for the women themselves. Instead the researchers identify what the costs might be and document them.

Summary

Based on simulations of current practice and future practice, we know that the cost of assessment and treatment of women who have abnormal Pap smears is a significant component of the economic costs of Australia's cervical cancer screening program. More conservative approaches to CIN 1 might realise some cost savings over other policy options. As yet there has been no Australian research that has considered the costs of treatment based on knowledge of current treatment practices.

Previous studies have documented that many women experience significant psychosocial consequences as a result of their abnormal Pap smear. The study by Posner and Vessey (1988) is the only study that provides an indepth account of women's experience. To my knowledge there has not been a published study of the experiences of Australian women who have an abnormal Pap smear. However, a study based in Sydney is examining the psychological consequences of screening for cervical cancer.

Conclusion

Cervical screening exemplifies some of the difficulties encountered in population-based screening programs. I have shown that there are many scientific uncertainties about abnormal Pap smears. Although cervical screening is an effective way to reduce cervical cancer incidence and mortality, the Pap smear itself is subject to error. Significant lesions may be missed and abnormalities may be under- or over-reported. The importance of some minor abnormalities is unknown. The significance of an individual having a particular abnormality cannot be determined. The economic and personal costs of current clinical practice and abnormal Pap smears may be substantial.

Abnormal Pap smears present dilemmas to clinicians, women and public health practitioners. The risk of an individual developing cancer must be weighed against the consequences to the individual and society of referring and investigating further every woman who has an abnormality. How are we currently managing the uncertainty of individual women receiving an abnormal Pap smear result?

Chapter Three

Age-specific patterns of Pap smear and colposcopy use

This chapter provides a population account of current clinical practice regarding abnormal Pap smears. Based on data from the ACT, current patterns of Pap smear and colposcopy use are described and the cumulative population effects of current patterns of referral for colposcopy simulated.

Background

Much of the research in this thesis relies on Medicare statistics. Some of the findings are adjusted for the proportion of women in various age groups who have not had a hysterectomy. Before presenting the research findings of the chapter, therefore, a brief outline is given of how the Medicare estimates and the estimates of the proportion of women who have had hysterectomy were derived.

Medicare estimates

Medicare, introduced in 1984, is Australia's national health insurance scheme. Private sector outpatient and inpatient medical services are provided on a fee for service basis. Medicare gives rebates for the services either directly to the medical practitioner or via a partial reimbursement to the patient. Item numbers describe the different services. For example, item number 35614 is the item number used for colposcopy. Scheduled fees, adjusted through periodic inquiries, are set for each item number. In most instances, the level of Medicare rebate is 75 per cent of the scheduled fee for inpatient services and 85 per cent of the scheduled fee for outpatient services. Medical practitioners can charge any amount for their services and patients using the service pay the difference between the Medicare rebate and the fee charged by their doctor. For example, the Australian Medical Association (AMA) recommends a higher set of fees than the scheduled fees determined for rebate purposes.

Samples derived from Medicare statistics are used in this chapter and in Part C of the thesis. The Medicare Estimates and Statistics Section of the Commonwealth Department of Human Services and Health (DHSH) extracted the Medicare statistics used here. To ease data extraction, most data were derived from a ten per cent sample of Medicare enrollees. In 1993, 97.8 per cent of the Australian population and 99.1 per cent of the ACT population were enrolled in Medicare. Due to strict privacy provisions, Medicare data are only released in aggregated form. Cells with fewer than six episodes are not released and there is no access to unit record data.

Medicare data are used to calculate the total number of services, the proportion of women undergoing various procedures, and the ratio of women who claim for some procedures compared with women claiming for other services. To calculate the standard errors of these estimates, which are based on the ten per cent Medicare file, the formulas in Appendix A were used. When the average cost of various services is calculated (used in Part C) the standard error was calculated by DHSH because of lack of access to the individual data.

The denominators used in the calculation of the proportions and to estimate the size of the sample and populations, were the Medicare enrollees in the relevant age group for the relevant financial year. The number of women in each age group who were enrolled in Medicare are published in the Annual Reports of the Health Insurance Commission. In this chapter, the figures published in the 1989-90 Annual Report, which pertain to Medicare enrollees as at June 30 1989, are used (Health Insurance Commission 1990).

Hysterectomy estimates

Adjustment for the proportion of women who have had a hysterectomy should be made when calculating the rates of Pap smear and colposcopy usage. Cervical cancer screening is unnecessary for women who have had a hysterectomy unless the hysterectomy was done because of cervical neoplasia, or its precursors, or the hysterectomy was subtotal (the cervix was not removed). (Commonwealth Department of Health, Housing and Community Services 1991). Most women who have a hysterectomy therefore are not at risk of having a colposcopy or Pap smear. Hence the denominator for Pap smear and colposcopy rates should not include women who have had a hysterectomy. If hysterectomy rates increase, colposcopy rates will fall

if the total population of women is used, since fewer women will be at risk of colposcopy.

The Australian National Health Survey conducted in June 1989 was used to estimate the proportion of women in different age groups who had had a hysterectomy[1]. The Medicare statistics presented in this chapter and in Part C of the thesis pertain predominantly to 1989/90. Because the National Health Survey was conducted over a similar time frame the numerators and denominators used to estimate the age-specific rates were derived from women from similar birth cohorts.

Table 3.1 Age-specific proportions of women who have had a hysterectomy (%)

	ACT/NSW		Australia	
Age group	Proportion (%) *	95% confidence** intervals (%)	Proportion (%) *	95% confidence** intervals (%)
18-24	1.1	0.4, 1.9	0.9	0.5, 1.3
25-34	4.1	3.6, 5.6	4.0	3.4, 4.6
35-44	12.8	11.1, 14.5	12.6	11.5, 13.4
45-54	24.6	22.1, 27.1	24.8	23.1, 26.5
55-64	24.0	22.1, 25.9	24.1	22.4, 25.8

* Estimates from the National Health Survey June 30 1989 unpublished data

** The standard errors for these estimates were calculated using the method described in Appendix C pages 48-9, Australian Bureau of Statistics 1991, 1989-90 National Health Survey Summary of Results, AGPS (Canberra).

The age-specific proportions of women who had undergone a hysterectomy are similar across New South Wales, the ACT and Australia. Nearly one quarter of women between the ages of 45 and 64, who were interviewed for the National Health Survey, had had a hysterectomy. For the remainder of the thesis Australian proportions are used because the NSW/ACT estimates are based on small sample sizes and lack precision. Some of the data presented in this chapter include women between 15 and 18 and women between 65 and 74. For women between the ages of 15 and 24 and 55 and 74

[1] The National Health Survey, conducted between October 1989 and September 1990, collected data from 22,000 households and 57,000 persons (about one in 300 of the population). The survey was conducted by trained interviewers. The questionnaire was completed by 96.1 per cent of people eligible for the National Health Survey. The women's health questionnaire was a mail survey given to all female respondents between 18 and 64. In the women's health questionnaire women were asked whether they had had a hysterectomy. Only women between 18 and 64 were asked to respond to the women's health questionnaire. Ninety-seven per cent of women participating in the National Health Survey completed the women's health questionnaire.

the proportion of women who had undergone a hysterectomy between the ages of 18 and 24 and 55 and 64 respectively have been used.

Age-specific rates of Pap smear and colposcopy use

Age-specific Pap smear frequencies

Four pathology laboratories process the cervical cytology of ACT women. One laboratory is funded through the public hospital grant and does not receive a Medicare rebate. The public laboratory collects statistics on the number of women having smears in each age group. The other three laboratories operate in the private sector and their services are rebated through Medicare. Using the ten per cent patient file the number of ACT women claiming through Medicare for a Pap smear has been estimated. The Medicare estimates are added to the public laboratory totals[2] to give the number of women having Pap smears in each age group.

Although both Medicare and the one public sector laboratory total can provide figures on total numbers of women having a Pap smear, rather than just total numbers of Pap smears taken, it is possible that a woman may have had more than one Pap smear which were processed by both a public and private laboratory. In such instances, women would be counted twice in the numerator of Pap smear frequencies resulting in an overestimate of Pap smear frequency. However, the public laboratory only processes 15 per cent of the smears taken in the ACT and therefore it is unlikely that double counting will seriously bias the results.

There is another possible source of bias from the use of public laboratory data. The public laboratory may process cytology from some women outside the ACT. Including these women in the estimation of Pap smear frequency will also overestimate the frequency of Pap smear use.

Table 3.2 shows the age-specific rates of Pap smear use for ACT women in the financial year 1989/90. Forty-four per cent of ACT women had a Pap smear in 1989/90. The highest frequency of Pap smear use was in the 25 to

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[2] The public laboratory provided data by calendar year whereas the Medicare data were given by financial year. The public totals for 1989 and 1990 were therefore added and divided by two to calculate the number of Pap smears by age group for the financial year 1989/90.

44 year age groups where over 50 per cent of women had a Pap smear in 1989/90. These Pap smear data relate to a time period over which the ACT Pap smear campaign[3] was operating, hence these frequencies may be slightly higher than might ordinarily be expected. It is currently recommended that women begin screening between the ages of 18 and 20 and cease screening at age of 70, provided the two previous smears have been normal (Commonwealth Department of Health Housing and Community Services 1991). Therefore the younger and older age groups may not be homogeneous in terms of the frequency of participation. Inclusion of women between 15 and 19 and 70 and 74 may underestimate frequency of use for women between the ages of 20 to 24 and 65 to 69.

Table 3.2 Annual age-specific Pap smear frequencies adjusted for hysterectomy (%) (1989/90)

Age group	Estimated frequency of women having smears (%)	95% confidence interval (%)
15-24	33.0	31.1, 34.8
25-34	54.1	52.2, 56.1
35-44	52.7	50.6, 54.8
45-54	43.9	39.9, 45.8
55-64	33.5	30.0, 37.0
65 and older	23.2	19.1, 27.2
Total	43.9	42.9, 44.9

Table 3.3 shows the age-specific frequency of Pap smear use in different states. Unfortunately the age groups are not directly comparable; the studies were conducted over different time periods the age-specific frequencies shown relate therefore to different cohorts of women. In addition, different methods of adjusting for hysterectomy were used.

ACT women however, appear to have a slightly higher frequency of Pap smear use than other states. The differences in screening frequency in the ACT and other states may be related to the higher socio-economic status of ACT women. Women in the higher socio-economic classes have higher screening participation rates than women in the lower socio-economic classes

[3] The ACT Pap smear campaign was funded as part of a nationwide program to prevent cancer of the cervix. The campaign, which operated from June 1989 to September 1990, carried out promotional, educational and clinical services.

(Armstrong, Rouse et al. 1986). Like previous studies, participation in cervical screening in the ACT decreases in the older age groups.

Table 3.3 Recent Australian reports of annual age-specific frequencies of Pap smear use adjusted for hysterectomy

Age group	WA (Straton, Holman et al. 1993).	Victoria (Mitchell and Higgins 1993).	NSW (Shelley, Irwig et al. 1990).
Year of study	**1992**	**1992**	**1987/88**
20-29	43%	38%	28%
30-39	44%	46%	35%
40-49	39%	46%	34%
50-59	29%	37%	25%
60-69	13%	20%	13%

Age-specific frequencies of colposcopy use

All colposcopy services in the ACT are provided in the private sector. The ten per cent Medicare sample is used therefore to calculate the annual age-specific frequencies of women having colposcopy.

Table 3.4 Annual age-specific frequencies for colposcopy adjusted for hysterectomy (1989/90)

Age group	Frequency (%)	95% confidence intervals
15-24	2.51	1.92, 3.08
25-34	2.94	2.32, 3.62
35-44	2.59	1.95, 3.22
45-54	2.66	1.77, 3.55
55-64	0.86	0.21, 1.51
>65	0.76	0.00, 1.56
Total	2.46	2.38, 2.55

Nearly one in forty ACT women had a colposcopy in 1989/90. Between age 15 and 54 similar frequencies of colposcopy use were found, with the frequency falling after age 55. The age-specific frequencies of colposcopy and Pap smear utilisation had a similar pattern in 1989/90. There have been no previous age-specific frequencies of colposcopy reported in Australia, thus it is impossible to compare how these results contrast with other states.

The colposcopy rates have been adjusted for women who have had a hysterectomy. It is possible that a small number of these women had vaginal colposcopy. This means that the annual age-specific colposcopy frequencies may be slightly inflated. This may affect the estimates for the older age groups because the prevalence of hysterectomy increases with age.

Age-specific patterns of follow-up

To examine patterns of follow-up two ratios for each age group have been estimated:

- smears taken to number of women having smears
- women having smears to women who have colposcopy

The first ratio is devised by estimating the number of smears taken in the ACT in the financial year 1989/90 and dividing this by the number of women who have a Pap smear. It is an estimation of the average number of smears taken per woman. Many of these repeat smears will be because of abnormalities or inadequate or inconclusive smear reports. Others will be repeated because of persistent symptoms such as bleeding or discharge. The second ratio provides information on relationships between gynaecological follow-up and Pap smear utilisation for each age group.

Table 3.5 Age-specific ratios for repeat smears and colposcopy

Age group	Smears taken: women having smears*	Women having smears: women having colposcopy	95% confidence intervals
15-24	1.18: 1	13.2: 1	13.0, 13.4
25-34	1.18: 1	18.2: 1	17.9, 18.5
35-44	1.16: 1	20.4: 1	20.0, 20.7
45-54	1.32: 1	16.1: 1	15.6, 16.6
55-64	1.09: 1	39.0: 1	35.4, 42.6
>65	1.09: 1	30.1: 1	25.4, 36.1
Total	1.19: 1	17.8: 1	17.7, 17.9

* It is not possible to calculate confidence intervals for these ratios for the reasons outlined in Appendix A.

The higher the ratio of smears taken to women having smears, the greater the proportion of women in that age group who have had more than one smear in 1989/90. Interestingly, the 45 to 54 year old age group of women had the highest ratio of smears taken to women screened; for every woman screened in this age group 1.3 smears were taken. Overall, there were nearly 20 per cent more smears taken than women screened during the financial year 1989/90. In Victoria, in 1992, eight per cent more smears were taken than women screened. (Mitchell and Higgins 1993).

On average, eighteen women had Pap smears for every one woman having colposcopy. For the age group 45 to 54 there also appeared to be more intensive colposcopy follow-up; 16 women had Pap smears to every one woman who had colposcopy. The highest ratios of smears taken to women having smears and the lowest ratios of women having Pap smears to women having colposcopy are found in women less than 55 years of age. It is possible that women over 55 who have Pap smears have participated in regular screening and thus may be a group with a low prevalence of abnormalities. Alternatively, clinicians may respond differently to Pap smears indicating abnormalities or reported as inadequate for women of different ages. It is possible that practitioners and patients have different interpretations of the significance of abnormalities for women of different ages.

Current and predicted trends in colposcopy use

In this section current cross-sectional incidence rates for colposcopy are computed and the cumulative risk simulated of ever having colposcopy if current rates of colposcopy follow-up continue.

Methods

The number of women claiming for colposcopy between January 1 1989 and April 30 1990 was obtained from the ten per cent Medicare file[4]. Women who had claimed for colposcopy in the previous two years were excluded. Therefore women included in this sample were assumed to be women claiming for a new episode of colposcopy. This number was multiplied by

[4] These data were collected over a sixteen month period so that I could directly compare the assessment and treatment practices of gynaecologists in the ACT and Australia with the practices of the gynaecologists operating in the clinic in which the study outlined in Part C was based.

7.5 (equalling $\frac{12}{16}$x10) to provide an estimate of the number of women claiming for colposcopy in a twelve month period because data were obtained from ten per cent of the population and collected over a 16 month period.

Because all colposcopy services are undertaken in the private sector in the ACT, Medicare statistics can be used to estimate age-specific incidence rates for colposcopy. After estimating the number of women in each age group claiming colposcopy the incidence rates and cumulative risk of colposcopy were calculated using a lifetable approach. This is detailed below.

The terms used in the lifetable are:

$$nMx = \frac{\text{No. of colposcopies for women aged between x and x + n}}{\text{Mid - year population of women between the ages x and x + n}},$$

nCx = no. of women who have never previously had a colposcopy who have a colposcopy between ages x and x + n,

lx = no. of women who have not had a colposcopy by age x,

lx + n = no. of women who have not had a colposcopy by age x + n,

nmx = rate of colposcopy among women at risk of having their first colposcopy.

nCx is derived from the Medicare data.

Therefore,

$$nMx = \frac{nCx}{nWx},$$

where nWx is given by the number of women enrolled in Medicare on June 30 1989 between ages x and x + n.

However, nMx does not equate to nmx [5] from a conventional lifetable. Women who have previously had colposcopy are included in the denominator. Therefore, one cannot use the conventional method that converts rates to probabilities to derive lx.

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[5] In a conventional lifetable nmx refers to the rate of an event, usually death, between ages x and x+n. Death removes people from population counts, however nWx includes all

lx can be derived with knowledge of nMx, however. The method assumes that women were exposed to the same incidence of colposcopy in the past as they are now. To calculate lx I use the method described below, which is the same as the method described by Dickinson and Hill 1988.

The proportion of women who have had a colposcopy between ages x and x + n is

$$nPx = \frac{lx + lx+n}{2l0}$$

Where l0 = no. of women who have not had colposcopy at exact age 0, or who have not had colposcopy at the beginning of the simulation

Therefore nmx (the rate of colposcopy among those women at risk of having a first colposcopy) is

$$nmx = \frac{nCx}{nWx.nPx}$$

(ie nLx = no. of women years at risk of first colposcopy = nWx.nPx)

And,

$$nmx = \frac{(\frac{nCx}{nWx})}{nPx} = \frac{nMx}{nPx}$$

$$= nMx.(\frac{2.l0}{lx + lx+n})$$

We know that

$$nmx = \frac{nCx}{nLx} = \frac{lx - lx+n}{n.lx+n+\frac{n}{2}.nCx} = \frac{lx - lx+n}{\frac{n}{2}(lx+n+lx)}.$$

Therefore the above two equations can be equated

$$nMx.(\frac{2.l0}{lx + lx+n}) = \frac{lx - lx+n}{\frac{n}{2}(lx+n+lx)}$$

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women whether or not they have had a previous colposcopy. Therefore nWx will include women who are not at risk of first colposcopy.

Therefore,

$$_nM_x \cdot l_0 = \frac{l_x - l_{x+n}}{n}$$

and,

$$n \cdot {}_nM_x \cdot l_0 = l_x - l_{x+n}$$

hence,

$$l_{x+n} = l_x - n \cdot {}_nM_x \cdot l_0$$

The hypothetical cohort starts at exact age 15 with 1000 women.

These rates have been used to derive l_{25}, l_{30}, l_{35}, l_{45}, l_{55} and l_{75}.

If one assumes that women who have had a hysterectomy are no longer at risk of colposcopy[6], the denominator for colposcopy rates should be adjusted to include only women who have not had a hysterectomy between ages x and x+n. To adjust for hysterectomy, ${}_nW_x$ has been multiplied by the proportion of women between ages x and x+n who have not had a hysterectomy, before adjustment for colposcopy is made. The cumulative risk of colposcopy is also shown after adjustment for hysterectomy has been made.

From l_x ${}_nm_x$ (the incidence of first colposcopy with denominator adjusted to remove women who have previously undergone colposcopy) can be derived.

$$_nm_x = \frac{{}_nC_x}{{}_nL_x} = \frac{l_x - l_{x+n}}{n \cdot l_{x+n} + \frac{n}{2} \cdot {}_nC_x} = \frac{l_x - l_{x+n}}{\frac{n}{2}(l_{x+n} + l_x)}.$$

Findings

Table 3.6 shows the lifetable probabilities for colposcopy by ages 25, 35, 45, 55 and 75 with and without adjustment for hysterectomy. Whether or not an adjustment for hysterectomy is made, if current cross-sectional rates of colposcopy continued, and current screening participation rates were maintained, most women would have had at least one colposcopy by age 75. In contrast, the lifetime risk of cervical cancer in a Western-style country in the absence of a cervical cancer screening program is only 1.6 per cent. (IARC Working Party on the Evaluation of Cervical Cancer Screening

[6] It is possible that some women who have had hysterectomy may have a vaginal colposcopy.

Programmes 1986). Thus there is mismatch between the risk of cervical cancer and the risk of further investigation with colposcopy.

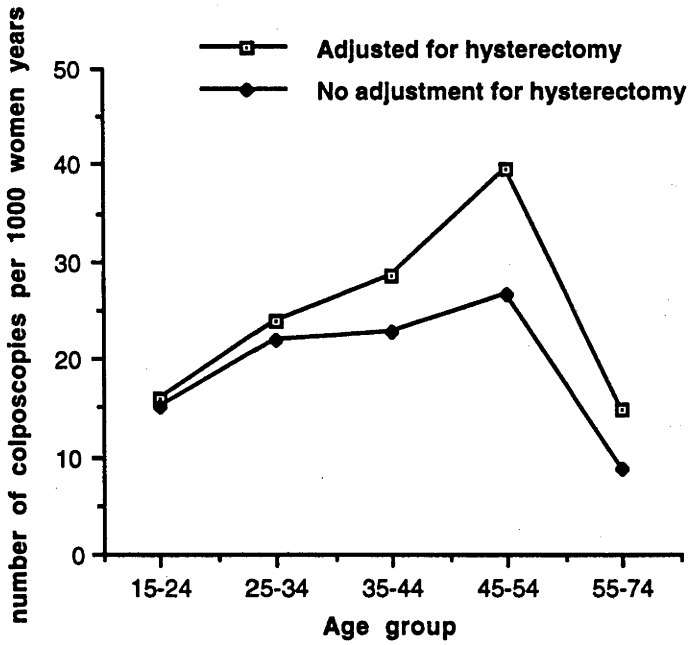
Table 3.6 Lifetable of colposcopy with and without adjustment for hysterectomy

	No adjustment for hysterectomy			Adjusted for hysterectomy		
Age (x - x+n)	nMx*	lx	Cumulative per cent	nMx	lx	Cumulative per cent
15	14.6	1000	0.0	14.6	1000	0.0
25	17.6	885	11.5	18.3	852	14.8
35	14.8	710	29.0	17.0	669	33.1
45	13.3	565	43.5	17.7	502	49.8
55	3.5	431	56.9	4.6	336	67.4
75		362	63.8		249	75.9

* no. of colposcopies per 1000 women-years

The annual incidence rates for colposcopy in the ACT are shown in Figure 3.1. These were calculated using the lifetable method described earlier.

Figure 3.1 Annual age-specific incidence rates for colposcopy (ACT) calculated from simulation



Incidence rates are similar if between the ages of 25 to 54. After adjustment for hysterectomy the highest incidence rates of colposcopy are in the 45 to 54 year old age group where a rate of 39.6 per 1000 women years was found.

Table 3.7 shows the incidence rates of colposcopy without adjustment for hysterectomy and the incidence rates for cervical cancer in New South Wales and the ACT in 1989. Again a mismatch is obvious. The incidence rate for colposcopy is many times the incidence of cervical cancer. The overall ratio of annual colposcopy incidence rates to the annual incidence rates for carcinoma of the cervix is 122:1. The ratios of colposcopy incidence to incidence of cervical cancer are 1096:1, 185:1, 124:1, 138:1 and 36:1 for the age groups 15 to 24, 25 to 34, 35 to 44, 45 to 54 and 55 to 74 respectively.

Table 3.7 Simulated annual incidence rates for colposcopy and cervical cancer per 100,000 women years*

Age groups	Colposcopy (1989-90)	NSW** (1989)
15-24	1534	1.4
25-34	2202	11.9
35-44	2279	18.4
45-54	2674	19.3
55-74	877	24.5
Total	2042	16.8

* Neither of the figures is adjusted for hysterectomy

* *1989 incidence figures for cancer of the cervix for NSW 1989 from the NSW Cancer Registry. Unpublished data.

The International Agency for Research on Cancer published estimated incidence rates of squamous cell cervical cancer for women in a Western-style country without screening. These were 5, 15, 25 and 45 per 100,000 women-years for women in the 20 to 24, 25 to 29, 30 to 34 and 35 to 69 years, respectively. (IARC Working Party on the Evaluation of Cervical Cancer Screening Programmes 1986). Let us assume that precursor lesions take an average of ten years to develop. That is, those in the 20 to 24 year old age group would have an incidence of cervical cancer of 25 per 100,000 women-years in ten years' time, if they were not participating in a cervical cancer screening program. In a cohort of 100,000 women, 1534 would have a colposcopy annually (without adjustment for hysterectomy) at the ages 20 to 24; 25 would develop cervical cancer in ten years' time. That is, 98 per cent of the women who have colposcopy would not develop cervical cancer in ten

years time. The same results are obtained if one uses the IARC incidence rates ten years hence for the age groups 25 to 34, 35 to 44 and 45 to 54; 98 per cent of women in these age groups who have colposcopy now would not develop cervical cancer in ten years time.

Conclusion

It has been shown here that if current patterns of referral for abnormal Pap smears continue most women will have a colposcopy during their lifetimes, although very few women would ever develop cervical cancer. The ratio of incidence of colposcopy to incidence of cervical cancer is many times greater in the youngest age group.

There are some limitations to the lifetable approach to deriving cumulative risk of colposcopy and age-specific annual incidence rates for colposcopy. These are:

- The numerator may include women who had a colposcopy more than two years ago. Inclusion of these women will inflate estimates of incidence because women who have had a previous abnormality are at greater risk of another abnormality than other women (Mitchell, Medley et al. 1990).

- The method assumes that women were previously exposed to current rates of colposcopy. Instead women were probably not referred for colposcopy as commonly in the past. In fact the use of colposcopy has only expanded in the last fifteen years. This assumption will also inflate the incidence estimates.

- This simulation includes all women. If a woman does not participate in screening she is not at risk of colposcopy. If it were possible to adjust the denominator to include only women who participate in screening[7] the cumulative risk estimates for these women would be greater at the ages shown.

- Some women in the ACT may have had a colposcopy in a public sector service in NSW. These women would not appear in the Medicare estimates. Omission of these women will underestimate colposcopy rates.

[7] The only way to do this would be to construct a computer simulation model. For example, a microsimulation model could be used. This is beyond the scope of this thesis.

However, if one assumes that nMx is inflated by 50 per cent the cumulative risk of colposcopy at age 75 would be 38 and 34 per cent, with and without adjustment for hysterectomy, respectively. A clear mismatch between risk of colposcopy and risk of cervical cancer is still evident.

Discussion

There is a disparity between risk of cervical cancer and use of cervical cancer screening and colposcopy services and the mismatch is greatest for younger women.

The highest frequencies of Pap smear and colposcopy service usage were found among women under age 55. Although women younger than 35 have much lower rates of cervical cancer than women over 35 years of age, their patterns of follow-up were similar to those of women aged between 35 and 54, and their rates of follow-up were higher than women over 55, even though they have a lower incidence of cervical cancer than older women.

About one in forty women between 15 and 54 had a colposcopy in 1989/90 whereas less than one per cent of women between 55 and 74 had a colposcopy. These differences in colposcopy use by age may be explained by differential rates of referral for colposcopy after Pap smear, different length of follow-up (it is possible that younger women are followed more intensively, increasing the prevalence estimate), and higher frequency of Pap smear use in the younger age groups.

Women in the 15 to 54 year old age group appear to have more intensive follow-up. More Pap smears are taken for each woman screened and they are more likely to have colposcopy. The differences may be explained by different ranges of abnormalities across the age groups. Additionally, clinicians may respond differently to abnormalities for women of various ages. It is possible that the older age groups include women who are previously well screened and hence have a lower risk of abnormalities than other women. Without clinical data it is impossible to disentangle the reasons for the age differences in follow-up. However, in 1992, only two per cent of smears reported in Victoria showed evidence of CIN and only 1.7 per cent of smear reports recommended referral to a gynaecologist. (Mitchell and Higgins 1993). It is likely that many of the women having colposcopy have minor abnormalities of unclear significance.

The age-specific incidence of colposcopy, constructed from the lifetable simulation, follows a similar pattern to the prevalence of colposcopy. Women over 55 have a much lower incidence of colposcopy. The high referral rate of women younger than 55 partly explains the high incidence of colposcopy in these age groups. They also participate in screening more frequently. The implications of current practices are significant. If current cross-sectional rates of colposcopy continue it is estimated that 76 per cent of eligible women will have colposcopy by age 75.

It is impossible to compare the practices in the ACT with other states or territories because no comparable data are available. It is possible that the ACT has a more active referral pattern than elsewhere. The higher proportion of women participating in screening in the ACT compared with other states will also increase colposcopy rates.

As a screening test, Pap smears must differentiate between those women who are likely to develop cervical cancer and those who are unlikely to do so. This study suggests that if current referral practices for colposcopy continue most women will be defined at some time as likely to develop cervical cancer. Women who would not develop cervical cancer but nevertheless have further investigation could be thought of as having 'pseudodisease'. These women could also be considered to be false positives. Although the screening tests may identify women with an abnormality, current practices do not distinguish between those likely to develop cervical cancer and those who are not.

The mismatch between risk of cervical cancer and risk of referral demonstrated may be a consequence of the different perspectives of public health practitioners and clinicians.

For the epidemiologist risk describes categories of people, not individuals. Risk summarises the experiences of an aggregate of people who share a particular characteristic, for example, class or age. Each individual in that category either does or does not develop the disease studied over a specified period of time. The experiences of different sets of people (their risks) are compared. In epidemiological terms, risk of a particular disease resides within that collection of people, not within an individual.

Although cervical cancer screening is conceived at a population level it is instituted in clinical practice where clinicians see individuals. Thus population-derived risks must be translated to individuals. The aggregate's risk becomes the individual's. Direct translation is seldom possible, however. An individual may share characteristics of several categories or have characteristics not previously described. Also, the conditions under which risk was computed, may not correspond to the clinical situation.

From interviews with physicians practising in Canada, Beresford (1991) identified many sources of uncertainty. Scientific knowledge was often incomplete. Frequently scientific research had not clearly described the particular clinical problems. Clinicians sometimes found their own knowledge was insufficient. Abstract data from scientific studies were difficult to apply to individual situations. They were required to take the general to the specific. Clinicians' experiences with uncertainty had consequences for their practice. They performed diagnostic tests to assure their patients and themselves, for fear of litigation and to achieve diagnostic certainty.

Clinicians may fear litigation if they do not refer a woman with an abnormal Pap smear for colposcopy. An Australian study found most doctors were very aware of the threat of litigation and this appeared to contribute increased levels of servicing. It meant they were more likely to order tests and procedures, take time to explain risks, spend time keeping records, and suggest preventive consultations. (Commonwealth Department of Health 1993).

Clinicians are concerned about the consequences of making a mistake. Gifford (1986) interviewed surgeons who saw women who had benign breast disease, a risk factor for breast cancer. These surgeons interpreted the women's risk of breast cancer as their own risk of making a mistake. This encouraged them to perform investigations and procedures in order to reduce their own uncertainty.

Clinicians who do not avail themselves of a test when they are unsure of a diagnosis are going against the grain of usual clinical practice. Gathering information enables them to assuage their uncertainty a little. It also means they have used all possible technologies to achieve the most accurate diagnosis. Such practices might be understood as acting in the best interests

of the patient. They are moving towards the best description of the patient's problem so that they can then offer the best possibility of cure.

However, in the case of cervical cancer screening, the clinical aim for diagnostic certainty results in many more women being investigated for the precursors of cervical cancer than would ever develop cervical cancer. Investigating a large number of women may increase the sensitivity of the screening program but the trade-off is a substantial reduction in program specificity. Colposcopy will become the norm, the Pap smear will be an inefficient screening test, and the goal of the cervical cancer population-based screening program — to achieve a cost-effective reduction in cervical cancer incidence and mortality — will not be met. The high rates of investigation with colposcopy will also cost the community financially and women will incur significant personal and financial costs.

In this chapter, the public health significance of current practices relating to abnormal Pap smears have been identified. I have shown that if current patterns of referral do not change many more women will be investigated for an abnormal Pap smear than will ever develop cervical cancer. Let us now turn to exploring current practice from the perspective of women who have had abnormal Pap smears.

Part B

Women's accounts

Chapter Four

Methods

This chapter describes the methods of the qualitative study undertaken to explore women's accounts of cervical abnormalities. The study design, context and processes of the research and analysis are also outlined.

To my knowledge there has been no published research in Australia which addresses women's experiences of cervical abnormalities. Consequently there has been limited capacity to consider women's experiences in policy and clinical practice even though cervical abnormalities are common.

This is an exploratory study with broad aims to capture the range of women's experiences. The intention was to describe the consequences of abnormal Pap smears for women who receive the diagnosis; to explore how women understood their abnormality and its consequences; and to document their experiences of clinical services.

Characteristics of abnormal Pap smears

This section reviews particular features of abnormal Pap smears which may influence how women feel about their abnormality and their clinical care.

Secondary prevention through screening and treatment of precursor lesions is an important element of modern public health practice. Risk factors for disease, defined in terms of a collective experience, are modified at an individual level to prevent disease. There is no way of knowing for sure whether the individual would get the disease. The drug and dietary management of high serum cholesterol illustrates this situation. In epidemiological terms CIN is not a risk factor. It is considered a precursor of cervical cancer, and therefore, as part of a disease process that sometimes results in cervical cancer. HPV, on the other hand, is generally thought of as a risk factor, that is, HPV confers women with a higher risk of developing cervical cancer in the future. In current thinking HGSIL might be conceived as a precursor and LGSIL could be thought of as a risk factor. No matter the

precise definition, both HPV and CIN signify a future risk of cervical cancer. The public health paradigm asserts that modification of individual risk reduces the epidemiological risk of disease and the incidence of disease is decreased. Within this paradigm, women who are unlikely to get cervical cancer receive treatment by the health care system because it is impossible to discern who will develop cancer and who will not at a given level of cervical abnormality, and there is no other means of eliminating these abnormalities. But how do individual women who are diagnosed as having a cervical abnormality experience risk?

Gifford (1986) found that both clinicians and women thought of risk as a 'specific property of an individual'. Benign breast disease, which had been associated with future risk of breast cancer in epidemiological studies, came to define individual women as 'at risk'. This risk became something that could be diagnosed, managed and treated. Cervical abnormalities share many similarities with benign breast disease; both conditions are biologically defined states that are associated with future cancer and both are specific to women.

Within Western medicine, diseases are understood to be 'abnormalities in the structure and function of body organ and systems' and illnesses are 'experiences of disvalued states of being and in social function' (Eisenberg 1977). Clinicians deal with disease and patients experience illness. Presence of disease does not necessarily imply illness nor illness disease. (Eisenberg 1977).

Most conditions produce symptoms or signs of which a person with the condition is aware. In the typical clinical model an individual recognises their symptoms as deviating from implicit normative standards. The decision to seek a professional opinion usually involves discussion and advice from members of one's social networks. (Eisenberg 1980). In the clinical encounter individuals tell of their symptoms, and doctors interpret them and seek out signs. Doctors make sense of individual illness within a biomedical framework and construct a diagnosis and treatment plan (Good and Delvecchio Good 1980).

However, abnormal Pap smears differ from the usual work of clinical medicine. Diagnosis relies completely on a test. Asymptomatic women are given a diagnosis which, in medical terms, denotes a pathophysiological process. Symptoms are not part of the diagnostic process. Treatment is

technological. The diagnosis is constituted almost independently of women's own experience. The cervix, an invisible part of women's genitalia, is diagnosed and operated upon. Women cannot see what is happening. They have no yardstick, no thermometer, no symptom or sign, with which to recognise or monitor their cervical abnormality. They have no basis on which to dispute their doctor's diagnosis.

The risk factors for cervical cancer and its precursors, described in epidemiological studies, may also shape women's experiences. For example, sexual behaviour has long been identified as a risk factor for cervical cancer. Discourses concerning cervical cancer and its precursors may construct particular meanings for cervical abnormalities.

Study design

As this research was exploratory the most appropriate study design is qualitative since this enables an intricate investigation of women's experiences. Detailed individual interviews were therefore conducted with women who had cervical abnormalities.

The research was conducted in two phases. In 1990/91 pilot interviews with ten women were performed. After preliminary analysis and feedback from women involved in the pilot interviews, 19 more interviews were conducted during 1991 and 1992. The study was approved by the Ethics Committee of the Australian National University.

Recruitment of women

Women who had an abnormal Pap smear, and who had had gynaecological assessment and treatment, were eligible for the study. Most of the women responded to a pamphlet or poster describing the study, placed in the gynaecologists' rooms. Additionally, three women were recruited through the ACT Women's Health Service (all of these participated in the pilot study).

Women volunteered for the study. Although one gynaecologist asked women if they wanted to participate, the others refused to ask women directly fearing that women might feel compelled to participate.

Interview procedures

An interview schedule, in the form of a theme list, was used to guide the interviews. Interviews lasted between 45 minutes and two and a half hours and were tape-recorded and transcribed. Each woman signed a consent form indicating they had agreed to the interview and that they were free to decline to answer specific questions or to withdraw at any stage. Personal identifiers were kept separate from the data.

Interviews were flexible and allowed women to explore their own issues and ask questions. I was identified as a medical practitioner, as someone who had expert knowledge of disease and illness. So, just as I gathered information from women about their experiences, they gathered information from me about their cervical abnormality. My practice followed that of Ann Oakley, who was often asked about her own experiences of motherhood or for advice when she was studying women's experiences of motherhood (Oakley 1981). I therefore responded to questions and provided advice when asked. After the interview I often gave women written material. Several women rang after the interview for advice about their ongoing gynaecological care.

The first interview schedule included the themes: diagnosis, treatment, effects of treatment and decisions about treatment as well as questions about cancer and precancer, the effects of this condition on women's relationships and sexuality and how this diagnosis affected their own and other people's perceptions of the woman's health. These themes reflected my experiences as a medical practitioner and as a user of health services. There were no predetermined questions, rather, the schedule served to remind me of the issues I wanted to explore.

After the ten pilot interviews, a preliminary analysis was performed on the interview transcripts and the memos recorded after each of the interviews. Recurring themes were identified. A discussion group with the women from the pilot project was also organised. Through preliminary analysis of the pilot interviews and discussions with women a second more focussed interview schedule was developed (see Appendix B). This interview schedule was used for the remaining 19 interviews. In the second round of interviews the following issues were focused on: experiences with their health care providers; understandings and explanations of their abnormal

Pap smear; perceptions of their cervix; perceptions of control; and feelings about how this experience had changed their lives.

Following the interview socio-demographic data were collected using a precoded questionnaire. Most interviews were conducted in women's homes. A few women were interviewed in an office at the National Centre for Epidemiology and Population Health at the Australian National University.

Characteristics of sample

Women saw one of six gynaecologists. There was only one female gynaecologist who was seen by two women in the study. Four of the gynaecologists worked from the same clinical premises and shared the same receptionist staff. All women in the study were still seeing their gynaecologist for follow-up at the time of interview.

Tables 4.1 to 4.4 provide details of the sample of women interviewed. The median age was 34 years. About half the women in the sample were enrolled in or had completed a tertiary qualification. Most women were living in married or defacto relationships. Canberra's population has higher education status than elsewhere in Australia and this is reflected in the sample. Most women were born in English-speaking countries; all women spoke English at home.

When reporting direct quotes a pseudonym is used for each woman. A brief description of each woman is provided with her pseudonym in Appendix C. When reporting the quotes in the text I use upper case for my questions. The women's responses are in lower case and are single-spaced and indented.

Table 4.1 Age of sample

Age group	Frequency
15 - 24	5
25 - 34	10
35 - 44	6
45 - 54	6
> 55	2

Table 4.2 Education of sample

Educational status	Frequency
Some secondary school	6
Completed secondary school*	10
Trades or apprenticeship	0
Certificate or diploma	3
Bachelors degree or higher	10

* Five women in this category were enrolled in a bachelors degree at the time of interview

Table 4.3 Marital status of sample

Marital status	Frequency
Single	4
Married or defacto	24
Divorced or widowed	1

Table 4.4 Country of birth of sample

Country of birth	Frequency
Australia	24
United Kingdom	2
France	1
New Zealand	1
Malaysia*	1

* Her parents are Australian.

Judging the research findings

In order to produce an accurate representation of women's accounts, the research instrument must be flexible so that it can incorporate new and emerging themes. The researcher must be sensitive to the ways particular research questions obscure some constructions and highlight others. After ten interviews, reflections and input from some of the women interviewed facilitated the refinement of the interview schedule so that it focussed on exploring more fully the developing themes.

To ascertain how accurately the women's experiences had been reported, a summary of results was sent to the women interviewed and they were invited to comment. Several women contacted me by phone and described

their pleasure at reading about themselves and other women like them. One woman commented that she felt her GP had been extremely good at providing her with information. Another wanted to publish the research in a magazine with which she was involved. Another wrote explaining that her partner had been most supportive and understanding. I organised a meeting with participants to discuss the research findings. At this meeting women commented on the document they had received.

> I regret not getting my highlighter pen out - there were so many points I agreed with at the time and now. ...I identified strongly with the stigma. I really struggled with my conscience on that one. (Amanda)
>
> I think the common thread that runs through this is the fact that the information is not available and of course then you have fear and then you have other problems associated with it. But it was very informative, it was a very informative document about yourself and about others too because you're not alone are you? (Jenny)
>
> I suppose I read this and I thought yes, yes, yes but I felt more stronger about it than the way it was put and that made me wonder whether feelings I had were stronger than what other people felt or whether it was just the way you'd written it. (Amy)

Amy's comment prompted me to reflect on the difficulty of representing all women's experiences in one document. In summarising the whole, I had understated Amy's experience. Lather (1991) calls this 'shattering the individual narrative' (Lather 1991).

Most comments from women related to the descriptive, rather than the interpretative, research findings. This is probably because they did not have the time or opportunity to immerse themselves in the text as I had done. Many women described the 'click of recognition' that Lather maintains is essential to establishing the validity of a study (Lather 1991).

Lather (1991) argues that a study is worthwhile if the findings are useful for the people studied and other relevant stakeholders. The group who met to discuss the findings spoke about how, at the time of diagnosis, they had wanted better information and someone to talk to who shared their own experience. This group decided to set up a support group so they could help other women who were faced with the diagnosis of an abnormal Pap smear. Despite initial enthusiasm the support group has not continued. Findings of the study have also been reported to gynaecologists who said they found it

interesting and that it had given them a different perspective on their practice.

As the research was based in Canberra, the socio-economic status of the sample was less varied than if the study was based in another Australian city. Most women were of Anglo-Saxon descent. There were no Aboriginal women or women from non-English speaking backgrounds. The project only included volunteers who were being followed by private gynaecologists. These women may supply a different account from women who did not volunteer for the study or who were followed up elsewhere.

All the women interviewed had seen a gynaecologist because of a cervical abnormality. These women are more likely to have accepted professional ways of understanding and interpreting this experience than women who did not attend a gynaecologist. Interviews with women who did not seek gynaecological advice for their cervical abnormality may have revealed alternative meanings for cervical abnormalities.

Data analysis

The text of the interviews constituted the data for the analysis. All 29 (pilot and subsequent) interviews were analysed. A coding framework to organise data into categories was developed. The coding framework was constructed from the aims of the research, the interview schedule and emerging themes. The framework has three topic headings: explanations and understandings, interactions with health services and relationships with others. Within these topics there are up to ten more categories and in some cases there are subcategories within the categories. Each interview was also coded for socio-demographic data (age, marital status, education) and clinical data (diagnosis, treatment, time since treatment).

The text of the interviews were entered into the computer software program NUDIST (Non-numerical Unstructured Data Indexing, Searching and Theorising) (Richards, Richards et al. 1992). This involved entering the text of the interviews into the NUDIST program. The segments of text that corresponded to various categories in the coding framework were coded.

Tesch (1990) maintains that qualitative research can be divided into four groups. This research is concerned with two of these groups: the discovery of

regularities and the comprehension of meaning in text or action[1]. These groups have overlapping features. The aim of the analysis was both to describe and interpret women's accounts, so the analysis concentrated on considering the meanings of particular themes and exploring how these might relate to other ideas. For example, under the category of precancer the meanings of precancer for women were examined. Under the category of general practitioners the common themes women mentioned when discussing the role of their general practitioners were examined.

As the analysis is based on small numbers of women, and this study is concerned with the meanings and themes, it is inappropriate to present my findings in terms of the number of women who experienced a particular event or spoke about particular concepts in similar ways. Therefore, when discussing the research findings terms such as some, most, several and a few, are used to provide an indication of the rough frequency of a particular interpretation or theme.

To code the categories under the first heading of the coding framework 'explanations and understandings' models were used, developed within interpretative medical anthropology, as the basis of the coding scheme.

Explanatory models

The explanatory model framework offers a method of investigating how women make sense of their abnormality. It is a means of organising the data and facilitating interpretation. The framework enables some interpretations of the data and prevents others.

Some medical anthropologists conceive the health system as comprised of professional, popular and folk sectors (Kleinman 1980). In Western society, clinical medicine constitutes the professional sector. The popular sector includes family, social and community networks. In Western culture, the folk sector includes healers such as herbalists and naturopaths. (Kleinman 1980). Most episodes of self-identified illness are managed in the popular sector. In deciding to consult a doctor or folk healer an individual may consult with their own social networks and evaluate their symptoms against implicit normative standards (Eisenberg and Kleinman 1980).

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[1] These two groups include many research perspectives such as grounded theory, phenomenology and hermeneutics. It is not within the scope of this thesis to describe the features of these different perspectives.

Explanatory models, formulated by medical anthropologists, provide a framework for exploring how health professionals and lay people make sense of a particular illness episode and evaluate approaches to treatment and healing (Kleinman, Eisenberg et al. 1978; Kleinman 1980).

> Explanatory models are notions about an episode of illness employed by those engaged in the clinical process (Kleinman 1980). p105

Kleinman (1988) argues that all systems of healing are to some extent concerned with questions about the disorder such as: cause, onset, what is wrong, future course, sources of improvements and exacerbations, and approaches to treatment. Thus explanatory models are considered to consist of five elements — aetiology, pathophysiology, onset of symptoms, course of an illness, and treatment. (Kleinman, Eisenberg et al. 1978; Kleinman 1980). Specific features of the explanatory models are emphasised in particular illness episodes, by different participants in the clinical process (the sick person, the professional and the folk healer), and in particular cultures (Kleinman 1980). I use all the features of the explanatory model, except onset of symptoms, as a coding scheme under the major topic heading, understandings and explanations. The categories of aetiology and pathophysiology have subcategories which were formulated from themes arising within the category (for example 'stress' under the aetiology category). I do not consider explanatory models to be entities in themselves, rather I used them as a tool which enabled me to gain insight into the ways women made sense of their abnormal Pap smear and the meanings it held for them.

The way individuals come to understand and explain particular illness experiences is shaped by the personal meanings they bring to an episode of illness from their own life experiences. Particular illness episodes also shift those systems of meaning. Illnesses thus become incorporated into and shape individual identities and life trajectories. (Kleinman 1988). Illness experiences are also culturally shaped. Thus, members of a particular social group may hold particular meanings for symptoms or illnesses. (Kleinman 1988). For example, in Iran heart distress described a syndrome that had a series of related meanings about Iranian women's sexuality and the oppression they experience in their everyday lives. Heart distress was a culturally specific idiom, a collective representation of an illness, which described something about the stresses and conflicts of the lives of Iranian women. (Good 1977). Illnesses such as cancer have a range of meanings in

different cultures. In Western culture, cancer is used metaphorically to describe uncontrollable growth (Sontag 1977). In contrast, the Navajo describe cancer as a 'sore that does not heal'; cancer represents decay (Csordas 1989). Social groups, such as those defined by class, gender and race, may also share particular meanings. These culturally shared interpretations of symptoms and illnesses enable communication between individuals who share the same culture or social group. For example, 'tension headaches' have particular meanings in Western culture. Individual interpretations of what another says when they describe a symptom or syndrome, such as tension headache, are also shaped by their ongoing relationship. Within that relationship particular meanings for the symptoms and illness are constructed. (Kleinman 1988).

The professional, popular and folk sectors have particular cultural models of sickness. In Western society the professional sector is predominantly concerned with disease. Disease is a concept used to describe biological dysfunction or the way doctors understand the experiences of individuals who consult them. The doctor reconstitutes an individual's illness complaint as disease, which describes an alteration in that individual's biological functioning. Professional explanatory models are therefore mostly concerned with disease as a universal biological entity. (Kleinman 1988). For example, Blumhagen (1980) found that the professional and popular interpretation of hypertension differed. The professional interpretation was high blood pressure and the popular understanding was excessive tension or anxiety. (Blumhagen 1980). The contrasting professional and popular meanings for high blood pressure offer quite different alternatives for managing the condition.

Although the professional, popular and folk sectors are usually considered as separate, they feed into and shape each other. For example, an English study found that both general practitioners and their patients drew on scientific and folk accounts of colds and fevers. The germ theory of disease did not conflict with the folk model of 'feed a cold, starve a fever'. Instead, folk and professional models were mutually reinforcing. (Helman 1978).

Explanatory models are dynamic. The models vary over time so that an illness experience can be incorporated into an individual's changing life circumstances. Particular explanations and meanings are reworked, elaborated or expunged as a consequence of social interactions (including interactions with physicians) and life experiences. In this way explanatory

models are grounded in individuals' lives. (Hunt, Jordan et al. 1989). Cultural representations of illness are also historically contingent. Farmer (1990) reported on the representations of AIDS (SIDA) in a Haitian village. He found that at the beginning of the epidemic, before anyone in the village had suffered from SIDA, it was not a frequent topic of conversation. At that time SIDA was a disease of city people, men who slept with other men, and was characterised by diarrhoea. There was no collective representation of SIDA. When three villagers became affected, the cultural model of SIDA shifted. SIDA became incorporated into previous interpretative frameworks for illnesses. SIDA was associated with divine punishment, North American imperialism, the corruption of the country's leaders and the ongoing suffering of Haitian people. The cultural model was related to the political events in Haiti at that time. (Farmer 1990).

My interviews were conducted at a particular point in the course of women's clinical care. Women's reflections revealed some of the fluidity of their explanations. No doubt a series of interviews over the period of their abnormality and treatment would have enabled further insight into how women's explanatory models were extended and modified over time.

Summary

I have described the purpose of this investigation, the context of the inquiry, the process of the research, the sample of women and the applicability of the research findings. The results of the analysis are reported in the following three chapters.

Chapter Five

What is a cervical abnormality?

The following two chapters explore the meanings of cervical abnormalities for women. The central argument of this chapter is that this diagnosis shifted women's conception of their risk of cervical cancer so that their risk came to reside within their body. This embodied risk meant they were in an ongoing liminal state of neither health nor illness. Rather, they were in a state of potential ill health. I conclude the chapter with a discussion of how cervical abnormalities reshape women's perceptions of their cervix, reproductive systems and self-definitions.

Women constructed their meanings for cervical abnormalities from their past experiences (both within and outside the health system), popular medical culture and scientific medicine. First, I explore how women understood the terms HPV (or wart virus) and precancer. I show how women's interpretations of these terms drew on their previous beliefs about the meanings of warts, viruses and cancer.

Interpreting medical terminology

Wart virus infection

Wart virus manifests in a variety of ways (see Chapter Two). Treatment of HPV is difficult. Ablative treatments such as laser or diathermy and anti viral ointments or creams such as idoxuridine are commonly used. The natural history of wart virus infection is one of regression and recurrence both with and without treatment. HPV presents diagnostic and treatment difficulties.

Previous beliefs about warts and viruses influenced how women interpreted the diagnosis of wart virus infection. This diagnosis was understood in the context of their more general understandings of viruses, warts and similar infections. For example, from previous experience with the medical system

they knew viruses were rarely treated and usually went away. Treatment did not make sense in the context of their general understanding of warts and viruses.

Wart virus infection was linked to growths commonly found on one's hands. Their doctors' explanations about the different strains infecting the hands and genitals were often discounted. Viruses were expected to circulate in the bloodstream and spread throughout the body — similar to the common cold.

> A wart to me is something you get growing on your hand... and everybody wants to get rid of them. And a virus is something that spreads...I had this vision of having 50,000 warts down there. (Ruth)

Given this perception local ablative therapy was hard to understand.

> ...if it is all wart virus that the whole thing stems from, how do you treat warts with laser? I only had the virus from what I understand. If you've got a virus in your bloodstream, how can you treat it with laser? (Adrienne)

For some women, recurrent or persistent wart virus infection after ablative treatment could be understood because they believed that ablative treatment could not address the infectivity of the virus. Virus implied that the condition did not only reside in the genitalia. Several women suggested that treatment was unnecessary as viruses went away without medical intervention. Often women drew parallels, and occasionally equated wart virus infection with genital herpes or cold sores.

Information about wart viruses contradicted previous beliefs. Women's understanding reflected sophisticated reasoning within the biomedical paradigm. Yet, women's understandings were often dissonant with contemporary medical practice. Recent policy is more congruent with women's models for wart virus infection. The recently released report: "Guidelines for the Management of Women with Screen Detected Abnormalities" states:

> It must be stressed that the human papilloma virus cannot be eradicated by current methods of treatment. (Commonwealth Department of Human Services and Health 1994). p18

Precancer

Women had not heard the term precancer before they had their cervical abnormality. When they first heard it, many thought precancer was the same as cancer which was equivalent to death.

> I didn't know anything about precancer, soon as it was linked to cancer I thought I'd had it. (Valerie)
>
> I really did think I was going to die, because I had never heard about it before and then when I went to this doctor that first gave me the Pap smear, it was told to me that it was CIN 3, the last stage of cancer. (Rosemary)

Rosemary, and a few other women, still believed they had had cancer at the time I interviewed them.

Women's interpretation of precancer was drawn from their understanding of cancer.

> As soon as you hear the word cancer, you think the worst. It's a word you dread. You just don't want to hear. (Carmel)
> One mere mention of the word cancer is enough to really frighten you. (Heather)

The word cancer was imbued with frightening connotations. Women described how mentioning cancer caused a healthy man to die quickly and made rational people become irrational. People withdrew from cancer's victim and cancer meant a slow and painful death. The word cancer created fear.

Sontag (1977) maintains that diseases such as cancer, which are poorly understood and have no effective treatment, are often 'awash with significance'. The diseases themselves become metaphors. Cancer, which is viewed as the modern day epidemic, represents 'our culture's insult to the natural order'. (Sontag 1977).

Cancer was sometimes perceived as equivalent to death.

> There's a part of me that has this real pessimistic outlook on cancer which is cancer is death. And no matter how much I see people around me and read a lot about people who actually fight their cancers, I was scared. (Leslie)
>
> I thought "oh my god I've got cancer I'm going to die". (Phillipa)

A death from cancer was long and painful.

> Cancer makes me think of suffering. I had a few friends that died of cancer. It just makes you think of the horrible chemotherapy

> treatment and horrible death. Their wasting away and it's just really painful. Sort of grey coloured skin. (Lorraine)
>
> If I'm going to die young I want to go straight away and not go slowly...I just want to go at once. (Ruth)

Military metaphors similar to those by Sontag (1977) were used to describe cancer. Cancer was cast as the smart and deceptive enemy and the body as its vulnerable and sometimes defenceless prey. Cancer constantly threatened. Stress, smoking or anything unhealthy made one more vulnerable to a cancer 'strike'. Youth and health protected one against cancer. Young people with cancer were more perplexing, revealing the inadequacy of their body's defences against cancer — the mighty and skilled attacker.

Cancer invades one's body and robs you of your body and your life.

> I think I would much rather think I'd died a 'natural' death of old age rather than feeling...it's an invasion...the feeling is that cancer invades you as opposed to a natural deterioration of the body. (Jenny)

Cancer is a foreign force, taking over territory that it does not own. Cancer was cast as an attack upon the body. However, one could 'fight' or 'battle' cancer.

> I'm not scared of cancer any more. I think once you battle it, I think that's it, once you're over it you try and prevent it with things like Pap smears. (Rosemary)

A few women spoke of cancer as 'in the family'. There were cancer families. In this situation cancer symbolically spread beyond the boundaries of individual corporeality to other bodies within one's family.

Women spoke of cancer as difficult to control. They could not prevent nor recognise cancer.

> If it was a heart attack problem you could think of it as the heart not doing its job properly or that the valve is blocked - it's more tangible, whereas cancer seems to be a very insidious disease that just creeps around and you can't control it or see where it is. It's hard to describe but you can't come to grips with it as easily as something where you can see what it's doing or what it's not doing and why. I think it's just the insidiousness of it. (Anna)

Cancer was perceived in punitive terms. For several women, it signified the general unhealthiness of modern society.

> ...there seems to be a higher incidence with our lifestyle at a more hectic pace, more highly processed foods and chemicals and things, whether that's bringing it about, I don't know...(Phillipa)
>
> I think it is a fact of life at the moment, in our world, in our society, we live with it all the time, and the fear of it. (Jenny)

In summary, cancer was considered an enemy, striking when one is most vulnerable, spreading and taking over the body, resulting in a painful, prolonged death. The meanings cancer had for women shaped their descriptions of the nature of precancer, and their reactions to their cervical abnormality.

By the time of interview most women distinguished precancer and cancer. Cancer provided the conceptual framework for making sense of the term precancer and women reworked the meaning of precancer within this framework.

Many women distinguished precancer from cancer.

> The receptionist was the one that allayed my fears in relation to cancer. And then he [the doctor] said to me, look it's not cancer, it's precancerous cells, that made a big difference as well, to know that it wasn't cancer. And then his confirmation that it is all gone and that basically we are just dealing with wart virus now rather than with precancerous cells. (Sharon)

For Sharon wart virus was not precancer. Other women referred to wart virus as a precancer. Because of the ominous meanings cancer holds in our culture women were often reassured by differentiating cancer and precancer.

For most women precancer was a condition that could develop into cancer if they did not have treatment.

> I took it to mean that if the condition was untreated it would proceed to cancer. That is why I had no hesitation having treatment. (Maeve)

For Ruth precancer inevitably resulted in cancer.

> ...I guess precancer is something, when you think of cancer you think of it being incurable. So with me when somebody says precancer, you think oh its going to turn into cancer and that is going to be it. You don't think of it as a stage that can be stopped. (Ruth)

Ruth describes precancer as a condition that will turn into cancer despite intervention. Precancer, like cancer, is incurable. Ruth's description of precancer is indistinguishable from cancer.

> Get it [the treatment] done quickly. I know it was precancerous, it can stay a couple of years but I wanted to get rid of it.
>
> WHAT WERE YOU THINKING ABOUT?
>
> That it would multiply and when I went back in next week, or in two weeks, it was going to be all over me. Nobody could put that out of my mind. I was convinced I was infected. I felt incomplete, unhealthy. I felt my whole body was unhealthy. I had this growth and felt really unhealthy about the whole thing. I just wanted to get rid of it. (Ruth)

Precancer was going to spread in the same way as cancer. Precancer, like cancer, was separate from her and spread throughout her body. While precancer was present she felt unhealthy. Precancer defined her in a new state of ill heath.

Precancer was cancer, as well as not cancer, as well as a precursor to cancer in women's descriptions of cervical abnormalities. Sometimes these definitions occurred simultaneously. Precancer was interpreted in relation to cancer, in terms of what it is not or what it might become; it did not have intrinsic meaning in itself. Therefore, precancer is an ambiguous state, for lay women as it is in medical discourse.

Healthy or ill?

Women tried to make sense of their cervical abnormality in terms of the conventional definitions of health and illness. The lack of symptoms and their newly defined state of risk was understood as neither a state of health nor illness, rather it was a liminal state of potential ill health.

Lack of symptoms

> ...if you've got a wound on your arm you can see what is happening to it, if you've got a pain, well at least you've got a pain, but you just don't have anything, nothing at all, which is very confusing. (Anna)

Perplexity, such as that expressed by Anna, over the lack of symptoms was a recurrent theme.

Women with cervical abnormalities rarely suffered symptoms. However, symptoms are central to modern definitions of illness. Illness is constituted from symptoms.

> REMEMBER BACK TO WHEN YOU FIRST HAD AN ABNORMAL PAP SMEAR. WHAT DID THAT FEEL LIKE?
>
> It was horrific. Actually my life wasn't good and it wasn't bad but I was coping. As soon as I found out the results I just went downhill, I couldn't cope any more. I became ill. Even though physically I felt well. I was going to the gym etc., I just all of a sudden thought, I'm sick and made a physical illness for myself. ...As soon as I was told the results I was ill. All of a sudden. Then it became interlinked with depression. I automatically became different. All I wanted to do was stay in bed and I just felt lethargic and I thought I had cancer. If you've got cancer, you don't do anything because you're sick. (Lorraine)

Despite being asymptomatic at the time of diagnosis Lorraine developed symptoms with the diagnosis. Lorraine describes how the diagnosis of the cervical abnormality move her from a state of health to illness. Transformation to this state of ill health rests on the diagnosis of the abnormality and the presence of symptoms. Furthermore, because she is sick she has a different relationship with the world — she no longer does anything.

Not all women responded in this way. Judith did not consider her cervical abnormality as an illness.

> I thought this was something like when I had warts on my fingers; the doctor froze them or burnt them off or something. I saw it in relation to that - something that was there that had to be taken off - I didn't really think of it as an illness or sickness or anything severe. (Judith)

Her cervical abnormality was perceived to be a physical entity. However, it was not an illness, she does not suffer any symptoms that would define her as ill.

Sarah did not experience any physical manifestations of the diagnosis, but she was emotionally affected by it.

> I wasn't even sick, that's the problem, like it's not being sick, I didn't feel sick, I know I didn't look sick. So it was really on an emotional basis. Sure there was the physical stuff you had to fix up, but it was the emotional stuff you attach to abnormal smears which could lead to cancer, which could lead to death. So that stuff was worrying me, but not physically. (Sarah)

Sarah used sickness to refer to physical not emotional experiences. Yet Sarah 'suffered' emotionally because of her abnormality. The abnormality signified her mortality. She was neither sick nor well. No term adequately described her experience.

The lack of symptoms meant the condition could pass unnoticed.

> My sister in law had it just before or around the time I did. She ended up having a full hysterectomy. But she was bleeding all the time so...I didn't have any of that. I didn't even know. I mean I wouldn't have known there was anything wrong with me. That's the scary part. Like you don't have a pain and say, "oh I am sick I have to go to the doctor and have it checked". Only through these tests. And then I heard, it was on the radio or something that they couldn't pick it up in all cases, that the lab could overlook it, or the human eye. That is scary. In my case now that I've had it twice, the bad cells, if they don't check carefully enough now...(Carmel)

Carmel recounts her usual experience of sickness. She recognises symptoms and the doctor diagnoses and legitimises her as sick. In this instance, she does not recognise herself as sick because she has no symptoms. Also, even the doctor and tests may 'miss' the diagnosis. The fear is related to the cancer that could result from such an error.

Symptoms and signs mark the individual in a way that identifies them as ill. They and others respond to them as ill. Without such symptoms women are not ill, unless they developed symptoms like Lorraine. They were not healthy either, however. They were in an ill-defined liminal state of neither health nor illness.

The physical nature of cervical abnormalities

Abnormal cells, precancer, wart virus and CIN referred to conditions from which women suffered. They were not abstract, depersonalised, disembodied risk factors for women with cervical abnormalities.

> WHEN YOU HEARD THE WORD PRECANCER DID THAT BRING UP ANYTHING FOR YOU?
>
> It is a bit like knowing that I had something, a condition that could lead to cancer if I didn't monitor it or be vigilant about it. It was just a feeling like having something wrong with my body that I had to keep checking on or that I had to ask other people, like doctors, to check up for me. (Brenda)

Clearly precancer is a condition that is part of Brenda's body. As in medical discourses, her risk of cervical cancer is a physical entity. Even after

treatment her risk is still considered to be 'something wrong'. Her risk still resides within her body. She is a state of potential cancer that is a disease in itself.

In contrast, Maeve and Phillipa spoke of their cervical abnormality as a physical entity that had been removed.

> I'm sure that I'm fixed now but that doesn't mean it can't return in the future. Whatever was there has been fixed up and I don't have any worries at all. (Maeve)

> I feel quite open and happy about it now, it's not perturbing me, I mean it's not going to send me grey for the next 30 years. All the cervix is cleared and the abnormal cells have gone so that's the main thing. (Phillipa)

However, the cervical abnormality itself needs to be fixed. Their bodies have a future risk of disease. With the abnormality gone Maeve and Phillipa have no concerns. Like Brenda, their cervical abnormality is not a part of a healthy body; however, unlike Brenda, removing 'it' returns her to a healthy state.

Women spoke of getting, fixing and being cleared of their cervical abnormality.

> it's only three or four months that I have actually been clear of it. (Leslie)

Cervical abnormalities had physical boundaries. Ineffective treatment failed to remove the entire abnormality. Several women wondered, on their follow-up visits, whether all of 'it' had been completely removed.

> I'll probably worry until I go back in September - did he get everything? (Mary)

Cervical abnormalities were definitive physical entities that encapsulated women's risk of malignant disease — they were not abstract risk factors that exist separate from an individual. For most women, they were conditions and disease in themselves. Treatment reshaped women's perceptions of their cervical abnormality. For some women treatment returned them to a healthy state since their abnormality had been removed. For others, for example Brenda, even treatment of their cervical abnormality did not remove their embodied risk.

> [prior to her abnormal Pap smear]...I never considered that I'd be at risk at all. (Louise)

This condition signified women's vulnerability to cervical cancer and death. Women became aware of their 'risk' of cervical cancer and death. Some women experienced a new found state of vulnerability in terms of their own health. In epidemiological and clinical terms, this is not a new risk, but the diagnosis of the cervical abnormality brought this risk into women's consciousness.

> I think I am going to get it eventually. [when she goes for Pap smears] ...I am just waiting for him to say "it's not looking good, you are in for it"...I have always gone for regular checkups and not thought a lot about them. ...I can't look at it the same way now, I can't have a smear done and be relaxed. ...They say "well you're being watched a lot more than anybody else so your chances of getting it bad are not as high". But it is just me. I think it is because I know that it can happen and it makes me a lot more aware. (Ruth)

Ruth speaks of her risk as a certainty; she believes she is going to get 'it'. Her cervical abnormality altered her awareness of her risk. Her risk of cervical cancer has a different quality from before she had her abnormal Pap smear. She is now constantly aware of her risk. The risk is now part of her. In this quote Ruth speaks of risk of cancer and death.

> I was concerned about the implications of being on the pill for somebody who had a risk ...who had a history of abnormal smears. (Amy)

> They [the doctors] didn't really tell you anything that you could do to change your risks. (Veronica)

Amy and Veronica possess their risk of cervical cancer. It is not a risk factor that is objective and describes groups of women like them. Instead, they are now defined by and live their risk of cervical cancer.

Some women described risk in relative terms.

> I don't feel I am a different person now. I have had this problem and it has been fixed, or not fixed, but I am back in the same boat as everyone else and I don't feel like I am more likely to have problems than they are. (Anna)

Treatment has returned her to the same risk state as everyone else. Her likelihood of risk is described in relation to others. In assuming the same 'risk state' as everyone else her risk is no longer a problem.

Many women said they had not considered themselves to be at risk of cervical cancer prior to their abnormal Pap smear. Prior to the diagnosis of their abnormal Pap smear they felt at no risk of cervical cancer.

> ...he [her gynaecologist] told me that once you had treatment, particularly laser treatment, your chances of abnormal cells goes back to zero. (Leslie)

Leslie implies that the time before her abnormal smear she was at no risk of a cervical abnormality. After treatment she returns to this state of no risk. In epidemiological terms she would be considered to be at risk, both before and after treatment, of cervical cancer or an abnormal Pap smear. She does not experience this risk, however.

Because of their cervical abnormality, women now experienced a sense of their own risk of cervical cancer. For many women their cervical abnormality symbolised their vulnerability to cancer and its consequences. Women frequently became more 'aware' of cancer generally.

> because it is all cancer related, I check my skin, moles and things like that and get straight to the doctor if I thought there was something wrong. I think it has made me a lot more aware of cancer generally. (Ruth)

> But on the other hand it is a reality to me now that I might get cancer there. And it has made me think more about cancer in other areas, like breast cancer. So it's made me think more of cancer related to females. (Ruth)

Not only is her cervix a site of potential disease but her whole body, especially parts of her anatomy that are defined as uniquely female, are potentially diseased. Mary's response to this newly defined awareness of her own susceptibility to cancer was to suggest removal of any parts of her that were 'unnecessary' and liable to cause her problems.

> I think the bits that I don't need, they may as well have and just leave me with the bits I need. Before, I probably would be scared stiff if they took my appendix out. Now they can whip them out and as long as they say, "you don't need it", they can have them. Because the tiniest bit can go wrong, and if that's not there well you can't have a problem with it. I'd be quite happy to go in and say "well I've still got my tonsils and I've still got this, rip them all out and I can go and I never have to come back again". (Mary)

In light of the vulnerability women experienced, several reflected on the quality of their own life and death.

> Life is important...you realise how important life is to you, and you want to live, you don't want to die. You want x amount of

years ahead of you and you are not going to waste them. You are going to enjoy every second of those, in whichever way, shape or form it takes, you are going to enjoy it. So it's very positive. I felt I came out of it, out of that particular period, feeling very positive about myself. (Jenny)

It's certainly changed the way I think, I don't worry about six months' time now. (Mary)

Carmel reflected on her own mortality.

DO YOU THINK IT HAS MADE YOU THINK ANY DIFFERENTLY ABOUT YOUR LIFE?

Yes it has. It made me think that you are not invincible, that you can, anything can happen to you. Like there was a little boy killed across the road here. That sort of thing really frightens me and it is out of your control in a lot of cases. Someone can come with a gun and blow you away. Like in the shopping centre in Sydney or this little boy at the bus stop. (Carmel)

Carmel reflects on the nature of the human condition (she uses 'you' rather than 'I'). Her experience is compared with indiscriminate killing. She realises that she, like everyone else, is susceptible to death. All of us will die. Frequently this is out of our control. One does not have control over one's bodily processes or one's own death.

In summary, a cervical abnormality had a physical reality for these women. Their risk of future cancer and death became part of them. They felt and experienced their risk. The diagnosis shifted or developed their awareness of their risk of cervical cancer, so that it came to reside within their bodies. This awareness of their risk resulted in many women experiencing a sense of vulnerability. Their sense of their own bodily integrity changed. They now experienced their cervix, and sometimes other parts of their physical body, as potential sites of cancer — as dangerous.

The cervix: the site of the abnormality

Meanings for the cervix

The cervix was defined in terms of its reproductive capacity and reproduction constituted the essence of femininity. Some women spoke of how their cervical abnormality, and the medical treatment of it, affected their femininity and sexuality.

> ...because your cervix is such an integral part of your being, your sexuality...I think it's a bigger emotional deal than if it was another part of you. (Leslie)

For many women a cervix gone awry affected femininity — a distinguishing organ of womanhood was out of order.

> [In relation to how she felt when she found out she had a cervical abnormality]...I think the fact that it is [that] part of your anatomy, you feel your femininity is affected...Not so much the precancerous cells, it goes through your head, but on top of that what is wrong with me, I'm not so much a woman any more. (Heather)

Heather links a healthy cervix with womanliness. Her disordered cervix made her less of a woman.

Yet medical treatment involved 'management' of the cervix as if it were separate from the rest of oneself. Some women explained how organ-specific management of their cervices conflicted with their perception of their cervix as interconnected with the rest of their body and central to their femininity and sexuality.

> I remember at one point...that I felt really dislocated from my cervix, that it was something nasty that I did not want to deal with. Like I wish I could get rid of it. So instead of feeling good about myself and my body I began to feel really bad about it. (Leslie)

Only women have cervices. A cervix is a feature of womanhood. A cervix is often defined as the 'neck of the womb' — as integral to women's reproduction. Medical treatment generally attempts 'cervix conserving' treatment in women of reproductive age. Once a woman feels she has 'completed child bearing' (or her clinician judges her to be so) or is menopausal, hysterectomy is a more readily acceptable option. In the realm of medical practices cervices are reproductive organs only and reproductive organs are of no use when a woman is not 'reproducing' (Fisher 1986). Rubin (1984) maintains that genitals are generally construed as the most inferior part of one's body. (Rubin 1984). In a New Zealand study, McDonald (1993), found that women did not think of their cervix separately from other reproductive parts. Some women did not use the term cervix. Therefore, for some women this abnormality may have defined their cervix for the first time. So, what did it mean to women to have a part of their body which was constructed within medical discourses to be reproductive and might be more generally considered to be an inferior part of the body?

To explore further the meaning of the cervix I asked women how they would feel if treatment had involved removal of their cervix. Women considered three factors when assessing the impact of the removal of their cervix. First, the cervix was less readily perceived by women than other parts of the body. Some women spoke of how they did not experience sensations such as pain from it. Also, the cervix is less readily touched than other parts of the body. Second, they were concerned about loss of fertility due to removal of the cervix. And, finally, they spoke about its relevance to their sexuality and femininity.

Removal of the cervix was often contrasted with removal of the breast. Breasts are visible, part of women's image of who they are, and therefore a mastectomy was perceived as more disruptive to one's self definition.

> I don't think it would worry me as much as having a breast removed through breast cancer, because *you can't see it, so you don't feel.* You can take the whole lot it wouldn't worry me. I wouldn't have any problems psychologically because I can't see and you don't think about it. Whereas if they were taking your breast, you see it everyday and it would stick in your mind. (Mary)

The cervix, as an invisible part of Mary's body, is less important in Mary's construction of her body than other, visible parts of her.

The cervix was often thought of in terms of its role in female reproduction. Some of the women who had completed their families or were menopausal, were unconcerned by the possible removal of their cervix.

> I've stopped having my periods - I haven't had periods for a year, so all that...is not *working* now. I'm not going to conceive. I'm a fairly practical person, I don't think that [removal of the cervix] would have been an emotional upset. (Judith)

Because menstruation had ceased, heralding the end of her reproductive life, removal of Judith's cervix is less of a problem. The cervix is mostly defined in terms of its reproductive function.

Some women thought they would be upset because they would be unable to have children.

> It [removal of the cervix] would be really scary. It would be a surgical procedure to start with - and there would be the infertility. Losing your femaleness. (Anna)

Losing one's cervix prevented having children. Fertility was linked to femaleness. Infertility would make her less female. Reproduction was an integral part of femaleness. Again, the theme of the cervix as an essential

organ of womanhood because it is defined, particularly in medical discourses, as reproductive, arises.

A few women who said they did not intend to have any more children still did not want to lose their fertility.

> I don't think it would make me feel any differently about myself if they did take my cervix out, or they did a hysterectomy... it's just that I wouldn't be able to have any more children, I don't want that possibility being taken away from me. (Amanda)

Amanda thinks of her decision to have more children as something she possesses. It is something she has control over. Removal of her cervix means that she loses that control.

Reactions to removal of one's cervix in terms of its effect on one's fertility constructs a view of the cervix as a reproductive organ. Its function, and therefore its definition, is in terms of its role in reproduction. Reproduction is part of one's femininity. Judith illustrates this when she describes her cervix and uterus as not 'working' once her periods stopped. This construction of the cervix is consistent with the medical definition of cervices as reproductive organs and useless in women who are not having children.

The impact of the cervix being denoted as a reproductive organ was assessed in different ways. Some women accepted or rejected its removal only in terms of their capacity to have children. Other women believed that removal of their cervix would affect their femininity which they linked with their capacity to reproduce. Both these judgements about the effect of removal of the cervix are related. Both groups of women, like gynaecology, construct cervices as reproductive organs.

In contrast, a couple of women thought of their cervix as like any other part of their body. For Ruth, her cervix was not considered 'special' but was important like any other part of her body. She wanted to maintain her body as complete.

> WHAT ABOUT AN OPERATION FOR HAVING YOUR CERVIX REMOVED?
>
> ...I would feel, not that I am not whole as a woman any more, but just that I'm not complete any more. As if they took my arm away. I would feel the same way, that something is missing. (Ruth)

Gladys was not concerned about removal of her cervix at all.

> Your tonsils are part of you but they're ripped out constantly. They're not part of the reproductive system of your body so people just accept it. I've still got mine. Why because another part of your body has broken down should it be any different than any other section that needs repair and removal? It makes no difference to me. None whatsoever.

Neither Gladys nor Ruth consider their cervix to be special because it is reproductive. Gladys and Ruth have different responses to the removal of any body part, however. Ruth thinks about herself in holistic terms; Gladys uses mechanical metaphors to describe herself. Such views of the cervix were the exception.

Several women spoke about how their cervical abnormality was further evidence for the disordered nature of women's reproductive systems.

> [Talking about the responses of other people she told of her abnormal Pap smear responses]. My mother was the only one who seemed to be worried about it. My girlfriends all seem to have some problems with their reproductive systems. One of them had a hysterectomy; another one is having problems with her periods. Everybody seems to have something wrong down there. (Sally)

Many women considered reproductive disorders, such as cervical abnormalities, to be part of women's lot in life.

> [After telling her sister and her close friends]. They understood, I s'pose it's just part of being female, you sort of find these things... (Mary)

Reproduction, which defines women, is disordered by nature. Like Sally, many women spoke of how their cervical abnormality was indicative of women's reproductive disorders. In some situations reproductive disorder was conceived as one's 'natural' state. Reproductive disorders, such as cervical abnormalities, both threatened one's femininity and caused one to redefine it.

Several women were stigmatised because the condition affected a part of their genitalia and the cervix signified their reproductive capacity.

> DO YOU THINK YOU WOULD HAVE FELT DIFFERENTLY IF IT DIDN'T INVOLVE YOUR GENITALIA?
>
> I wouldn't have felt anywhere near this vile. It is to do with the fact that it is sexually transmitted and it has to do with unclean aspects if you like. ...If I had a melanoma removed, which is

> exactly the same thing supposedly, I could have told everyone that I was having a melanoma taken off. (Amy)

For Amy the condition is stigmatised because of its sexually transmitted origins and because it deals with her 'unclean aspects'. (The stigma of cervical abnormalities as sexually transmitted is developed in Chapter Six.) A melanoma is not related to sexual transmission and is not a condition that involves female genitals. Consequently she does not tell others of her abnormality, but she would tell them if she had a melanoma.

Amy carries the stigmatisation of those aspects that define woman, her reproduction and genitalia, to a logical conclusion.

> There's also the feeling that I think is really deeply ingrained in a woman's psyche, the sense that basically you're unclean.

For Amy, woman is unclean and woman is stigmatised.

Through women's discussion of abnormal smears a view of the cervix as reproductive and woman as reproductive emerged. This construction of the cervix and of woman is drawn from the medical assessment and treatment of cervical abnormalities as well as from other lay and medical discourses. The definitions of the cervix and of women as reproductive shaped women's experience. A disordered cervix impacted on their femininity, and resulted in stigmatisation for some women.

The physical nature of the cervix

Medicine, the privileged knower of bodies, has greatest access to visual interpretations of the cervix. Doctors have visual access (via the speculum) to a part of the body not normally accessed by anyone, except in unusual circumstances, through the medium of touch.

Colposcopy involves magnification of the cervix so that abnormal cells are seen. Cytology and histology entail microscopic examination of the cells of the cervix. Colposcopy and microscopic techniques extend the view beyond the naked eye, dissecting the surfaces of the cervix to render the cells that constitute the cervix visible. Microscopic is understood in terms of the absence of visual access by the naked eye, rather than an absence of texture for example.

> I haven't seen my cervix but I think it's like a dome, pointing downwards, with a hole on top of it. I think I remember that from the plastic model at the Pap smear clinic, or maybe from drawings

> inside the tampon packet. If I had warts, it would probably have blistery things on it. With CIN it would look normal because they said you couldn't see anything. (Adrienne)

Adrienne describes her cervix in terms of how she visually imagines it. She is uncertain of her translation, uncertain of the accuracy of her description in relation to a real cervix — a cervix which is visually constructed. Also, her cervix is depicted by a model of a cervix as like all others.

Women tended to 'know' those parts of their body they could see.

> If you've got a skin cancer you can love it. It's like a baby or a child, if they fall over you rub its knee to make it better. If it's getting worse you can see it. You can't see this. (Lorraine)

Brenda uses her visual interpretation of her cervix, obtained through medicine, to 'know' her cervix.

> I've seen my cervix on photographs [taken at colposcopy], I've also seen my cervix in smear testing, and I've felt it lots of times now. It's a bit odd but I feel like I've made friends with it now because I realise, especially after *seeing* it in the mirror, that it is part of my body that needs to be cared for, so I've actually gone out of my way to find it and feel it with my hand so I know it's there.

Despite knowing her cervix through the medium of touch as well as sight, 'seeing' was the key way Brenda came to recognise her cervix as part of her. In fact, it is the medically acquired visual knowledge which enables Brenda to 'know' her cervix as part of her.

Many women wanted to see their cervix during colposcopy. Seeing her cervix on a video monitor during the colposcopy reshaped Louise's visual knowledge of her cervix.

> Having the monitor helped a lot, because you could see it all. It was just a mass of discoloured cells, you could see it wasn't green and gangrenous. ...Before I visualised it as horror, absolute horror. I imagined it as a big black mass of growth...

In Louise's situation visual (and therefore medical) access to her cervix, was important in forming a more positive image of her cervix. Many women felt that seeing their cervix, or a video of the procedure, would enable a better understanding of their cervical abnormality.

Others did not want to see their cervix. Some felt it would be worse if they did. They would 'really' know how 'bad' their cervical abnormality was.

> I put a lot of trust in the sense that I couldn't see it. I suppose if I could see it, it would be a lot worse, because I would be looking at it. Because it was there and I couldn't see it I probably did not think it was as bad. (Ruth)

Many women found pictures, diagrams and video representations useful. In fact, many women commented that if they could see their own cervix during colposcopy it would enable them to understand their problem better. However, although medically assisted visual access to their cervix enabled women better understanding of their cervical abnormality, such knowledge will always be inferior to medical knowledge — whose gaze is finer and more accurate because it is microscopic. Also, medical knowledge of the cervix holds visual knowing as privileged. Within medical practices and discourses about abnormal smears women's ways of knowing their cervix is inferior. There is no space for definitions of the cervix developed through sensations other than sight. However, Brenda appropriates medically accessed visual knowledge of her cervix, along with her own knowledge acquired through touch, to construct her own cervix.

Discussion

I have shown that the diagnosis of a cervical abnormality resulted in women redefining who they were. Their understanding of who they were shifted as a consequence of the abnormality. In doing this, they drew on their current diagnosis of a cervical abnormality and previous beliefs about the nature wart virus, cancer and female reproductive systems.

Women now considered themselves to be at ongoing risk of cervical cancer and death. This risk was not an abstract risk that existed separately from them. Instead the risk inhabited their bodies. The risk was corporeal. For the epidemiologist, risk is an abstract notion that exists outside of the individual. In contrast to the epidemiologist, individual women experience the risk, used by the epidemiologist to characterise a category of people, as part of themselves. The risk meant that they were neither healthy nor ill. The lack of symptoms further blurred the definition of health and illness. Women moved into a socially ill-defined state of possible future ill health.

The findings relating to risk that are reported in this chapter, are similar to those described by Gifford (1986) who performed indepth interviews with women who had benign breast disease. She found that women with benign

breast disease who attended outpatient hospital clinics, came to 'live' their risk of breast cancer. Like women in this study, this risk was ambiguous and meant they were neither healthy nor ill. (Gifford 1986).

Women's newly experienced appreciation of their risk of cancer caused some women to reflect on their mortality. Women came to have a different awareness of their own vulnerability.

Redefinition of femininity also occurred. Broom (1989) described how 'women are sick, and sickness is feminine' (Broom 1989). p131. This diagnosis meant that women now experienced their cervix as a site of possible derangement. Most women considered reproduction to be defining of women. Cervical abnormalities both characterised femininity, since female reproductive systems are constitutionally disordered, and endangered it.

As shown in Chapter Three many women will have further investigation because of an abnormal Pap smear. Women who receive such a diagnosis might come to experience their risk of cervical cancer in the way I have described. If this occurred most women would come to perceive their cervix as potentially disordered even though few women would develop cervical cancer if they had never had a Pap smear.

If I had conducted interviews with women prior to their diagnosis of an abnormal Pap smear, I could have documented how women's perception of their risk was shaped by their diagnosis and treatment. However, women in this study reported, retrospectively, that their appreciation of their risk had changed since their diagnosis of a cervical abnormality.

In summary, I have shown that cervical abnormalities result in women experiencing their own risk of cervical cancer and death. The diagnosis also caused some women to reshape their notions of their femininity. In the following chapter, I examine how women sought to manage their physical experience of their own risk of cervical cancer.

Chapter Six

Managing risk

WHAT DOES PRECANCER MEAN TO YOU?

> The fact that if I don't look after myself there is every possibility, a very high possibility, of me contracting cancer, through basically not looking after yourself. (Gladys)

Cervical abnormalities, such as precancer, symbolise Gladys' risk of cervical cancer and her responsibility for managing her experienced state of risk. If she developed cancer it would be through her own mismanagement.

This chapter describes how the women sought to manage their recently developed and experienced, state of risk. Control was a crucial concept. Therefore, before turning to the ways they sought to handle their embodied risk of cervical cancer, I discuss how the women employed the concept of control. Then, I discuss how they managed their state of risk by subjecting themselves to their own and medicine's regular surveillance and by identifying ways of modifying their risk through lifestyle changes. Through their explanations for their cervical abnormality this experience became woven into their lives and became part of their life trajectory.

The concept of control

Control was mentioned in relation to treatment decisions, procedures performed and one's risk of cervical cancer.

Women used control to describe actions they could take to modify their risk of cervical cancer.

> I really believe that stress is going to cause a lot of cancer. If I don't learn to control my stress it's probably what I'll end up getting, or a heart attack ...worry myself stupid. Then I'll eat and put on weight and my cholesterol will soar. (Phillipa)

Phillipa uses control to reduce her stress. She is both the subject, the individual exercising control, and the object, the site of the stress that calls for the control she exercises.

The women spoke of exerting control on the disease process or their risk of cervical cancer. Sometimes they spoke of lacking the control to cure or avoid contracting their abnormality.

> [after Anna was told of her abnormal Pap smear] I couldn't achieve much that weekend. I was like a zombie. Not really knowing what is happening ...what is happening to your body, something that you have no control over. You can't see anything, you can't feel anything. (Anna)

Anna does not have control over her body. Her body behaves almost independently of her. For some women, the absence of any action they could take to reduce their risk or foster recovery meant they did not have control .

> Heart attack in our society means cut down on your cholesterol, you can do something about it. Precancerous cells, the whole idea of cancer is much more uncontrollable, much more wriggly. (Leslie)

Leslie speaks of precancer as cancer, which is a disorder that is difficult to control. At another point in the interview she seems to talk about doctors preventing her from having control over the abnormality.

> We put so much faith in doctors because I was motivated by fear, I don't think I had a lot of choice until I overcame that. I was angry with myself at the time that I did go ahead and have these treatments because I knew it wasn't dealing with it the way I wanted to deal with it. I knew that giving up control and saying OK just zap me wasn't the answer for me. In an emotional sense, in a physical sense.
>
> ...people believe wholeheartedly that all they have to do is close their eyes and have this magic performed on them and it is going to be all right. It means that you don't take control of the issue yourself, it means that you are happy to give over responsibility to the doctor. (Leslie)

By having medical treatment Leslie 'gives up' her control over 'it' and she does not 'take control' of the 'issue'. 'It' and 'issue' appear to refer to her cervical abnormality. Later, Leslie chose to have herbal treatment, following which her CIN 3 was no longer present. The success of this treatment meant that Leslie shifted from not having control to having control.

> I think that now I can do something about it, I think that now I have much more control, ...I still feel I have definitely got the potential [to develop an abnormality] but I also know that if I choose I can do something about it. (Leslie)

Leslie now appears to be speaking of actions she can take which enable her to have control over her risks of developing a further abnormality.

Like Leslie, several other women also felt they did not have control over medical treatment.

> I felt totally out of control. That's why I wanted to try herbal medicine and homoeopathy because I was in control. ...It was like: spread your legs, laser treatment, and that's it. No control, no control whatsoever. (Lorraine)

Some women however suggested that only doctors had the capacity to exercise control over women's abnormality and future chances of cancer.

> It's under control now. There is a possibility it will come back but it doesn't worry me. If it does they will treat it again the same way as they did. (Adrienne)

On several occasions the women expressed a desire for more information about how they could alter their lives so that they had more control over their risk of a further abnormality. They spoke of this information exchange as doctors 'giving' them control.

> If they'd just *give* you more control. Even if it's just crap, telling you to eat a couple of lentils everyday. You'd think well at least I am doing something for myself. (Lorraine)

> The doctor never *gave* me any indication as to whether there was something I could do to have any control over getting it or not getting it. (Sharon)

Medical information enabled Heather to feel in control over decisions about treatment.

> I certainly felt under control. Dr X sort of gave me all the information and the decision was up to me. (Heather)

In contrast, although Anna sees the benefits of better medical information, such information does not mean she feels in control.

> ...Perhaps if I had more information about it - you wouldn't feel any more in control but at least you'd understand why you had it. (Anna)

Anna is referring to feeling in control over her risk of cervical cancer rather than treatment for an abnormal smear. She wants information to address the question of why she developed her cervical cancer.

Often exercising control was contingent upon circumstance. Amy describes how she can exercise control only sometimes.

> It makes you acutely aware of the way you live your life, the things that you perceive that you have, that you are in control of -

like how much you eat, and how you can reduce your risks. (Amy)

I didn't feel I was in a capacity to make judgements about treatment. I couldn't see a problem, had no indication other than what the doctors told me about what was going on, and I thought - well, you make decisions, you're the qualified one. Over things that I did have control of, like what contraception I used, I felt pissed off about that ...in the way that he made judgements about that. (Amy)

Amy perceives herself as 'having' control over taking the pill and what she eats; she does not have control over decisions about her treatment. Amy, like Leslie, only speaks of possessing control over something if she perceives herself as having a capacity to act. Thus, Amy speaks of having control over whether she takes the pill. She does not consider herself to have control over treatment. In contrast, Leslie perceives herself to have control over treatment. Her decision to have herbal treatment is construed as exercising choice.

For Amy, 'handing over' control did not preclude 'feeling' in control.

I felt in control in as much as I was totally happy handing over control. [in relation to decisions about medical treatment].

Allowing her doctors to make decisions about her treatment meant that she felt in control.

Information enabled some women to shift into states of feeling in control regarding treatment. In relation to medical treatment and follow-up the women felt differently about their states of control. Many found that treatment and their own actions could change their perception of their control over their risk of cervical cancer.

Surveying risky cervices

Managing one's risk of cervical cancer involved participating in medical surveillance. The women's descriptions of follow-up used visual and disciplinary metaphors of surveillance. Both women and medicine surveyed women's cervices.

Surveillance enabled transformation of the women's perception of their risk.

Even though the laser treatment's no big deal, I'll always be running into doctors' surgeries and getting checked. That worries me a bit. But I can't see that I'll ever develop cancer because I'm so

> vigilant now and if I develop any sort of cancer it will be something else. (Brenda)

Brenda's perception of reduced risk rests upon regular surveillance. However, the vigilance she describes is contingent upon her recognising her risk. Although Brenda perceives the dimension of her risk to be lower, her awareness of her risk is now different from what it was prior to her abnormal smear.

An analogy is relevant to emphasise the point further. Suppose someone is burgled. After such an event, the person increases security to prevent a recurrence. They then consider they may have less risk of a repeat burglary because such security measures reduce their risk. However, the event itself has brought to consciousness the risk of burglary. The person becomes aware of their risk of burglary. The dimension of the risk may be thought of both objectively and subjectively as changed but the quality of the risk is different; it is now part of the person's experience.

Heather describes how her awareness of her risk reduces her chances of cervical cancer.

> I know it is something that I need to keep an eye on but no more than everybody should be doing. Certainly I don't see it as something that is going to hang over my head for the rest of my life. ...Because I am more aware of what can happen and how easily it can be treated I think I probably have less chance [of cervical cancer]. (Heather)

The women are now aware of their risk even though the risk may be perceived as less than prior to the abnormality. The cervix is now always a potentially diseased organ. The risk now has a reality and a presence.

The terms used to describe the follow-up of a cervical abnormality suggest a surveillance of individuals by an institutional authority — medicine. Individual bodies are inspected, checked, watched and looked upon by this institution, and are transformed from an ambiguous state of ill health to an ongoing state of potential ill health.

The women's perception of being at low risk of either recurrence or cancer rested on two, sometimes separate, premises. First, the notion that treatment was effective, and, second, the effectiveness of surveillance.

> I feel that having had the laser treatment, I don't suppose it's a guarantee it won't happen again, but I'll just keep an eye on it, it's not worrying me. (Maeve)
>
> When I went back and had the inspection he said everything looked fine. I do realise that it could come back again but at the moment I feel it's been treated, it's all gone, and I don't have to worry about it for six months. If I ever have it again, I think I'll feel OK about it. I'll just go and have the treatment again. (Judith)
>
> It's under control now. There is a possibility it will come back but it doesn't worry me. If it does, they'll treat it again the same way as they did. I've always had Pap smears, probably not religiously, but from now on I'll make sure I have them every year - if I get over this. (Adrienne)

So far I have used several quotes that draw on visual metaphors to describe follow-up after a cervical abnormality. Maeve and Heather mention that they need to 'keep an eye on it' and Ruth mentions being 'watched'. Maeve and Heather are the 'lookers' and medicine 'looks' in Ruth's case. Both medicine and women survey cervices to prevent cancer.

> I find the fact that they really keep *a close eye* on you very reassuring because you are actually under *closer scrutiny* than a woman who has not had that sort of treatment and so for a year and a half you have really got them pouring down and *looking at you* and nothing can go wrong while that is happening, presumably, so that is really quite reassuring. (Veronica)

Veronica is 'observed' meticulously by medicine, is the object of the medical gaze, which prevents anything going 'wrong'.

Other metaphors used to describe this surveillance were disciplinary.

> I don't feel under *threat* any more, because I know whatever happens to me I am well *checked*. If there is any *threat* of anything coming up it will be found fairly quickly. I don't know how accurate Pap smears are, all I know is that when I have had them something has been found, but whether there is something that happens and it doesn't always get it I don't know. But I've been lucky so far and it hasn't been *allowed* to develop into anything serious. (Louise)

Cancer no longer 'threatens'. (The military metaphors employed to describe cancer have been discussed earlier.) Now one is checked and the condition is not allowed to develop. Again, the condition, which is cast as separate from Louise, is the object of this medical surveillance. Louise too is the object of the surveillance — 'I am well checked'. Judith, above, spoke of her follow-up

visit as an 'inspection'. She too is the object of the medical gaze, which decides whether or not her cervix is diseased.

Effective surveillance rests on care and frequency. The more frequently Pap smears are done, the less risk. All women spoke of how they would have Pap smears regularly because of this experience. Several women thought they would have Pap smears more often than recommended to reduce their risk further.

> ...even though I get Pap smears once a year, I will probably be more inclined to have them twice a year, even though the doctors told me that it is not necessary. The laser clinic doctor and my GP told me that it is not really necessary to do that. But, I probably will get a Pap smear more often. Maybe every eight months or something like that. But I feel the Pap smears are going to be important to keep tabs on it. (Sally)

Again, managing one's risk involves greater medical supervision.

In fact, participating in medical surveillance was cast as morally correct behaviour.

> HOW LONG SINCE YOUR OTHER PAP SMEAR BEFORE YOU HAD THIS ONE?
>
> I can't remember off hand I think it was a couple of years. Before that, I used to be very slack because I didn't really like having them - no-one does. The doctor would practically take me by surprise: right you're having it. But now I will be very *good*. (Peggy)

'Good' meant having Paps. Abiding by medical guidelines was morally correct, as well as necessary, to manage one's risk. This position rests on two assumptions. First, that medicine is an appropriate source regarding norms of correct behaviour in relation to one's health.; and, secondly, that an individual is responsible for their own health. It is argued that the notion of individual responsibility for one's own health is part of contemporary Western culture, because modern-day diseases affect individuals alone rather than the collective suffering of the past (for example, through the plagues) (Herzlich and Pierret 1987). This notion of individual responsibility arises again when I discuss how women 'explained' their cervical abnormality.

Through participating in the surveillance women manage their risk of cervical cancer. They construe the surveillance as exercising control over their risk of cervical cancer. The form of surveillance described by the women is similar to the disciplinary power Michel Foucault described in

prisons, armies, schools and hospitals (Foucault 1979). Both women and medicine contribute to the surveillance of their cervix. And their cervix becomes an organ of potential disorder and danger that requires occasional adjustment.

Why me, why now?

> [after Leslie had a cervical abnormality that recurred despite two treatments] it wasn't like something that I could say I am just not going to deal with it. If I left it [her cervical abnormality] I was in for trouble, probably serious trouble. So I decided I was going to do something different about it and I was going to deal with it. ...My friend was going to see a herbalist and she said why don't you go and see her. I was in the middle of my degree and I postponed that. I just started approaching life differently. ...stopped taking some drugs, stopped smoking cigarettes. I started eating better, I started meditating twice a day, doing yoga, Tai Chi every morning. ...really combining things together and not living on adrenalin. ...I guess I knew it was something that I had to do regardless of the abnormal cells.
>
> Because I started studying again I have really let things slide. Just before you arrived I was seeing a friend of mine who helped me through ...I haven't seen the herbalist for a long time and I actually should be having more treatments. Once I am doing my academic work I become focussed and it is really bad because I just let these things slide...I have not gone far enough in working myself out, doing these things, I have let things slide and I would not be surprised if I get it again...it is just like a warning sign - I am not looking after you, I will come back and get you. (Leslie)

After two recurrences of her abnormality, following diathermy and laser treatment, Leslie's cervical abnormality becomes significant. It becomes a symbol of her need to take control of her life. If she does not take control then she faces the consequences of cervical cancer and death. She makes dramatic changes to her life. Her cervical abnormality disappeared after her herbal treatment. However, the abnormality remains a symbol of her belief that she can control her own health. She is responsible for her own health. At the time of interview, Leslie believed that she had let her lifestyle 'slide'. Because of this she perceived herself to be vulnerable, as likely to have another cervical abnormality. Her risk of cervical cancer is cast as a being, she speaks of it as 'I', that is observing her and ready to 'get' her should she become irresponsible about her own health.

In this section I discuss how women sought to make sense of this abnormality. Some women, like Leslie and Gladys (quoted at the beginning

of the chapter), conceived their abnormality as signifying their need to take control of their own health. These women invoked explanations that firmly located this abnormality in the life narratives. The abnormality became part of their lives and shaped them as individuals who were in control of their life circumstances. In doing so, these women identified ways they could change their lives. Their narratives about their cervical abnormality became linked to their narratives about control. Other women saw this as a minor event. Their ways of understanding their abnormality did not offer them such capacity for life changes and tended not to be linked to narratives about control.

Explanations were invoked retrospectively because the women had no knowledge of their abnormality prior to its diagnosis. Their explanations were multifactorial and complex and drew on both scientific medicine and popular medical culture. To explore how the women made sense of their abnormality I used the approaches of interpretative medical anthropology outlined in Chapter Four. I am interested both in the structure of the women's accounts and in the meanings they ascribe to the development of their abnormality.

The women's explanations can be condensed under seven overlapping headings: stress, lifestyle factors, personal experiences, outside influences, sexual transmission, individual susceptibility, and luck or fate. Most women used explanations from several categories.

Stress

Some women considered their abnormality using narratives of stress. The notion of stress was used in a variety of ways. Most commonly, stress connected unpleasant experiences or events in a woman's life with her cervical abnormality.

> I think it is probably significant that I got this, at this time, in fact even a friend had suggested this to me, because I was married and it was a very, very bad marriage and it was just very, very stressful for me and I think that is why it happened then. (Brenda)

For Brenda, her stress narrative enables her to make sense of why she developed a cervical abnormality at this time in her life. The stress idiom located women's abnormality in their life context. Women used stress to link their inner and outer worlds and connected events that otherwise seem unrelated.

Stress was a polysemic concept. Stress was an action, an entity, and a state of being. That is, stress acted upon the body, stress described a situation or an event, and stress was something that one experienced or felt (sometimes described as an illness or personality state). Often stress had multiple meanings in the one interchange.

> Well I explained it to myself that I was under a lot of stress [stress as action]. And that it was probably just a reaction to stress and yeah that's where I kick myself now, I think I wish I trusted my own body. And my own intuition don't get it fixed up, just go along and maybe I smoke, so I thought maybe cut down on smoking, look at my diet a little bit more and take away some of the stresses [stress as entity]. And don't just take them away but reduce them. I had moved house and all those things were stressing me out [stress as state of being] but they were going to and you know they had peaked. And they were going to go back down anyway. So that naturally I tend to think the body would have just calmed itself down and healed in the way it needed to heal. (Sarah)

In this quote stress has many meanings. Stress acts on Sarah so that she becomes sick. Stress is also an entity. Moving house is an example of stress as entity. Stress as an entity could also reside within an individual. That is, an individual could have or take away stress. Sarah herself is 'stressed out'. Stress describes how she feels and experiences herself. The notion of stress enables her to link her abnormality with other life experiences. Stressful events or experiences cause her to experience a state of being stressed. In fact, this stressful state of being requires healing itself. It is not a healthy state. Through the concept of stress Sarah's cervical abnormality becomes part of her life story.

This unhealthy state of being 'stressed' meant one was more vulnerable to diseases such as cancer or diseases that signified one's risk of cancer (cervical abnormalities).

> ...there's also the idea that cancer strikes at times of stress. That worries me a bit - that if I am run down, then I might face this condition repeatedly. (Brenda)

Events and experiences are defined retrospectively as stressful because women have no symptoms of their abnormality prior to the diagnosis. The concept of stress was used to make sense of the abnormality if women identified the time preceding the diagnosis as 'stressful'. Brenda attributed her first abnormality to stress. When her abnormality recurred the stress explanation was not consistent with her experience.

> I can't fathom why it happened again in May last year because I certainly hadn't experienced the same stress levels as I had the first time. (Brenda)

For Brenda, stress was only a credible reason for her abnormality if external events or experience were identified as stressful.

Phillipa did not remember feeling stressed, but particular events in her life were identified as stressful. She associated her abnormality with stress.

> It was later on the lady was telling me about a study relating to stress that she'd done on a course [a discussion with a nurse in the clinic] I pieced together the last eight months ...You think you're not stressed, but when you're working full time and you've got four kids and you're travelling 100ks a day and you've got them on you're own...Peter [her husband] was over here [Canberra] and I was in X [a country town]. I'd leave home at ten to eight in the morning and get home at 5, 6, 7 whatever, and had all the kids on my own... And for six months that's what I did and then I resigned and I stewed about that - what am I going to do unemployed, that's all I can do, I don't have any skills - and you go through all that trauma and then there's selling our house and then two moves in a month... Moves are horrendous. Apparently on the stress list moves are up near the top... (Phillipa)

Stress described Carmel's nature.

> ...I am a stressed out sort of person. Although I try not to be, I try to be calm most of the time and I try not to let things worry me, but yes I do get stressed. (Carmel)

Stress narratives enabled women to feel in control of their own risk of cervical cancer. This was done in two ways: by changing exposure to stressful events and, secondly, by modifying one's response to those events so that they did not feel 'stressed'.

> I have to go for a walk. At least that gets stresses out. That's the way I relieve my stress. (Carmel)

> I think, don't get too stressed about things, that is something that I have changed. I am determined not to get too bothered about things because, I think, in the long run it doesn't help my body. (Ruth)

Carmel and Ruth speak of modifying their own experience of feeling stressed. Ruth relates how her state of being stressed affects her body. Her body is conceived as separate from her. Her state of being stressed acts on her body. Earlier Sarah spoke of reducing or taking away stresses. When Leslie developed a second cervical abnormality, she changed aspects of her life. She deferred her university course, had counselling with a friend and

took up Tai Chi. Thus, through their stress narratives these women located their cervical abnormality in their own lives and identified ways in which they could control their risk of cervical cancer.

Some women who used the stress explanation experienced the treatment as inappropriate. The treatment failed to address the underlying problem. Leslie describes the dissonance between her stress explanation and medical treatment.

> I am not saying that it is a total physical manifestation of an emotional crisis but I think there was some connection and maybe that is why I found the treatment I was getting was wrong because it was isolating that and saying OK here is your cervix, here is the problem, zap it off, it wasn't saying what is wrong with the total person (Leslie).

In Leslie's case, a fragmented part of the unwell body is treated and the cause of her condition is left unaddressed. Treatment failed to address the root of her problem. Narratives of stress integrated the women's abnormalities into their everyday lives. Medical treatment dealt only with a small part of their body as if it was separate from the rest of their body and life. Earlier Leslie described how submitting to medical treatment meant she 'gave up control' to medicine. Her herbal treatment, on the other hand, together with other life changes that she makes, moves her perception from 'giving up' to 'having' control over her risk of cervical cancer.

Stress is a culturally specific concept. Popular usage of the concept occurred in Western societies following the second world war (Pollock 1988). The notion of stress, however, is not unique to lay explanations of disease and illness. It is part of both modern popular culture and biomedicine. While its origins are in the natural sciences — first recognised in physics and later biology through animal laboratory experiments — it now has wide acceptance in the medical and social science literature. Selye (1956) first described stress, a term he coined from the physical sciences, to explain the physiological responses of animals to stimulation. Social science explored the concept of stress further. Life event scales, such as the schedule of recent experience used in epidemiological research (Rahe 1974), are examples of social science's application of the stress concept. Events and changes in the subject's life are given a numerical value. Adding the scores provides an index of 'stress' in the subject's life. At a population level high scores have been linked with the onset of disease and illness. In this application, stress is constructed as something that is universal and that exists separately from an

individual. The meanings that individuals attribute to events are ignored. In social science literature, events and experiences cause an individual to develop disease because they become emotionally aroused. An individual's response to stress is dependent on their intrapsychic ability to deal with external stressors.

Stress is integral to the biomedical concept of psychosomatic diseases. Irritable bowel syndrome is an example (Drossman, Powell et al. 1977). The relapsing course of chronic diseases such as diabetes have been linked to stress (Stein and Charles 1971). Several authors suggest that biomedicine and empiricist social science locate the pathology in the individual (Young 1980; Pollock 1988). In doing so, responsibility for the illness is shifted to the individual or their environment, away from biomedicine (Helman 1985). Young (1980) maintains that stress discourses reinforce and legitimise the social order. The pathos of society is objectified and located within the individual (Young 1980). Pollock (1988) maintains that stress discourses position responsibility simultaneously within an individual and society. Stress discourses encapsulate beliefs about the deleterious effects of modern society on individual health.

Narratives of stress tend to be invoked, both by physician and patients, in the context of diseases that are characterised by ambiguity in biomedical understanding and treatment. Responsibility for this illness, both for its cause and treatment, is shifted away from medicine. Although cervical abnormalities are characterised by ambiguity, treatment strategies for abnormalities are well established. Several studies have examined the relationship between life stressors, an individual's coping style, and the progression of CIN (Goodkin, Antoni et al. 1988; Antoni and Goodkin 1989; Goodkin, Antoni et al. 1993). In these studies the stressors are conceived as events, entities that exist outside the individual, devoid of the meanings an individual may attribute them. Individuals' coping styles moderate the effect of these stressors on their biology.

Some physicians agreed with (or did not dispute) the women's assessment of their cervical abnormality as stress related. However, medical consultations regarding cervical abnormalities did not usually include questions about stress or advice about reducing it. Consultations for conditions which are accepted as psychosomatic, illnesses with less clear medical treatments, routinely include inquiries about stress.

The women were aware of the popular literature on stress, mentioning stress scales and life events. Popularisation of social science research was taken as further evidence for the use of stress as a way of understanding their abnormality. Exposure to the popular literature enabled this view. However, women used the concept of stress in a different way from both social science and clinical medicine.

Doctors use stress to describe an individual's response to external stressors that have universal meaning defined by medical and social science discourses. When clinicians employ the concept of stress the individual is the pathological unit. The context in which stress manifests in individuals is ignored. In contrast, the women in this study group used stress to problematise their own life circumstances. Their stress narratives were linked to narratives of control. This diagnosis signified their lack of control over their own health. By deploying the stress idiom the arbitrariness of their cervical abnormality was reduced. Instead, their cervical abnormality become part of their narrative about who they were. They were constituted as having control over their own life circumstances.

Lifestyle factors

Another popular explanation related the women's cervical abnormalities to aspects of their lifestyle such as diet, smoking, exercise and medications, particularly the oral contraceptive pill. Like stress, these ways of understanding their abnormality firmly positioned this event in the context of women's everyday lives.

Diet was commonly mentioned.

> You wonder sometimes whether you've got it because of something to do with your diet. There could be all sorts of complications, all sorts of things that come into it. (Valerie)

Several women associated their abnormality with the oral contraceptive pill. Although these explanations were developed from scientific research, clinicians tended to reject the pill as a possible source of women's cervical abnormalities. Amy believed that the oral contraceptive pill was related to her cervical abnormality.

> ...he went on with all this stuff about how there was no firm evidence to suggest a relationship between the contraceptive pill and ovarian cancer - and I said that the incidence of ovarian cancer is a lot less than the incidence of cervical cancer. Because I've had

> two abnormal smears I was quite concerned about the risk of cervical cancer. He just said he really didn't think there was any risk and I just thought it's all very well it's not your cervix and it's not your life. Anyway, in some ways out of the pressure I felt from him - he gave me a script for the pill and he said "if you feel like it take it", and I thought "what drug company are you working for?" So I ended up going on the pill and I wasn't really happy about it, but in some ways it was the convenience of it and not having to worry about ovulating. ...I had thrush for three months and stomach pains and everything else. In all the books I read, it said the contraceptive pill can be associated...it will make the candida worse, and that was the excuse to give it the flick. (Amy)

For Amy, the pill remained an important means of making sense of her abnormality, despite her doctor's refutation of the pill's relationship to her abnormality. Another scientific theory about the pill's association to candida eventually provided impetus for her to discontinue it. Several women discontinued the pill as a consequence of their cervical abnormality. Only one woman, Julie, accepted her doctor's rejection of the pill's association with her abnormality.

Maeve linked her cervical abnormality to a change in her medication. Her doctor disagrees with her.

> I blamed medication to myself ...When I changed over, I can't remember the name of the stuff I changed to, but what I was taking became quite expensive and the doctor said that he could give me a substitute that is not quite so expensive. So I changed to that. I always felt that was the reason and he said it wasn't that; he didn't explain it or wipe my worry away. I really thought that it was the change [in medication] that caused this cell change, but he said it wasn't. (Maeve)

Maeve's thoughts about the relationship between her medication change and her abnormality persists, notwithstanding her doctor's disagreement with her.

Some of the women changed aspects of their lives in light of their cervical abnormality. In a similar way to the stress, thinking of the abnormality in terms of lifestyle grounded the abnormality in the women's daily existence and enabled them to make changes in their life that would prevent recurrence, assist healing and maintain their general health. Narratives about lifestyle factors construed women as having control over their own health.

Environmental influences

A few women connected their abnormality with the unhealthiness of modern society.

> ...my sister [who also had a cervical abnormality] was very unhealthy. She was underweight, did not look after herself and did not eat regularly. That has got to have something to do with it. She is more likely to get it than me. I remember when I got it I was thinking ..."I am fairly robust. I think I am fairly healthy, so why did I get it?" I thought people like my sister are more likely to get it than me. Whenever I see programs on television about people that live near power stations and dumps I always think they are more likely to get cancer than other people. I am very aware of this with where we live, with pollution and I'm more conscious about spraying aerosols. I think it is all connected. Before I had it, I looked at myself and thought I looked fairly healthy, I don't think I am going to get it. (Ruth)

This quote demonstrates how Ruth's model for understanding cervical abnormalities shifted after she had a cervical abnormality. Initially she believed that only 'unhealthy' people developed abnormalities. In this model individuals are in control of their own health. When she develops an abnormality, her experience is not reconcilable with her previous construction. The model is reworked. Now she believes that cervical abnormalities, and other cancers, are a consequence of various environmental factors. In recent years these environmental factors have become part of both scientific and popular models of illness. Her cervical abnormality signifies the dangerous nature of contemporary society.

Life events

A few women related their abnormal smear to past experiences such as a rape, abortion and an episode of depression and self-hatred. Each of these explanations had different implications.

> Well it brought up all the horrible memories of 1983 because I had an abortion then. I thought - "does this mean I can't have children now?" ...I'm getting paid back for what I did then. (Anna)

For Anna the abnormal smear was a 'punishment' for her abortion. The notion of disease as a punishment for one's sins is still a common theme in contemporary Western culture (Herzlich and Pierret 1987). In Anna's case, although the abortion contextualises her cervical abnormality in her life

narrative, she is personally responsible, and her model does not offer her any way of changing her risk.

Mary related her cervical abnormality to a rape some years earlier. She connected both unfavourable events. In both instances she was a victim. She had no responsibility for her cervical abnormality.

Lorraine related her abnormal Pap smear to a period in her life which she described as 'self-destructive'. At the time she was depressed and she separated from her husband.

> I was on self-destruct. Therefore I probably wished it upon myself.
>
> I think I probably created it for myself. I was just so bad. I am sure that I will never ever get it again.

At the time of interview her life was much better.

> ...emotionally I feel so good that nothing can get me now.

Lorraine's narrative is similar to the stress narratives described earlier. In this model she is responsible for her own health. Her cervical abnormality is a symbol of her 'self-destructive' phase. She is clearly in control of her life. She construes herself as being able to destroy herself.

Although all these women related their cervical abnormality to episodes or events in their life, each narrative constructs a different relationship between the woman and her life world. For Anna, her cervical abnormality is a retribution for past sins; Mary is constructed as having little control over her life; and, Lorraine as responsible and in control of her own health.

Sexual transmission

Explanations involving the sexually transmitted nature of the condition were drawn from scientific research. This was the dominant cultural model of cervical abnormalities and cervical cancer. Most women talked about the sexually transmitted nature of cervical abnormalities. The rarity of cervical cancer among nuns was commonly mentioned. The misquoted studies on nuns and cervical cancer were widely accepted as true. This cultural model imbued cervical abnormalities with significance. Few women accepted sexual transmission as an explanation of their abnormality. Instead, they reworked their previous model and developed ways of making sense of their abnormality that was consonant with their own life circumstances and world view.

The following section begins with a discussion of the cultural meanings of cervical abnormalities. It is followed by a description of how the women modified the dominant popular and scientific explanatory models for cervical abnormalities. Later, I discuss how the prevailing cultural representation of cervical abnormalities as sexually transmitted affected women.

Cultural models for cervical abnormalities

> I read something that said it [wart virus infection] is typified by these great warts and that it is passed on by sexual intercourse. I thought how can it be? I've been really fastidious. I've only had one partner. I've followed all the rules.
>
> ...papilloma virus, I thought, how did I get that? I've been with one partner for nearly 20 years. When I went to the gynaecologist he asked me when I started having sexual relations. I said I was very *good* I was about 18... (Phillipa)

For Phillipa the acceptable form of female sexual expression is heterosexual monogamy. Phillipa describes how the most highly valued form of female sexuality involves sex at an appropriate age and level of commitment. Rules imply a generally agreed rather than an individual standard. Many of the women referred to sex too young or with too many partners. Implicit in these statements is a normative standard. Norms of female sexual behaviour were defined according to how often women had coitus and with whom. In addition, rules imply a code originating outside of oneself. Phillipa refers to cultural norms. The norms are constructed from scientific and moral discourses on cervical abnormalities and other discourses on female sexuality, and are perceived as almost naturally occurring. Obeying culturally accepted 'rules' prevents disease.

The women I interviewed, like Phillipa, referred to acceptable and unacceptable forms of female sexual practice. Central to this reflection is the assumption, common in Western culture, that disease is a punishment for one's sins. Transgression of sexual norms entails punishment in the form of disease or illness. Sometimes acceptable behaviours or norms were expressed explicitly but they were often unstated or implicit.

> As far as I know I'm hygienic. Except for the abortion there is nothing else I thought that could have been behind it. You associate these things with people who sleep around a lot - dirty habits. I didn't think it would happen to me. (Anna)

'You' implies everyone thinks of cervical abnormalities as sexually transmitted; that only women who have many sexual partners are likely to

have a sexually transmitted disease; and, that such behaviour is stigmatised — 'dirty'.

Sexual transmission as an explanation

> ...this girlfriend [who had a cervical abnormality] ...I said "was she promiscuous?" That was my first reaction. She said no, she had just had a boyfriend for a couple of years. I know the doctor said that normally it was with promiscuity that you got this sort of thing, but then he said you know nuns have had it, little old ladies or whatever. I tend to go along with that; but at first it's the embarrassment. (Valerie)

Valerie describes how her initial reaction to a friend having a cervical abnormality is to question her sexual practices. When she develops a cervical abnormality, she uses evidence from her doctor that nuns and 'little old ladies' also develop cervical abnormalities. This is taken as indicating that sexual practices are not always relevant. Valerie's initial way of thinking about cervical abnormalities was refashioned when she was diagnosed as having a cervical abnormality.

In most instances, the construction of cervical abnormalities as sexually transmitted did not provide an acceptable framework for women to make sense of their abnormality. In contrast, Woodward (1993) found the diagnosis of chronic fatigue syndrome provided sufferers with a coherent framework within which to make sense of their experience of their illness. The diagnosis of chronic fatigue syndrome enabled them to define the meanings of their illness and arrested deterioration in some cases. (Woodward 1993). The experience of people who have chronic fatigue syndrome and women who have cervical abnormalities is very different, however. Those with chronic fatigue syndrome experience symptoms that are concerning and baffling. The diagnosis provides an illness category to describe and synthesise their experience. However, women who have cervical abnormality are asymptomatic. The diagnosis is made almost irrespective of their experience. The cultural framework provided by the diagnosis of a cervical abnormality defines an individual as having sinned and results in stigma.

Some women spoke of how they initially believed that their abnormality was sexually transmitted but then rejected the explanation and its implications. Doctors' opinions were mentioned as justification for this change. Women were eager to accept medical statements about evidence that the wart virus

was not sexually transmitted in all cases. Doctors were particularly important in reshaping the sexual transmission hypothesis.

> I went to family planning, they explained that it was wart virus. So, then my first thought was, "you caught it off someone". Sexually transmitted yeah. And they sort of explained to me that not necessarily, 'cos I've only had two sexual partners. Then when I went to Dr X [her gynaecologist] and he explained that it could be in your body since you were born. And just sort of come out... (Penny)

Frequently, the women spoke of how they believed they were born with the wart virus or they acquired it non-sexually. They did not bear personal responsibility if they did not acquire the condition sexually. Some women, like Penny, who acknowledged the sexual transmission hypothesis and reframed it, spoke of the moral implications of such an explanation.

The women used the sexual transmission hypothesis to reflect on their own, their partners' and other people's sexual behaviour and, in so doing, invoked or rejected sexual transmission in their instance. For example, Valerie felt she caught wart virus because her husband had an affair some years ago.

> I have this deep down feeling that maybe women wouldn't get these things if men were faithful. ...so I am one hundred percent convinced that and there's never been anything said about this in the papers or whatever ...well I know three or four women who started getting vaginal infections when their husbands started playing up.

Reflecting on her own experience, Valerie concluded that conditions affecting female genitalia signified men's disruption of the moral order. Similarly, Brenda thinks she caught her condition from her ex-husband whose first wife also had a cervical abnormality. In light of her experience Brenda concludes that men cause many women's health problems.

> WHAT HAS BEEN THE EFFECT OF THIS EXPERIENCE ON THE REST OF YOUR LIFE?
>
> Well, I feel, and this may be an unfounded way to think or feel, I feel that women are particularly susceptible to illness and that male and female health are intrinsically linked. I know some babies are born with wart virus but I guess that makes a lie about what I am saying. But to me it reinforces the opinion that we must actually protect ourselves and I guess that's the affect it has had on me and I perceive men as being the cause of many problems, physically, and I'm sure a lot of people think that's unfair... We always seem to be having to protect ourselves. That's how I feel - that I actually have to be more careful of myself - more careful than I ever have. (Brenda)

Brenda casts women as liable to develop illness because of men's transgressions. For Brenda, the female body bears the marks of men's disruption of the moral order and it is women's responsibility to protect themselves from men. In Brenda's narrative women are cast as victims, but they are also conceived as personally responsible and able to protect themselves. Judith held her husband responsible for her abnormality. She believes that if she has her warts treated and they return later then she would 'prove' that her husband had infected her.

> The doctor told me that there was a good chance (80 per cent) that I had it from John, and because nuns got it so it definitely wasn't a 100 per cent chance, but because of that I was reluctant to have sex. ...I just thought that if I had them already, and if I got them from him, there would be a chance that I would get more. I'm going in and having them off, and then if they came back later then maybe that would be proof that they came from him. (Judith)

The women who resorted to the sexual transmission theory and suggested that their partner infected them were not held responsible for having their cervical abnormality. Instead, they were the victim of their partner's offence. Only a couple of women concluded that they were responsible for acquiring their condition sexually.

A few women, who thought their condition was linked to their own or their partner's previous sexual practices, avoided sex with their partners.

> It affected the whole thing [any form of sexual expression] but sexual intercourse was probably the hardest because I felt it was like it was going to be stirring up the cervix. I didn't feel sexual for months - I just didn't give a damn about it. (Amy)

Rosemary, who thought she was going to die of cervical cancer, feared sex because it could result in a recurrence of her abnormality.

> Me and my fiance just recently broke up because I just don't [want a sexual relationship]. It is something that I don't miss, having sex ...now because it frightens me.

Amy and Rosemary related their abnormality to sex. The abnormality also signified their own vulnerability to cancer and death. Sex was now considered dangerous. Their cervical abnormality symbolised the dangers of sex.

Many of the women described themselves as less sexual after treatment. They avoided sex because they felt invaded, sensitive, it was painful, or they wanted to prevent a recurrence. Women who avoided sex often felt guilty

because their partners' needs were not satisfied. Gladys maintained 'you should not change your sexual practices' (despite her feeling dirty) because 'you shouldn't buck the system'. She considered the system to be a generally agreed upon, perhaps even naturally occurring code which requires a woman to be sexual in accordance with male sexual needs.

Heather had a lot of pain with sex. She linked the pain to her vulval and cervical wart virus infection. She had recently married and has had pain with sex from very early in her current relationship. As a consequence she avoids sex.

> ...it does tend to knock your self confidence around and you think: I'm not much good for this and I can't do that - so you knock yourself unnecessarily because it doesn't make you any less a lovable person. But you feel a less useful person.

Part of her role as a wife is to have sex with her husband. She is unable to fulfil this role and is therefore less useful. Heather prevents recurrence and avoids pain by refraining from sex yet this action contravenes other codes of female sexual behaviour which require a wife to be sexually available to her husband.

The women experienced conflicts between two discourses. Popular and scientific discourses about cervical abnormality implicated women's sexual practices in its genesis. Women were cast as responsible for their own health. They were required to protect themselves from sexually transmitted diseases like their cervical abnormality. On the other hand, women were required to be sexual for men. For some women, both sex and no sex were perceived as problematic. Often, nothing was sanctioned. Female sexuality was aberrant. There was no unequivocally appropriate form of female sexual behaviour. Discourses about cervical abnormalities construct a view of female sexual behaviour as abnormal and dangerous, yet sexual norms derived from other discourses about female sexuality often require a woman to be sexual for men.

In summary, although most of the women spoke of sexual transmission as being related to cervical abnormality, most did not accept sexual transmission as a way of understanding their cervical abnormality. A few women suggested that the condition might be sexually transmitted but held their current or previous partners responsible for infecting them. Only a couple of women considered their own sexual behaviour to be associated with their abnormality. Some women who thought their abnormality may

have been related to sexual transmission changed their sexual practices. This enabled them take charge of their risk of cervical cancer.

Stigma

As a consequence of the principal popular and scientific explanatory models of cervical abnormalities, and the meanings they created, women experienced stigma.

> The way I explain it is it [the abnormal smear] seemed to confirm at a very deep-seated level, the fact that I was very bad and that if I hadn't been bad then I wouldn't have been punished. No matter how much you go through that...it sort of filters up to the surface. It's a combination of, you know "only sluts get this", or "if you hadn't had so many partners...who gave it to you, you don't even know who you got it off - and you know, if you'd been good this wouldn't have happened to you. (Amy)

By linking the presence of disease with punishment, Amy construes that her condition retrospectively defines one's sexual behaviour as outside of a moral order. Sexual immorality is stigmatised. When describing her transgression of this moral order, Amy uses 'you' instead of 'I', which distances her both from the sexual behaviour and the moral code, as though the code is imposed from outside. Women frequently used 'you' as a personal pronoun instead of 'I', and as a consequence distance themselves from their own experience. 'You' also generalises their experience. Any woman in their position would feel the same because this condition is stigmatised.

> [Discussion of an eye problem proceeds this comment]. At least when your eye's deteriorating or degenerating you're still a clean woman. That just happened. But there's just this horrible dirtiness feeling you get at the GP, that sexually transmitted cervical cancer is dirty. Do you know what I mean? It is like they put their gloves on. It is awful. ...you feel dirty. You feel like you have done something naughty. (Lorraine)

Lorraine refers to feeling dirty because of the disease and to feeling 'naughty' because of her implied sexual behaviour. In contrast, the eye problem is clean and the person is not responsible ('It just happened').

I asked women how having a cervical abnormality might compare with herpes or gonorrhoea. Women's responses to this question gave further insight into what stigmatises the disease and/or associated sexual behavioural risk factors. For example, do women who do not invoke the sexual transmission hypothesis avoid feeling stigmatised? In the case of

AIDS, some people with AIDS are portrayed as 'innocent victims' (such as Holly, a haemophiliac who died of AIDS). In contrast, others, who are by implication drug users or homosexuals, are guilty and responsible. (Lupton 1992). In this situation, one's behaviour (rather than the disease alone) stigmatises.

Phillipa, who felted 'tainted' because of the sexually transmitted nature of HPV infection, thought having gonorrhoea or herpes would be better than a cervical abnormality because they are treatable.

> The deciding factor is that there is no cure for papilloma virus, whereas from what I understand for gonorrhoea, I don't know herpes much, there are cures. ...Perhaps I wouldn't feel so bad if I knew there was a cure or a magic pill you could pop, or a needle or whatever, that could wipe this from your body. I think I could cope with gonorrhoea and syphilis, you think you've got this terrible thing, but when you look at it and take a course of whatever you have to take, and then you're fine and it's totally forgotten. (Phillipa)

For Phillipa, without a physical manifestation of the sexually transmitted disease, there is no stigma. At another point in the interview Phillipa described how she did not feel tainted after treatment because she had been cured of the abnormality. However, she was concerned by the propensity of HPV to recur.

Sharon freely discussed partners who, in retrospect, she thought might have given her wart virus infection. She readily contemplated sexual transmission. However, she was delighted to hear that it was not always sexually transmitted because it did not carry the same stigma.

> It was nice to know that it isn't (always) sexually transmitted in that it sort of doesn't have the stigma that VD or even herpes seems to have.

She considered that her abnormality was likely to have been a result of sexual transmission. She also understood that sexually transmitted diseases (STDs) carried stigma. She did not refer to feeling stigmatised herself, because this condition was not 'always' sexually transmitted, although it was likely to have been so in her case. Although she linked sexual transmission with stigma, she did not believe that the community considered HPV or CIN to be sexually transmitted and therefore these conditions did not carry stigma for her. Her cervical abnormality had neither the status of an STD, nor the stigma attached to it.

Sharon and Phillipa associate the presence of a sexually transmitted condition with stigma. However, they interpret it differently. Phillipa believes that cervical abnormalities carry community-wide stigma. Sharon, in contrast, believes that her condition is not generally considered to be an STD. As a consequence Sharon talks about her abnormality readily while Phillipa is secretive about hers.

Brenda spoke freely about the relationship between her sexual behaviour and her cervical abnormality. She linked her abnormality to her ex-husband whose first wife had the same problem.

> I'm beyond the idea of being tainted. It's a specific idea that we're given, I won't apply it to myself or to anyone else for that matter. (Brenda)

Although Brenda accepts the sexual transmission as a possible explanation for abnormality she rejects the cultural meanings of such an explanation. In doing so, she avoids feeling stigmatised. Brenda demonstrates discursive resistance to the dominant cultural meanings for cervical abnormalities. She was the only woman who tried to redefine the cultural meanings of sexually transmitted diseases. All other women worked within the cultural framework for STDs. They might have considered that their cervical abnormality was not sexually transmitted. However, the notion that STDs were stigmatised was never reframed.

Kleinman says this of cultural meanings:

> Cultural meanings mark the sick person, stamping him or her with significance often unwanted and neither easily warded off nor coped with. The mark may be either stigma or social death. (Kleinman 1988). p26

He suggests that the effect these meanings have for an individual depends on their 'place in the local cultural system'. Some people may be able to rework or resist the cultural meanings. For many women, the stigma associated with having a cervical abnormality meant they felt differently about themselves and were often reluctant to tell others about their abnormality.

Individual susceptibility

A few women thought they had an inherent susceptibility, constitutional or acquired, to developing a cervical abnormality.

Adrienne believed her abnormality resulted because she was more susceptible due to another illness.

> I thought it was because I'd got chronic fatigue syndrome. The doctor said when that starts, you're liable to pick up anything because you have no immunity.
>
> I think I was convinced that I wasn't going to live. I just thought this is it. Because I had come down with everything else it was just a matter of time before something was going to come and get me.

In Adrienne's account she is conceived as susceptible and unable to prevent cancer.

Several women thought they had a tendency towards warts, illustrated by a history of warts on their hands. This belief persisted despite their doctors' disagreement.

> I thought back to my early twenties and I did have a couple of warts on my thumb and somewhere else on my hand. It is possible that it's one and the same. The doctor says it's not, that it's a different strain. I can't help thinking that if you're susceptible to that sort of thing, it could be in you and you wouldn't even know about it - even if it is a different strain. I know a couple of people, and any time they get a nasty cold in the head they get a cold sore. I've never had one in my life, and I don't expect to, but some people have something there and they can't get rid of it, and it keeps coming back. (Valerie)

Except when used in combination with other concepts such as stress and lifestyle factors, explanations from this category did not offer actions that women could take to change the course of their abnormality.

Bad luck or fate

Some women felt there was no specific explanation for their having had an abnormality. It was just fate or bad luck.

> Having an abnormal Pap smear is nothing. You don't feel that anything you are doing is causing the problem. (Julie)

The feature that appeared to typify the experience of most of the women who had no specific explanation for their cervical abnormality was the low profile

their abnormality took in their lives. For example, Julie considered her cervical abnormality to be fairly minor in comparison to her inflammatory bowel disease, which was causing her ongoing problems. These women did not perceive their condition to be life-threatening and did not experience the same degree of vulnerability as many other women in the study. They were confident that future Pap smears would detect any further abnormalities and that gynaecological treatment was effective.

> ...it was just one of those things that happened. When you look at the statistics on how many women come out with this sort of thing or breast cancer I think it was pretty lucky it wasn't anything more serious...
>
> At this stage it is not life threatening and so you do have to be realistic about it and just understand what it is.
>
> WHAT IS THE MOST IMPORTANT ISSUE THAT HAS COME OUT OF THIS EXPERIENCE FOR YOU?
>
> In general, I am well open to anything, we are not an island, we are susceptible to anything, to be able to understand that we are only human and that these things are around in our society and what lies ahead for people. The medicine that we have available is there to help us and that we need to trust it. (Louise)

Louise construes her cervical abnormality as denoting the nature of the human condition. Individuals are susceptible to any disease or illness and one cannot protect oneself from such conditions. Prior to her abnormality Louise did not consider herself at risk of cervical cancer because she had only had one sexual partner in her life. Prior to her abnormal Pap smear, then, Louise linked sexual activity with cervical cancer. When she developed a cervical abnormality, however, and her experience was not consistent with her previous model, she shifted to thinking in terms of fate. Although Louise's quote illustrates that she has a new appreciation of her own vulnerability (she speaks of being susceptible), she viewed medicine as capable of managing her abnormality. She trusts her doctors and seems able to live with the uncertainty of her newly defined risk.

Another characteristic of women in this group is that they rarely spoke of control. On the two occasions they mentioned control, it referred to knowledge about treatment and experience of the examination. They never spoke of control in relation to the disease, their risk of cancer, or their own health.

Summary

In this section I have shown that the women's explanations for their abnormality were embedded within networks of personal and cultural meanings.

For many of the women the abnormality signified how they could — and should — have control over their risk of cervical cancer. Narratives about stress and lifestyle factors enabled them to make these changes in their lives. They became active participants in managing their risk. For these women, their cervical abnormality became part of their life narrative. They were women who could shape and have control over their worlds.

In constructing these explanations the women drew on popular medical culture and scientific medicine. However, they only appropriated those aspects of scientific research that were consonant with their own world view.

Many of these women experienced medical treatment as not enabling them to have control over their own health. Some spoke of medicine as taking control away from them. Furthermore, medical treatment involved their diseased cervix only. In contrast, the women's explanations were firmly rooted in their own life circumstances. Their cervical abnormality had become part of who they were. It had a reality and presence beyond the gynaecology clinic. Medical management of their abnormality was curative and technological. It failed to deal with the complex meanings the abnormalities had assumed within individual women's lives.

Some women did not seek an explanation for their abnormality. Their abnormality was just bad luck, fate, or was because they were susceptible. These women did not speak in terms of control over their own health. One feature of this group of women is that they perceived their abnormality to be minor. It was not a major health problem. Rather, it was something that could be easily managed, and although they were aware of their risk of cervical cancer as discussed in Chapter Five, this risk was easily managed by medicine. Medical surveillance and treatment did not conflict with the way they conceived their abnormality.

It is possible that because the condition was perceived as minor it did not throw up the question: "why me, why now?". It is unclear why some women came to see this as a significant health problem and developed complex ways of making sense of their abnormality, while others conceived the problem as

minor. Impressions of severity did not appear to relate to the degree of abnormality. Women like Leslie and Gladys (p107 and p114 respectively) had ongoing abnormalities even after treatment. Leslie and Gladys therefore experienced this as a chronic problem that required incorporation into their own life narratives. The women's perception of the severity of their abnormality was shaped, in part, by their interactions with health professionals. This is discussed in the next chapter. But, their perceptions of the severity of their abnormality was also shaped by their past life experiences, including various illnesses. Without developing a more complex account of each woman's life it is not possible to explore why the women came to view the severity of their abnormality differently.

Although I have presented these two groups as distinct — those women who seek explanations for their abnormality and those who do not — the groups overlapped. A few women discussed how there was no explanation for their abnormality, that it was just bad luck, and at another point in the interview suggested that their abnormality might be linked to aspects of their life.

Discussion

There are two major arguments in this chapter. First, in order to manage their newly-appreciated awareness of their proneness to cervical cancer, the women felt they must participate in continuing medical surveillance. This surveillance defined them as always likely to suffer cervical cancer or some such abnormality even after treatment. Second, the women sought to make sense of this abnormality and incorporated it into their life narratives.

Not only did the women come to experience their risk of cervical cancer, but within gynaecological practice this risk was only managed by medicine. They had been unable to identify their risk (this required the Pap smear) and they were unable to monitor or treat it. At the same time their risk was their responsibility. To manage it, they needed to subject themselves to medical surveillance and treatment. The women's narratives about stress and lifestyle factors might therefore be thought of as forms of resistance to the medical discourses about cervical abnormalities, which cast them as powerless and at the same time responsible.

The women constructed their explanations for their abnormality in ways that made sense to them. In doing so, they accepted and reworked evidence from scientific medicine and popular culture that were congruent with their own

lives. For some women, their abnormalities became firmly grounded in their everyday life and became part of their own identity. Yet their gynaecologists approached their cervical abnormality in isolation. Gynaecological care decontextualised the women's abnormalities as though they were not part of women's identities or their lives.

It appears that gynaecological practice has no space for ways of understanding cervical abnormalities that are not consistent with the current clinical approach to such abnormalities. It may be that, in the clinic setting, conversation and actions enable particular accounts of cervical abnormalities and prevent others. In the case of surgery, Fox (1993) argues that surgeons use the ward round as a strategy to manipulate conversation so that it upholds their position as healers. Patients' versions of what is happening to them could not be heard within the structure of the ward round. (Fox 1993).

How do encounters between gynaecologists and women who have abnormal Pap smears operate so that women's accounts are marginalised? The next chapter examines the women's experiences of the health care system. Not only were the women's accounts silent in the clinical setting, but many women felt they were not fully informed of the reasons for their clinician's approach to their abnormality.

Chapter Seven

Interactions with the health system

Interactions with health care professionals shaped this experience for the women in this study. In this chapter I discuss the importance to women of information, health promotion and policy material, and interactions with doctors.

Information needs

The women in this study group obtained information about their condition from many sources. Books, pamphlets, the media and the health care system were all important sources of information. Within the health care system, women consulted their own popular health networks as well as nurses, GPs and gynaecologists. Women felt that the most helpful information addressed their fears about the malignant and deathly potential of the abnormality, and dispelled concerns about its sexually transmitted nature (see Chapter Six). Individual women required different amounts of information at differing levels of detail.

Many women found the information they were received was difficult to understand.

> With your doctor, you're sitting in their office and they're telling you things but you're not absorbing them. It doesn't seem to make a lot of sense to you. You go out and you think, "what did they say about that ?" I can't even remember because you are feeling so nervous and wondering what is going to happen. The gynaecologist was good but he was talking on a technical level and you can't get basic information out of them. (Anna)

Instead, Anna sought the information from books. In contrast, Gladys found books too difficult and she, like several other women in the study, felt that she might misconstrue the detail given in books.

> I feel that if something bothered me sufficiently, I would give somebody a pain in the arse and I would get on the phone and find out exactly, rather than reading books that are possibly over

> my head and misconstrue what I am reading anyhow. Better to find somebody that will explain in language exactly what is going on. (Gladys)

These women used different sources to obtain 'basic' information.

Anna raises another issue — not only can information be too hard to understand but the nature of the clinical consultation makes it difficult for some women to take in all the information they are given. Frequently, women described 'not hearing' what their doctor said.

> I think you block it out when people talk to you about it. I know I did. Like when the doctor talks to you about it and they say "it's all right you'll get over it, ...you must be feeling this" but they don't really know what you're feeling. So I thought, "how would you know", so I didn't even listen sometimes. (Rosemary)

Like Rosemary, several women described this process of 'not hearing' in relation to information that did not address their own needs. She feels the gynaecologist does not understand her experience.

GPs and gynaecologists provided different kinds of information.

> He [her gynaecologist] talked more about the wart virus. She [GP] talked more about the stages - trying to reassure me that it was at this stage, and if it is untreated it moves on to another stage, but it wasn't at that stage. So she was more in counselling mode, he was more in clinical mode explaining where he was taking the biopsies from, the shape of the affected area, and that he was putting the stuff on it to see the cells change. (Veronica)

Some women thought their GPs provided good, more basic and understandable information. Other women felt gynaecologists had better information as GPs were not experts about cervical abnormalities. However, often doctors' receptionists were the source of the most needed information.

Some women found the best information within their own social networks. For Sharon, a colleague in the health area was the source of useful information about the prevention of a recurrence of her cervical abnormality.

> I was talking to Ruby [a friend who works in the health sector] about it and she was saying that recent literature indicates that the wart virus has a lot to do with pressure and stress ...so that if you are under stress and under pressure and are run down, you don't eat properly and you don't exercise, then you are more likely to get it, because your system's run down; so there is no natural defence to the virus. ...it made me feel good. I could actually make some improvements. ...I'm thinking positively because I have a new job and I will be working less hours. In terms of dieting, exercising

> and stress, I'm feel more positively about the fact that in the future I'll have more control and be more easily able to make lifestyle changes.

Sharon wanted to know what she could do about her abnormality. Her friend addressed this need. Sometimes friends also provided the most useful information regarding the experience of treatment and symptoms after treatment.

The nurses in the study spoke of the ease with which they related to technical biomedical information and their familiarity with the language used to describe their condition. They shared a knowledge base with their health care providers. The women used the information that was most congruent with their ways of understanding their abnormality and their life circumstances.

A central theme used by women when discussing information they found useful related to the rationale for treatment and the precautions recommended following treatment. Women expressed frustration when they could not make sense of the treatment and instructions they were given by their medical practitioners.

> I didn't like the first gynaecologist I saw. He did a Pap smear and I rang back and they said the results weren't back and to ring back in a couple of days, which I did. Having phoned back they said it has come up as an abnormal Pap smear, come in and get a prescription. I got in there and I asked if I could see him - and they said he was too busy ...I couldn't see him. I said "well how am I meant to know what's wrong?". And in the end the receptionist just said over the counter that I had thrush. Unless you actually tell someone what they've got and what they're taking the prescription for, it makes no sense. The other thing that I picked up was chlamydia, either through my husband or through a previous relationship. The thing that hit the hardest was when the first Pap smear came back and the receptionist just said it was abnormal. What does that mean? I didn't know what to do about that. But chlamydia, a friend of mine had had it and her mum is a nurse so I wasn't worried about that. I saw my GP and he was really good he gave me antibiotics and said to make sure my husband took them too. And everything was fine. That was the real thing that hit me at first, that made me really worried, I thought what is it, and then once I knew it was that I thought OK that it is fine and I don't need to panic. (Bronwyn)

Bronwyn describes two situations. In the first situation her gynaecologist does not tell her anything about her abnormality and just suggests she take

the medication he prescribes. In the second situation contact with a friend who has a similar problem enables her to understand the antibiotics her GP prescribes. She is happy to take the prescribed medical treatment as long as it makes sense to her. For Bronwyn, worry or panic is a product of her lack of knowledge and understanding of conditions which affect her. The doctor also fails to address the meaning of 'abnormal'. Similarly, Adrienne describes frustration at the lack of information about why she should not pursue certain activities.

> They didn't give me much information at all. Even as to what they were going to do. I just went in and they do the colposcopy - I knew what that was because I'd had one - and then he told me he was also going to do a biopsy. ...between the time of the biopsy and laser treatment there was no contact then except the phone call to make the appointment for laser treatment. I didn't know what to expect... they don't tell you you're going to bleed or have a discharge afterwards. They give you a little sheet of paper and it says "do not swim, do not bathe, do not wear tampons etc..." but they don't tell you why you can't do these things. (Adrienne)

Most women sought to make sense of the treatment suggested by their gynaecologists. Only a few women were satisfied with reassurances that merely told them not to worry. The few women who were satisfied with such reassurances were the least concerned by their abnormality and its medical treatment. They spoke of how they preferred not to 'know too much' and spoke of 'trusting' their doctor.

> I'm a bit of an ostrich - I'd rather not know. I know he'll say to me if it is wrong "quick we have got to do something", or if I come back earlier for treatment. I just trust him. (Carmel)

Carmel 'worried' that she may construct the condition as serious if she was given too much information. Earlier Gladys expressed a similar concern about written material.

The women wanted information in a variety of formats. Some emphasised the need for clear diagrams so that they could conceptualise the information. Others, for example Sharon, wanted detail about the disease process but not about the anatomical nature or location of her abnormality.

> I wanted to know all about the wart virus. But I mean he was drawing pictures of the cervix and where it was in terms of some canal thing and that meant nothing to me except that it was easy to get at and it was less likely to be scary and it was a very small area and those sorts of things. But you know it didn't make you feel

better or worse knowing where it was and this is what it looks like or any of that. (Sharon)

A few women described doctors who expressed their uncertainty in relation to their own lack of knowledge and long term outcome of their condition as honest. This honesty enabled women to trust their medical practitioner. When uncertainty was not expressed, and the condition recurred, women were upset that they had been led to believe their condition was definitely curable.

Similarly, several women found there were discrepancies between the cytology and histology results and interpreted these as signifying a worsening of their condition.

> I would say I'm scared to go back in September because it changed so quickly, when I went the first time it was CIN 2, by the time I got back for the biopsy it had gone to CIN 3. But it seemed like a matter of a couple of weeks. By the time I go back in September it may be back again. (Valerie)

However, Amy who initially had a Pap smear with only wart virus changes, later had one that demonstrated CIN 2. Her gynaecologist described to her the uncertainty that is part of pathological diagnoses.

> I knew that I had CIN 2. When I spoke to Dr X, I found that the definition is based on visual interpretation by the pathologist ...so you could have variations across pathologists in terms of how they define, whether they say its CIN 1, 2 or whatever else. It's not like running it through a machine that gives out a magnetic signal etc. (Amy)

With a clear explanation, Amy understood the imprecision of pathology reports.

Previous research demonstrates that medical practitioners often do not communicate the limits of medical knowledge and the dimensions of medical uncertainty (Fox 1975; Bloor 1976). All the women who experienced a recurrence of their abnormality or discrepancies in the pathological tests were surprised. Without information about the inherent uncertainty of medical information and procedures, women have no knowledge base from which to interpret the recurrence or apparent progression of their condition.

Relationships with medical practitioners

Trust was of crucial importance in the women's relationships with their doctors. Practitioners who spent time, answered questions and enabled women to make their own decisions were commended.

Trust or faith was mentioned in relation to medical science and doctors. Women who did not want 'too much' information (because they feared they would misinterpret it and construe the condition more seriously) spoke of trusting their doctors. These women trusted their doctors to give them 'enough' information and to make the 'right' decisions for them. Some women who did want more information also developed trusting relationships with their doctors. However, trust always referred to women's impression that their doctor was cognisant of their personal needs. Distrust, on the other hand, related to fear that one is only one of masses of women.

> I have a basic distrust in doctors because I always have this feeling that you're only one of millions and you can be missed. (Ruth)

Often, trust developed over a long period of time. For example, Maeve had 'faith' in her first gynaecologist but was unsure of the second.

> I went to Dr X for a number of years. He saw me through my baby's childhood and I went to him every year for a Pap smear and I got used to him. Then when this one came [a new gynaecologist] he was a bit younger and I thought new to the job and I was a bit concerned about having somebody new so that when this came up [the abnormal Pap smear result] I wondered whether it was accurate. (Maeve)

Those women who did not trust their doctor were liable to question their clinical competency and the information they gave. Amanda trusted her GP to make appropriate decisions, but she did not find him helpful in answering questions about her abnormality.

However, a couple of women said they trusted all doctors, trusting both their medical knowledge and professionalism.

> I generally have a fairly good faith in doctors. I imagine they sit there, the professionals, and they know what they are doing. (Judith)

The parameters for establishing trust varied among the women interviewed. For example, Maeve trusted an older gynaecologist whom she had known for many years and Judith trusted the institution of medicine itself.

The women commended health care practitioners who were readily available to give them information and answer their questions. Nurses in the specialist clinics and a few GPs were mentioned in this regard. Gynaecologists were often criticised because they did not respond to questions even within the consultation.

> It's quite hilarious really - you've got this thing over your knees and this doctor has got, have you ever seen that little thing that you put on top of the TV or something and it has got this nose which hangs down over the fence, well that is what the doctor looked like. He is talking to me while I was up like that [in the colposcopy chair], and it is not conducive to thinking of what you're meant to ask. ...He is looking at you as soon as you get out of the chair, he starts writing his notes, you get dressed, and he opens the door for you. There's really no discussion at all - you virtually just do as you're told. I have no hesitation to ask my own doctor, but this guy... his personality is pleasant enough - it's just that he seems in a hurry. (Adrienne)

Consultations with the gynaecologists were often perceived as rushed and lacking a structure that would enable women to ask questions.

Inclusion in the decision-making process was important for many women.

> Fortunately I have a very good relationship with our GP and he asked me who I wanted to be referred to and I was consulted at all points: do I want to or not, do I understand what it means, do I realise what the next step could be, what if I don't? He was very good he allowed me to choose the gynaecologist I wanted to see and I researched my options prior to going to see him so I knew from the research what I wanted and fortunately it was what he advised anyway. (Jenny)

Despite demonstrating how she was involved in decision making, Jenny casts herself in the position of the powerless. She constructs her doctor as 'allowing' her to take part in the decision making. In her account the doctor is the person with power to give away.

Compare Jenny's experience with Gladys'.

> I went to the health clinic to discuss the options of having laser treatment, and their response was I would take their advice. So again you're left high and dry, unsatisfied. (Gladys)

In contrast to Jenny, Gladys perceived herself as actively seeking the advice of medical practitioners regarding her treatment options so that she could make a decision. The practitioners she spoke with did not facilitate her taking such an active role, indicating that she should be a passive recipient of

medical advice; that decisions should be made *for* her, not *by* her. Consequently, Gladys is dissatisfied because she wanted to be part of the decision-making process.

Several women described their experience of gynaecological treatment with factory metaphors.

> You are just a number. I like Dr X, but I really feel like you go in there and he's very pleasant, and up you get and it's just another fanny here and off you go. He probably hasn't time for that sort of neurosis and you're there and you want to get it over and done with. (Phillipa)

> I would like it not to be a production line, in a slot, and that's as much time as your given. You're not allowed to deviate. I would have liked to discuss other things peripheral to it but that were important to me but you just feel this is your time and you shouldn't deviate. (Anna)

According to these women's accounts, each woman is treated the same and there is a schedule, a timetable, that guides the consultation. Asking questions disrupts the schedule.

In contrast, Julie felt 'involved' because her gynaecologist canvassed her opinions about the treatment.

> I didn't feel that I had to have it [the laser treatment], I just understood it was necessary. Seeing a woman doctor it was a bit nicer. And then after that, when I went back for a follow-up Pap smear, she asked my opinion of how I experienced the treatment. She gave me a couple of tablets beforehand and I felt really knocked out. She asked me how that was and whether I thought that was necessary. So I felt really involved not like a piece of meat on the table. (Julie)

Julie is not an unidentifiable slab of meat that is operated upon, but a person who is part of the clinical procedure.

The most important quality for health care professionals was a capacity to engage with women, individually addressing each woman's needs. This quality was necessary for trust to develop and for women who wanted to be involved in decisions about their treatment. Often women perceived gynaecologists as detached. Detached practitioners cannot engage with women personally. The emotional distance sustained the 'factory-like' environment of gynaecological practice.

Gauging severity

Women often used their practitioners' responses to gauge the significance of their condition. Some women maintained that the information given at the time of initial diagnosis was often inadequate and were often critical of what they perceived to be 'information gatekeeping' by their medical practitioners. Because they thought their doctors were not telling all, their doctors' behaviour assumed greater significance in the shaping of the women's impression of the severity of their abnormality, since they could not know enough from what the doctors said.

Most women were notified of their abnormal result by their GP, by phone or letter. This is in stark contrast to women's usual experience of the health system where communication with GPs outside the consultation is rare. Such written or telephone communication with their GP signified a serious condition. A few women felt their GP was panicking and construed this as signifying a serious problem. Similarly, prompt specialist referral also signified a grave condition.

Seriousness frequently equated with cancer and imminent death.

> It was April 1991 when I had a routine Pap smear. I hadn't had one for two years. Usually I have them every year or so. I went into my GP for a routine Pap smear and I didn't think about it much until the surgery phoned me in the afternoon after I came home from work and they told me to come and see the doctor straight away. I knew it had to be serious because the doctor didn't ring me at home. I've been going to him for ten years, and my children go to him, I immediately thought the worst. Two of my friends had died of cancer six weeks before this, of breast cancer. My grandfather died of cancer too. (Amanda)

Her doctor's out-of-the-ordinary behaviour was the source of Amanda's concern about severity.

Similarly, doctors' emotional responses were yardsticks for judging severity.

> So, I finally had that test [serum cholesterol] and they told me it would take ten days or whatever to get the result. I thought "what I'll do is I'll ring up the doctor when both the results were in and then I won't have to disturb the doctor twice". It was probably about six weeks since I'd had the Pap smear when I actually found out the results. When I phoned up, the receptionist said to me, "Oh, thank God you've phoned. We've been trying to ring you for weeks and weeks" - and there was all this panic in her voice. And I said, 'What?" I was practically hysterical and then she put me

> through to the doctor and said, "My God, we've been trying to get in touch with you for weeks and weeks. Where have you been? We haven't been able to contact you and we have tried and tried". There was all this air of panic and I said, "What's happening?". And she said, "You've got a bad test". And because it had all of this sort of air of panic, because they hadn't been able to reach me, I just went into instant panic myself. (Veronica)

The urgency with which it was treated by her doctor and her receptionist caused Veronica to feel concerned.

On the other hand, a few women concluded that because their doctor did not appear overly concerned that the abnormality was not serious.

> I received my notification about having an abnormal Pap smear in the mail. It was not long after my daughter was born. ...the doctor just sent my prescription in the post with an accompanying letter. That was my first introduction to abnormal smears. Having great faith in my doctor, a gynaecologist, I figured that if he thought there was no reason to have a heart attack, all must be well. (Gladys)

Gladys trusted her doctor to respond appropriately and was willing to follow the doctor's instructions regarding treatment. However, other women felt that their doctors might not communicate the full extent of their problem.

> Initially I got the feeling that they were blasé about it, Family Planning and Dr X, and I thought either it is very serious and they are not telling me or a lot of people get it and they don't think anything of it. In which case I started to think if it was serious are we going to miss it? (Ruth)

Ruth interprets her doctor's response. The possibility of her problem being serious can only be entertained — given her doctor's response — if her doctor does not tell her the full details of her condition.

Several women were told initially that they had a normal smear and were subsequently rung up (or in one instance told via their spouse who visited the doctor for another reason) to be told that their smear was abnormal. These women were angry with their GPs or receptionists who had initially informed them incorrectly.

Referral to a specialist also signified a serious condition. Several women spoke of an earlier abnormal Pap smear result casually. Until their Pap smear result caused their GP to suggest referral, their condition was considered minor. Several women thought their complaint to be serious because of the haste with which they were referred to a gynaecologist.

> He [her GP] said "there's nothing to worry about but you must see a specialist straight away". I opted to see my gynaecologist, Dr X, but he couldn't see me until February and my GP said "oh no that is much too long to wait. I suggest you see someone who sees you before that". That's why I saw Dr Y. That made me panic too, because I thought: "oh gosh, it's nothing to worry about but I can't wait to see my own specialist". I had to see someone a lot sooner. So that made me panic too. They are saying, "oh it's nothing to worry about but you must see someone straight away". (Lorraine)

The urgency of referral was not consistent with a minor complaint.

The need for treatment signified the importance of the condition for Leslie.

> I think to start with the result is only, you only have a slightly abnormal result and my doctor was so confident that it was very normal to have this, it is fine. I wasn't upset about it. I was quite ...I didn't like it but I wasn't uptight about it.
>
> YOU HAD SUBSEQUENT ABNORMAL RESULTS?
>
> Yes, my first result was sent to a gynaecologist and he diagnosed CIN 1 and he said we can leave it for a while and I think three months later it was CIN 2 and he suggested I have treatment and after that, I think it was at that point that I started to feel anxious about the whole situation. Because before then I thought it would just go away and when I got to the point of actually having treatment it started getting really ...oh no this is my body, what are you going to do to it. (Leslie)

Initially, Leslie's result was perceived by her doctor to be a normal occurrence. When treatment was suggested, her abnormality became significant, crossing the boundary constructed between normal and abnormal.

In contrast, Judith was not perturbed by her abnormality because she considered it to be routine.

> I wasn't too worried about it. I don't know why...I just saw it as something that had happened, it was routine, and it was going to be fixed up. (Judith)

Both the commonness and amenability of her abnormality suggested to Judith that her abnormality was not serious.

Many of the women described how they initially believed that cervical abnormalities were uncommon because they had not heard of anyone else who had had one.

> Actually I found out later that my sister had had that (an abnormal smear) but I didn't know that before. And various people since that have had abnormal smears. (Julie)

Like Julie, most women did not know anyone who had an abnormality prior to having one themselves. After they received the diagnosis they found other women who had experienced similar problems.

> It's like once you have a baby you see women who have had a baby. Actually another friend of mine had to go and have laser treatment for a similar thing ...plus this little girl she was having it and her mother was having it. So within a short period of time there were four people who had a similar thing. (Phillipa)

The apparent infrequency of the problem may partly be explained by Phillipa's explanation — that is, one does not become aware that women are telling you of their cervical abnormality until you have experienced an abnormality yourself. The precise nature of their problem may remain unclear until after you have experienced a cervical abnormality. It is possible that the apparent infrequency also relates to women feeling reluctant to speak of their abnormality because it is stigmatised.

> ...with this cervical stuff there's this insinuation that you got it from promiscuity, that, I think, keeps a lot of women quiet about it. (Brenda)
>
> DID YOU TELL ANYBODY ABOUT IT?
>
> No, not a soul. I'm tainted. I'm not going to tell anybody I've got this bloody wart virus. I didn't tell anybody. I told people that I had an abnormal smear and funny sort of precancer cells... (Phillipa)

Initially, many of the women thought that because cervical abnormalities were uncommon they were severe.

Some authors maintain that the linkage between uncommonness and severity in relation to disease is peculiar to modern experiences of sickness. Previously, diseases affected the collective and were, therefore, common. Severe diseases, such as the plague, involved collective suffering. Now severe diseases, like cancer, affect the individual and are uncommon. (Planz and Keupp 1977; Herzlich and Pierret 1987). However, a couple of women did not link uncommonness and severity.

Sharon, who was initially concerned about the hastiness of her GP's referral to a gynaecologist, was reassured when told that her situation was not

urgent. Her gynaecologist's assertion that if she were pregnant her treatment could be delayed was also reassuring.

> ...the first meeting with the gyno and he again said it was no big deal and said for example, if you were pregnant we would leave the treatment until after you had the kid. And that made me think that is great, that is nine months, and that slowed down my concern, because the way the GP had been treating me I thought "shit I was destroyed". (Sharon)

Interpreting health promotion and policy messages

Like practitioners' responses, health promotion messages and policy guidelines shaped the women's understanding of their abnormality. Two distinct interpretations of health promotion and policy were evident: strict participation in screening according to the intervals outlined in policy prevented cancer of the cervix, and an abnormal smear indicated cancer.

A few women spoke of how the time since their last normal Pap smear shaped their perception of the seriousness of their condition.

> I wasn't worried about cervical cancer. I thought having regular Pap smears I was fairly safe. I thought if there is a change it would be very slight. (Julie)

In Julie's view, having regular Pap smears indicates that her problem is minor. However, Sharon is concerned because she considers the interval between her Pap smears to be too long.

> It was nearly two and a half years since my last Pap, which just floored me. So having learnt that I felt even worse, I thought "oh God two and a half years what could have developed?". (Sharon)

Sharon and Julie, like many women in the study, understood the recommended screening interval to be indicative of the underlying course of the condition. At the time of the study the recommended interval for screening was changing from one to two years. Decisions based on effective population screening were translated at the individual level to bring meaning to the diagnosis.

Lorraine conceived that her risk changed because she did not have a Pap smear at the recommended interval.

> I always have a Pap smear every June but that year for some reason or another because I had little kids or whatever, I left it until November. I was in a panic because the media is telling you to have a Pap smear once a year, once a year. For those four or five

> months I was panicking because I had not had one in June. ...The media keeps telling you all the time to have it done, no-one is safe, whether you're Asian, Italian or a nun. If you have sexual relations with men, then you must have a Pap smear every year. Therefore I started to panic when I had not done it yearly. (Lorraine)

From the media messages she construed that she was at risk of cervical cancer. When she did not have her Pap smear at the recommended interval her perception of her risk shifted. She became anxious about her new state of risk. Lorraine uses the health promotion messages she was exposed to to construct her perception of her own risk. In epidemiological terms, Lorraine's risk of cervical cancer is only increased minutely by having the smear at a two-yearly rather than yearly intervals, yet Lorraine experiences a dramatic change in her risk state.

Policy guidelines were used as sources of information about the nature of cervical cancer. The women thought of policy as reflecting the underlying 'truth' about their abnormality. Given the notion that policy decisions were based on truth, they were used by women to discern the significance of their own abnormality.

Within the conceptual framework that policy reflects the nature of the cervical cancer, changing screening intervals requires a conceptual shift in thinking about the course of cervical cancer. Women frequently expressed concern about the policy change from a one- to two-year interval, fearing that the longer interval would mean that their abnormalities would be significantly worse before they were detected.

Most health promotional material is aimed at recruiting women to participate in cervical cancer screening at a defined interval. Health promotion messages do not address the detection of abnormalities on a Pap smear. Many women had not heard of abnormalities picked up by screening and concluded that any abnormality must be cancer.

> ...you either get an all clear or you have got cancer. (Ruth)

> I don't think I realised that you can have abnormal cells but it doesn't mean you have cancer. I think, I automatically thought if you had abnormal cells that it was the beginning of cancer. That is why when they told me that it didn't mean that, it was reassuring. (Peggy)

The failure of health promotion material and health care practitioners to address the process via which cervical screening prevents cancer of the cervix meant that many women thought cervical abnormalities were cancer.

Primary health care practitioners and health promotional material must address the way cervical screening prevents cervical cancer. At the time of doing a Pap smear practitioners could discuss with their patients the purpose of the test and explain the significance of any abnormality that might be detected.

Gynaecological examination and treatment

I spent four months in a private gynaecology clinic whose major service was laser treatment of gynaecological abnormalities. My task during this period was to record data from the clinical records for Part C of this thesis. However, during this time I observed the arrangements in the clinic, women entering, waiting for their consultation with their gynaecologist and leaving the clinic. (I did not observe the clinical consultations.) I draw on my own observations and women's accounts to describe the clinic experience.

The role of woman as patient

Eisenberg (1980) maintains that "patienthood is a psychosocial not a biological state". Only by consulting a physician can a person become a patient. On entering the clinic or hospital a woman became a patient. Entering this role meant that women now had to behave in particular ways. If they could avoid it, women did not sit next to each other or enter into any conversation unless initiated by the clinic staff.

However, women who come to the clinic embody a multitude of other capacities. For example, women are household managers, professionals, academics, bush-walkers, but in the clinic setting the role of patient prevails. Unlike most other identities in women's lives, however, this role is a temporary one and is relevant only to the clinic.

> ...look so many people say I hate going into hospital but if you've got to go, you've got to go. And if you have to go I accept it, and righteo I'm a nurse one minute and a patient the next. You play the role of patient. (Gloria)

For Gloria the transformation from nurse (the role she assumes prior to entering the hospital, even though she has not practised in a professional

capacity for some years) to patient is even more dramatic because the role of nurse and patient are not compatible in the one encounter.

The patient role requires that a woman be quiet both in the waiting room and within the clinical consultation.

> I was very determined with this laser treatment not to make a sound and I didn't. (Phillipa)

When another woman is heard crying out during treatment this is perceived as embarrassing.

> I must have gone to the toilet about three times because I was really nervous, and to make matters worse one lady was before me, I could hear her crying out, she let out this really muffled scream, and I thought that was that - and I cringed down like this. Poor lady. It was embarrassing. (Phillipa)

Occasionally one could hear a woman cry out when she was having treatment. Such reactions were ignored. These women were stigmatised by her reaction, much like someone who is disabled. No one looks for fear they will be construed as staring.

The waiting room was not the forum for women to air personal concerns. I observed, on a few occasions, women speaking of 'personal' matters loudly. For example, one woman spoke loudly to the clinics' reception staff about different sexually transmitted diseases she had contracted. The clinic staff tried to quieten her and the women waiting tried to ignore her. When she left her behaviour was commented on by the clinic staff and by women waiting, at the invitation of the staff. She was dressed shabbily and the staff suggested that she had a psychiatric illness. Her behaviour was quite clearly outside the code of behaviour that a patient should assume.

Exposing oneself

For their colposcopic examination and treatment women must remove their underclothes so that their genitals can be examined by the gynaecologist. Women described this process of undressing as 'exposing' oneself. As Gloria says:

> I was embarrassed [with the examination]...the other day, there's still a sort of getting up and exposing yourself. You know I get undressed and put a towel around me and get up on that lovely couch, it almost looks like a dentist's chair to me. And I get up and put a towel around me, you know until the last minute, and its

stupid because I see my patients doing it. [Gloria is a nurse] You are just the same as they are.

Removal of her underpants does not just expose her genitals as a part of her anatomy, as rolling up a shirt sleeve 'exposes' an arm. It exposes *all* of Gloria to the medical gaze. Embarrassment is a consequence of 'exposure'. A towel postpones exposure for a while. This exposure and its consequent embarrassment is typical of women who have gynaecological examinations. Gloria realises she is just like any other patient.

Exposure embarrasses, stigmatises and reduces one's dignity. Rosemary avoided having Pap smears for these reasons.

WHAT HAD BEEN STOPPING YOU HAVE A PAP SMEAR BEFORE?

I think it's the stigma attached to it really. ...I was embarrassed, I was embarrassed having a baby, so I am very embarrassed about things like that...

The chair in the clinic, which many of the women described in vivid terms, symbolises the position of woman as a patient.

CAN YOU DESCRIBE WHAT THE LASER TREATMENT WAS LIKE?

It was in Dr X's office. And it's, oh there's this terrible chair and it makes you feel so embarrassed. (Rosemary)

The specialist is confronted with the woman's genitalia, with almost no view of any other part of the woman's body. The woman, on the other hand, is unable to see her own genitalia. She too has only a partial view of herself.

Within the context of a sexual relationship, exposing one's genitals to a man was acceptable.

I suppose it's just the way you know. You don't mind being exposed to your partner but when it comes to a doctor, someone else putting instruments inside you, you know it's a different thing. (Penny)

In our culture the 'exposure' of female genitalia to a man is only sanctioned in a relationship that is acknowledged as sexual. The gynaecological encounter is not a sexual relationship. Exposure of genitalia outside of a sexual relationship was undignified.

The thing that gets difficult after a while - you get sick and tired of going to sit in a chair with yet another fellow, and it's not the

> world's most comfortable or demure position. There aren't many female gynaecologists. (Bronwyn)
>
> I don't know, probably because I'm a bit old fashioned, I'm of that generation. I haven't been sexually active with anybody except for my husband. You feel undignified, exposing yourself to a man, and he is sitting down, and you're right up in a chair. I know it's nothing, and he sees everybody all day, but you just feel a little bit undignified. (Judith)

Many women spoke of a preference for female gynaecologists. A few women felt more comfortable with older rather than younger men. Perhaps these women felt that female and older male gynaecologists were less likely to regard their genitals sexually.

Lorraine claims that her cervix shifts from a sexual organ to a non-sexual organ within the gynaecological encounter. In order that she 'trust' her gynaecologist she must perceive him to regard her cervix as non-sexual.

> I've trusted these people or they haven't revolted me. They're not looking at me with dirty eyes or pornographic eyes - they're looking at my cervix as a cervix and not as a sexual part. (Lorraine)

However, the definition of the genitalia or cervix as non-sexual only has meaning in reference to what it is not. A non-sexual organ does not have its own essence. As such the medical definition of the genitalia as non-sexual is a precarious one.

The shift in meaning of the cervix, as part of the genitalia, from sexual to non-sexual was more readily made by women who have had children.

> After three or four kids nothing they could do really worries you. You have that many things shoved up inside you and...you don't care any more. (Mary)
>
> I think I block off. I'm just used to it you know - being a woman and having given birth twice. I think I block off actually and think they're just looking at another part of my body. (Lorraine)

For these women the exposure of genitals outside a sexual relationship was not as unusual an event. They were more used to experiencing their cervix and genitalia as non-sexual.

Emerson (1970) describes how the medical definition of the female genitalia, within a vaginal examination, as non-sexual is sustained by certain behaviours and activities such as draping and the detachment of the

gynaecologist. She suggests that other meanings become manifest during the gynaecological encounter and that a careful balancing act takes place that enables the examination to proceed.

Unlike women patients, gynaecologists (of whom most are men) have the immense experience of medical situations where female genitalia are regarded as non-sexual.

Sustaining the two separate realities of 'up there' and 'down there'

Procedures such as draping and the angle of the gynaecological chair means that women cannot view their own genitalia and the gynaecologist cannot view the upper part of women's bodies easily. Women are physically separated into two parts — 'up there' and 'down there'.

In the context of the gynaecological examination two separate realities coexisted, referred to here as 'up there' and 'down there'.

> Last time I was having laser this nurse/receptionist came in and she said "well what have you been doing in your holidays?" Well you're sort of up like this, and I went "Oh, I've been to the beach lately". And then I felt embarrassed because the gynaecologist had an observer in, which I agreed to on the day, but I was a bit pissed off about it. I knew I could say no, but I thought no ...so he had another gynaecologist with him as an observer. He was talking about me and what was wrong with my cervix, and this woman was chatting, and I said "excuse me do you mind if I listen to what they [the gynaecologist and his observer] are saying", and she just went away. I felt in a really odd situation because on the one hand I've got these two men talking about me and my genitals and my cervix and then I've got this woman at my head asking me what it is like at the beach. I thought "I can't stand this..." I didn't want to penalise her because I suppose she was trying to relax me by talking about the beach but I had these two men talking about what my labia looked like and all this and I actually want to talk to them, or at least get in on their conversation, not because I think it's more important talking to them but because they were discussing me and my body and up the other end ...I just felt completely again, that complete disassociation. (Brenda)

The nurse 'chats' to Brenda and the doctors talk about her pelvis. Brenda experiences herself as separated into two parts. Brenda wants to be part of the 'down there' conversation. Instead the nurse distracts her from 'down there'. The two separate realities of 'up there' and 'down there' facilitate the split between body and mind and contribute to women's experience of their pelvis as an object of the medical gaze.

Unlike Brenda most women found this separation comforting.

> HOW DID THE NURSE MAKE YOU FEEL BETTER?
>
> She'd keep your mind on other things. She talks about your baby and work and school or whatever it was. She talked to you about anything. Plus you wouldn't try and think about what was going on and when it hurt she'd talk about something else and you'd get your mind off it. Trying to keep you away from it and it felt much better because you weren't just sitting there just with the doctor and you feel like he's talking to you and you have to talk back and you think gosh you know how embarrassing and he's trying to talk to me and I wish he'd leave me alone. (Rosemary)

By talking to the nurse 'up there' Rosemary is removed from the examination of her genitals. They are objectified and separate from Rosemary. However, she is unable to converse with the doctor. She experiences dissociation. He is 'down there' and in order to talk to him her genitals must be part of her. Rosemary feels a need for sustaining these two separate realities.

Several women reported difficulty talking to doctors while they operated on their genitals.

> HOW DID YOU FEEL DURING TREATMENT?
>
> Rather strange. You feel stupid sitting there - the way you are sitting is not the most elegant - and this gynaecologist is talking to you from between your legs, trying to carry out a normal conversation. I didn't really feel like being intellectual in that position. The nurses were really good, trying to distract you from what he was doing. (Anna)

Topics of conversation 'up there' only occasionally referred to 'down there'. Almost no conversation was possible between the woman 'up there' and the doctor 'down there'.

Both Anna and Rosemary use 'you' rather than 'I' to describe their own experience. In contrast, Brenda, who asserted a right to listen, used 'I'. 'You' removes the woman from the experience. Not only are the genitals objectified and separated from the self, but the experience of the gynaecological examination and treatment is also separate from 'I'.

On two occasions the nurses did not chat to the women 'up there'. In these circumstances both women experienced themselves as objects of the nurse's gaze.

> The most embarrassing thing was that the Sister was walking around and having a look all the time and you feel really up for

> inspection. I know that she was looking to see that everything was in place and that's part of her job - I realise all that - but I'd rather not know that she was doing it. (Maeve)
>
> ...I felt like asking her what was she looking at. If she'd been handing him a glass of water or whatever, I could have coped with that, but there she was... I couldn't see any rhyme or reason to what she was doing. I guess I felt more comfortable at the GP's: there was just him. (Winnie)

The nurse's participation is necessary to create the reality of 'up there'. Instead, in Maeve and Winnie's experience, women were merely objects of both the nurse's and the doctor's gaze. The nurse's gaze is not considered to have a specific medical purpose. An important question might be, what purpose did the construction of these two realities serve?

Metaphors of attack

Some women described the gynaecological examination using metaphors of attack. On two occasions the examination was spoken of in rape-like terms.

> I think about women who have been raped. I sort of think that it must be the same as the way they feel. Only [they feel] one hundred times worse. You know, being vulnerable like that. (Penny)

Women were exposed, unsafe and liable to attack. When a woman is having a colposcopy she is unclothed with her feet in stirrups and is no longer able to defend herself against attack.

> My gynaecologist in Melbourne said it was like a big microscope — they have a really good look inside and I thought, yes that's OK, but not knowing what to expect. It was more unpleasant than some of the examinations that I have had before but it was just again, it is the unknown and you are not sure what is happening. I mean it is never pleasant sitting anywhere with your legs in stirrups. That on its own is very daunting because you feel so vulnerable. (Louise)

The examination and treatment were described in terms such as violation and invasion.

> HOW DID YOU FEEL WHILE YOU WERE HAVING TREATMENT?
>
> It's not a comfortable position to be in. It never is, to be up in stirrups. It's quite an invasive thing to have done. (Jenny)
>
> He was really good but I just felt really violated. There was this burning sensation that I could feel, and I was bleeding and they

were dabbing away, and you feel really open. It felt like - well I was pretty slack anyway after four children, but I felt like Grand Central Station. (Phillipa)

Ruth considers the experience in terms of a foreign attack and feels uncomfortable within a sexual encounter following the gynaecological encounter.

> ...any sort of foreplay or anything I just wasn't interested. I think it was for both of us really. It was just feeling that something alien had gone inside and done this treatment, it is just off-putting. (Ruth)

As for cancer, the women used military metaphors to describe their experience of the gynaecological examination. However, unlike cancer, women could not battle or fight the invasion of a gynaecological examination.

Other effects of examination and treatment

Some women described feeling pain or discomfort during and after colposcopic examination or treatment. Many experienced bleeding or discharge following treatment.

Pain and discomfort

A few women experienced pain with the biopsy, local anaesthetic or laser treatment. Jenny experienced pain both during and after her laser treatment.

> [speaking of the pain of laser treatment] it's an insidious type of pain, it's something that builds, you could say, it's a sharp searing pain. It suddenly becomes uncomfortable and it becomes more and more uncomfortable but it's the whole area and it became unbearable. I can't say it was truly sharp pain, it was just unbearable. It was like someone was putting pressure for a continuous amount of time...
>
> I think the first eight hours the only place I could sit was in a bath of hot water with my legs hanging over the side. That was the only position I was comfortable in. When I saw Dr X he said I should have phoned him, he would have given me something stronger, but I didn't, I thought it would pass. I was not prepared for it because I did not expect it to be painful. I expected it to be uncomfortable because I was told I could not go to work the next day. (Jenny)

A few women experienced discomfort following treatment or biopsy. They described feeling 'sensitive' rather than experiencing pain. Ruth describes her experience following colposcopy and biopsy.

> I was glad it was in the doctor's surgery and not in the hospital. It was a lot more relaxing because the room is more pleasant. ...I remember getting into the car afterwards and feeling very, very sore and tender. But, in fact, I wasn't really sore, it was just my whole body had got into a high pitch, hypersensitive.

Ruth raises another interesting issue — the importance of the physical surroundings. She compares the doctor's surgery to the hospital. It is possible that if her examination and treatment had occurred in the hospital rather than the gynaecologist's rooms she would have experienced greater discomfort. Following treatment Ruth did not experience pain either.

> I didn't have any pain then either. I had discomfort for a couple of hours but not really sore. He said to me "you might have a lot of pain or a lot of discharge, come back". I was waiting for that, I thought I was going to get that, ...I was slightly tense waiting for this real soreness, but it did not happen, I got through it fairly easily.

Ruth was expecting pain. What she experienced did not compare with what she expected. Several women described how they had been told to expect pain and discomfort and their experience of pain was much less of a problem than they had anticipated. Others, like Jenny, were not expecting pain or discomfort following treatment, and when they did experience it, they were concerned that there was something wrong. In contrast, Judith, who described her pain as 'slight' understood her pain to be a consequence of cutting.

> Well, I realised that the laser treatment was like an operation and they had cut something off. I just thought it was from that because if you cut yourself you get pain. (Judith)

Knowledge that one might feel pain and having a way of making sense of the pain seemed to modify how an individual experienced pain. (It is possible that the women who did not experience much pain remembered their doctor's descriptions of the pain they might experience, because it was not consistent with their experience.)

Several women complained of the smell of burning.

> The smell was vile. It was very uncomfortable. You could feel the burn - you know like a steam burn if you put your arm over a kettle, it burns, that's what it felt like, only inside your body where

it wasn't deadened. The needle is gross enough and it hurt like hell. I felt really faint and I thought, oh no, I'm going to throw up. (Phillipa)

As a consequence of the pain and smell, a couple of women felt that they would prefer a general anaesthetic.

The women's experiences of pain, before and after treatment, varied. It is possible that the cervix was not always adequately anaesthetised. However, other factors are likely to have shaped the women's experience of their pain and discomfort. For example, information about the possibility that they might experience pain or discomfort and an explanation for what this could signify, would provide women with a conceptual framework for understanding their experience. Most women who experienced pain or discomfort were afraid they were suffering a complication of treatment.

Bleeding and discharge

Most women experienced some bleeding or discharge following treatment and for many women it was quite heavy. Several women attended GPs, the emergency department or their gynaecologists because of bleeding or discharge.

Two factors appeared to be important in the women's interpretation of the significance of their bleeding and discharge. First, some women, such as Maeve, did not expect to have heavy bleeding or discharge. They were concerned that their discharge or bleeding signified a problem. They had no conceptual framework for understanding the significance of their symptoms. Second, the meanings attributed to the bleeding and discharge were drawn from past life experiences and cultural understandings. These meanings shaped how the women interpreted their bleeding or discharge.

I started bleeding really heavily. I can't remember what they thought [she was admitted to hospital] but they did something and then it stopped. But I didn't even expect that. It didn't bleed at first so I thought I must be different from everybody else. Then it did.

HOW DID YOU FEEL WHEN THAT HAPPENED?

I felt pretty sick. I didn't know what was happening. I was really frightened. (Rosemary)

Although I had a sheet saying what could happen afterwards, I was a bit unprepared for the fluid that came away afterwards. It was a bit more than I was expecting from the notes. It lasted

> longer than I thought too. They told me that because I wasn't having periods any more, that it was quite likely to be very light - but there was quite a bit of fluid. (Maeve)

Maeve did not know when she should consult her gynaecologist. Although she had been told to contact him or his receptionist staff should she have heavy bleeding or discharge, difficulty arose in interpreting what they meant by 'heavy'. Other women expressed similar concerns about translating clinical instructions to their experience.

Gloria, a nurse, experienced heavy bleeding following treatment. She had difficulty deciding whether she should go to hospital.

> [Describing when she began bleeding about ten days after her cone biopsy] I went shopping, I went to the hairdresser and I had dark jeans on. My car was close so I bolted to the car and came home and I had these huge big clots. ...I thought gosh you can't contact doctors on weekends. Two or three hours after [she got home] I did. Dr X was going away for the weekend, I thought he was pretty blasé about it... he says "take yourself to hospital". Righteo I'm a nurse, at what stage of the problem do I go up to the hospital? If I was a nurse visiting someone in this situation I would get the GP there and then do something - take the patient to hospital... But I thought "righteo when do I go? How long do you expect this for?"

Despite knowing how she would respond if she saw someone else with the problem, Gloria could not discern whether the bleeding was significant in her case. Her interpretation of the significance of the bleeding was shaped by her nursing experience.

> ...at the back of my mind I remembered being a young nurse. I can remember the threatened miscarriages coming in and these poor girls coming in and they'd bleed and bleed and bleed and they were passing these clots. I was a young nurse and you wonder if they have any blood left. I associated it with that time. (Gloria)

Gloria had seen young women lose a lot of blood from miscarriages. She had given them blood transfusions and cared for them. These women's experiences were reference points for hers.

Adrienne had an infection following the biopsy.

> I had an infection after the biopsy - which apparently is very common. I didn't know that. You're told not to have a bath, you're not to this that or the other - and I followed all the rules and ended up with this infection. You begin to worry that what you are doing is not clean. (Adrienne)

Brenda had a way of interpreting her bleeding following treatment.

> The second time I was annoyed because it took me a month or so to stop bleeding. In fact I rang Dr X and told him it had gone on too long. But, he told me not to worry. I went to see him anyway - I almost insisted on having an appointment. I resent people saying don't worry because this is the only body I've got to live with and if I lose it - everyone will say don't worry. ...I don't take no for an answer very much any more. ...I was worried about not healing and becoming infected because I thought if it's still bleeding it hasn't healed. It wasn't heavy - it was just bleeding. (Brenda)

Assurances from her gynaecologist did not change her interpretation that she had not healed. After a follow-up colposcopy she was reassured, however.

Those women who expected some bleeding or discharge seemed less concerned when they did experience these symptoms. As for pain or discomfort, the women needed a way of interpreting their bleeding or discharge. Most women did not expect to experience bleeding or discharge. When they did, they were concerned that it was symptomatic of a complication of their treatment. Some did have complications that required further treatment.

It is important that the possible effects of treatments be discussed with each woman. As discussed previously, with respect to treatment gynaecologists need to work with the women who see them towards a shared understanding of the possible effects of treatment. An information sheet for patients with advice on what to expect and what steps to take may be useful. However, the relevance of each piece of advice should be discussed with each woman, and a shared model of notions like heavy bleeding (such as how many pads are soaked over a specified period of time) developed.

Recommendations made by women

The women's recommendations concentrated on information. Adequate information was perceived as crucial to women taking part in and making informed decisions about their treatment.

> I am quite capable of deciding what I need to do as long as you are given the information in terms you understand as well. Not like reading a medical text. (Anna)

The women wanted more detailed information in a comprehensible format. They suggested a variety of forms that this information should take. Firstly, the GP or gynaecologist should provide more detailed information within the

consultation. Women wanted more time with their practitioners, enabling the provision of more detailed information and an opportunity to ask questions about issues that concern them.

The women also suggested counselling and information services about abnormal smears. Again, they raised the key issues of time, detailed information and opportunities for asking questions.

Finally, some women wanted access to visual information about their abnormality. Several women felt that seeing their cervix at the time of the procedure would be useful.

> ...like when you have an ultrasound done and they've got the TV screen and you can actually see it, if they could do the same thing when they do a colposcopy you'd feel a lot better because you could see what they're talking about and probably understand it a lot better. ...they just say that's what it is and you have to take their word for it. (Mary)

Many women thought a video or pictures providing information about the abnormality and the procedures would be very useful.

> I certainly would have liked to have a picture of it [her cervix]. Even if it didn't have what was going on, just a photograph would have been very, very good. (Valerie)

The final recommendation related to cost. Many women found the cost of gynaecological care prohibitive.

> Apart from that I would also like to see it on Medicare so that we don't have to pay for it as well. Laser treatment is quite expensive. It cost hundreds of dollars for one visit. The people who need it most simply can't afford it. (Anna)

Gynaecological care is rebated on Medicare. Women pay the difference between the Medicare rebate and the specialist fees which is often a substantial difference. However, on most visits more than one item number was accrued. This can result in sizeable out-of-pocket payment for women. This issue is addressed in Chapter Nine.

Discussion

In this chapter I have shown that health professionals, particularly GPs and gynaecologists, shaped this experience for women. The information doctors gave, the way they behaved and whether they spent time answering questions and listening to each individual woman were of crucial importance for women.

The arguments developed in this chapter flow from Chapter Six. I have shown that the women responded to information that was congruent with their own lives. Women were not passive recipients of medical information, rather they used it selectively and actively to make sense of their abnormality.

Most women wanted to understand the rationale for various treatments and instructions about what they should or should not do after treatment. They needed knowledge about possible after-effects and how to interpret them. Doctors were important sources of such information. Yet many of the women were dissatisfied because they were not given enough information to understand their gynaecological care. Just as the doctor should listen to women's account of their abnormality, doctors must supply their account. Such information is crucial. It enables women to develop a conceptual framework for understanding their treatment and its after-effects. This information is also important for women who want to be involved in decisions about their gynaecological care.

Women used health promotion messages to interpret their cervical abnormality. Consequently they frequently assumed that an abnormality must be cancer. Health promotion messages must do more than simply recruit women into the screening program. Details on how screening prevents cervical cancer should also become part of health promotion campaigns. That is, health promotional messages should address the mechanism of prevention. When health care practitioners perform a Pap smear test they could also explain the reasons for the test. With such information from both health promotion material and health care practitioners women who have an abnormality would be better equipped to interpret its significance.

The gynaecological examination requires more attention to individual women as well. There is no single formula for doing a sensitive

gynaecological exam. Rather, each woman has different needs. For example, some women did not want a nurse present. Women should be invited to decide whether they find the presence of a nurse helpful. Some women wanted to see their cervix on a monitor. Provision of such a facility would contribute to those women's understanding of their gynaecological care.

The last two chapters have demonstrated the critical importance of the professional relationship for women who have cervical abnormalities. I have shown that the significance of this abnormality is in large part shaped information from health professionals, mainly doctors. For most women, their abnormality had a presence beyond the GP surgery or the gynaecology clinic. The abnormality signified their ongoing risk of cervical cancer — a risk which became integrated into their life story. In the clinic the gynaecologist's way of understanding cervical abnormalities was dominant. The clinicians approached the women's risk as though it had no salience beyond the clinic. It was risk that simply required their intervention, but doctors often failed to communicate clearly their approach and treatment. Two separative narratives about each woman's abnormality occurred concurrently — the women's and their doctor's. These narratives were often in conflict and neither person's account was communicated to the other. It is crucial that clinicians and women hear each other's accounts of the woman's cervical abnormality. Then they can work towards a way of approaching her abnormality that is cognisant of both perspectives. Such an approach would enable the women to make decisions about their gynaecological care and have a better understanding of the treatment and its effects. By listening to women's accounts, doctors could be more attentive to each woman's needs and life circumstances thus possibly reducing the emotional burden of the diagnosis.

Part C

A clinic's accounts

Chapter Eight

Method and sample characteristics

By describing the methods of data collection and the characteristics of the sample used for Part C of the thesis, this chapter sets the scene for the following two chapters, which examine the financial costs of the gynaecological follow-up of women who have abnormal Pap smears and the socio-demographic and clinical predictors of non-attendance.

This chapter consists of five parts: the methods of data collection; a description of the colposcopy clinic sample used for the study; a discussion of the concordance between cytology, colposcopy and histology; comparisons between the clinic sample and ACT and Australian Medicare samples to assess the generality of the findings of this study; and, a description of how I derived the cost estimates.

Background

In Australia, general practitioners usually refer women who have abnormal Pap smears to a gynaecologist. A woman is seen first as an outpatient. The gynaecologist then recommends assessment or treatment of a woman with an abnormal Pap smear as an outpatient or inpatient. In an outpatient service it is possible to follow each patient's gynaecological care, from the first outpatient visit through all further outpatient and inpatient services. For this, and for other reasons outlined below, the current study was located in an outpatient gynaecological service.

At the time this study was carried out, it was impossible to obtain an ACT population-based sample of women with abnormal Pap smears as there was no centralised system for following women with abnormalities. This was another reason for carrying out the study in an outpatient service.

A clinic sample has the advantage that the status of each woman's follow-up is known, providing answers to questions such as: did women complete treatment or not attend? did women move? and so on. Adjustments for the

status of follow-up can then be made in the cost analysis. It must be stated, however, that the treatment practices of one clinic sample are likely to differ from some colposcopy services elsewhere. For example, public hospital clinics are funded through the states and services are not rebated through Medicare and therefore may have different treatment practices and costs from outpatient services located in the private sector. However, there are no public clinics for colposcopy in Canberra.

A case note audit of an ACT private outpatient colposcopy service was used to estimate the financial costs to government and to women clients, of the gynaecological assessment and treatment of abnormal Pap smears. The financial cost estimates for different levels of presenting smear are compared, and the relative contributions to total cost of treatment of women who have different levels of abnormality are estimated.

Methodology

Sixteen gynaecologists practise in the ACT, only six of whom provide a regular colposcopy and laser service. The remaining gynaecologists only occasionally see women who have abnormal Pap smears. Four gynaecologists in the ACT work from the Canberra Laser Clinic (CLC), a private clinic dedicated to the treatment of women who have abnormal Pap smears. A CO_2 laser on the premises is the main method of treatment. The CLC was negotiated as the site of this study because most of the gynaecologists who perform colposcopy and laser treatment in the ACT practice from this clinic. They have a consistent method of record keeping and data collection.

The study was approved by the Australian University Ethics Committee. I recorded the data from the case notes.

Sample selection

I conducted a case note audit of the records of all women presenting to the CLC for their first consultation with abnormal cervical cytology (but no evidence of invasion) between 1 January 1989 and 30 April 1990. Women were only included in this sample if the abnormal Pap smear was the principal reason for their referral, as indicated in the doctor's letter. In order to follow the entire management of each woman's abnormal smear, only women who had never, as far as I could ascertain, had a previous

consultation with a gynaecologist for an abnormal Pap smear were included. A relatively wide case definition of abnormal Pap smears was used because the aim of the study was to describe current clinical practices as they relate to the range of abnormalities seen.

Data collection

I entered the data into a computer software program designed specifically for this research. Three sources of data were used to compile this audit: a case record completed by the gynaecologist at the initial consultation, case notes, and account details recorded on the clinic's computer-based accounting system. The clinic has a case record designed so that each gynaecologist asks each woman attending the clinic about their previous abnormalities, Pap smear frequency, marital status, parity, present contraceptive use, and private health insurance status[1].

The following information was recorded: case number, date of birth, previous Pap smear history and frequency, marital status, parity, private health insurance status, date of referral, source of referral, date and category of presenting smear, details of all tests, treatments and items associated with each clinic visit, and details of all hospital inpatient tests and treatments. Medicare item numbers were recorded from each visit and were then used to cost women's gynaecological treatment. Personal identifiers were recorded for those women whose test results were incomplete so that I could follow the results up with the laboratory. The data file did not have any personal indentifiers. The clinic coded information such as marital status, previous Pap smear history and frequency of Pap smears on a standard form. I used their coding system to code these variables.

Information on each woman's clinic visits and inpatient treatment was recorded until 16 August 1991 when the accounting data were down-loaded onto my computing system for this project. Thus, women who were first seen on January 1 1989 and 30 April 1990 had their notes audited for two years and seven and a half months and one year and three and a half months, respectively.

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[1] Private health insurance status describes whether or not women have private health insurance. In Australia, there are different levels of private health insurance cover. There were no details in the notes on the level of cover women had.

Coding categories for cytology and histology were as follows:

normal,

inconclusive,

inflammatory,

mild atypia,

HPV;

atypia + HPV;

CIN 1;

CIN 1 + HPV;

CIN 1-2 only;

CIN 1-2 + HPV;

CIN 2 only;

CIN 2 + HPV;

CIN 2-3 only;

CIN 2-3 + HPV;

CIN 3 only;

CIN 3 + HPV;

microinvasive cancer;

invasive cancer;

other; and,

not recorded.

The results of colposcopy, further cytology and histology were obtained from the notes and pathology reports. When more than one abnormality was present, the highest grade of abnormality was recorded. If the report indicated possible evidence of abnormality, the result was coded as if the abnormality were confirmed (eg possible CIN 1 is coded as CIN 1).

I coded the level of the women's presenting cytology (reason for referral) from the GP referral letters and the Pap smear reports accompanying the letters. Where possible, each woman's presenting smear result was confirmed with the laboratory to which it was sent. Only one woman in this sample was referred with 'an abnormal smear', the level of which was impossible to

discern from the letter or notes. Nor was it possible to trace her smear through the laboratories.

Description of sample (n=502)

In the following section I describe the socio-demographic and clinical characteristics of this sample. Because the clinical records were not always complete, most of the variables have up to ten per cent missing values. The percentages for each category of a variable were calculated using the number in the sample for which the category of the variable was known.

Socio-demographic characteristics

Table 8.1 shows the socio-demographic characteristics of the CLC sample. Approximately 70 per cent of women in this sample were under 35 years of age.

Table 8.1 Socio-demographic characteristics of CLC sample

Variable	No. of women	Percent (%)
Age (n=502)		
< 25	173	34.5
25 to 34	182	36.3
> 35	147	29.3
Health insurance status (n=446)		
No private health insurance	213	47.8
Private health insurance	233	52.2
Marital status (n=453)		
Married or defacto	330	72.8
Divorced, separated or widowed	25	5.5
Single	98	21.6
Parity (n=476)		
Nulliparous	234	49.2
Parous	242	50.8

Age was strongly associated with marital, parity and health insurance status. Compared with women over 35 years of age, women under 35 were less likely to have children (χ^2 = 146.7, df=2, p=0.00001); be married or defacto, or divorced, widowed or separated (χ^2 = 68.3, df =4, p<0.00001); or have private health insurance (χ^2 = 28.0, df=2, p<0.0001). Only 16 per cent of women

under age 25 had children, while 85 per cent of women who were 35 and over had children. Sixty per cent of women under 25 were married or defacto whereas 82 per cent of women over 35 were married or defacto. Most women over 35 years of age had private health insurance (69 per cent) while this was true of only 38 per cent of women under 25. The high proportion of women in this sample in younger age groups may explain the relatively small proportion of women who are divorced, separated or widowed, and the finding that nearly 50 per cent of women in this sample did not have any children.

Self-reported Pap smear history and frequency

Table 8.2 shows the distribution of the sample with regard to self-reported Pap smear history and frequency. Most women (76 per cent) reported having Pap smears at least biennially and so are at relatively low risk of cervical cancer. However, in previous studies of self-reported Pap smear history, women were found to over report the frequency of their smears (Bowman, Redman et al. 1991). Although this sample did not include women who had previously seen a gynaecologist for an abnormal Pap smear, 38 per cent of women reported having had a previous abnormality (Table 8.2). That is, 38 per cent of the sample had had a prior Pap smear abnormality that had not resulted in their referral to a gynaecologist for further assessment. Of the women who had had a previous abnormality, 90 per cent (158 women) reported having CIN 1 or less. Only three women reported having previous abnormalities of CIN 2 or 3, and 14 women (eight per cent) did not know the grade of their previous abnormality.

Table 8.2 Self-reported Pap smear history and frequency

Variable	No. of women	Percent (%)
Self-reported previous Pap smear history (n=464)		
Normal or no previous smears	289	62.3
Abnormal	175	37.7
Self-reported Pap smear frequency (n=448)		
At least biennial	342	76.3
Less often than biennial	106	23.7

Below I outline the frequency of categories of presenting smear and the distribution of the results of colposcopy and histology obtained on the women's first visit (initial colposcopy and initial histology). The concordance between cytology, colposcopy and histology in this sample is detailed later in the chapter.

Table 8.3 Frequency of presenting smear, initial cytology and initial histology

Variable	No. of women	Percent (%)
Presenting smear (n=501)		
Inflammatory, atypia or HPV	227	45.3
Inconclusive	3	0.6
CIN 1 +/- HPV	73	14.6
CIN 2 +/- HPV	142	28.3
CIN 3 +/- HPV	56	11.2
Initial colposcopy (n=497)*		
Normal or inflammatory	98	19.7
Atypia &/or HPV	82	16.5
CIN 1 +/- HPV	161	32.4
CIN 2 +/- HPV	113	22.7
CIN 3 +/- HPV	39	7.8
Microinvasive	1	0.2
Other colposcopic changes	3	0.6
Initial histology (n=498)		
Not performed	70	14.1
Normal or inflammatory	40	8.0
Inconclusive	3	0.6
Atypia &/or HPV	68	13.6
CIN 1 +/- HPV	138	27.7
CIN 2 +/- HPV	99	19.9
CIN 3 +/- HPV	76	15.3
Microinvasive cancer	1	0.2
Invasive cancer	1	0.2
Other	2	0.4

Many women in this study had only minor (CIN 1 or less) abnormalities. Approximately 46 per cent had smears that did not demonstrate CIN (ie they showed atypia, HPV, inflammation, or were inconclusive). Thirty-eight per

cent of initial colposcopies did not demonstrate any evidence of CIN whereas only 26 per cent of women who had biopsies did not have evidence of CIN on biopsy. However, of the 70 women who did not have biopsies taken at the first visit, 65 had colposcopies that were normal or had no changes of CIN (inflammation, atypia or HPV). Two women who did not have biopsies were pregnant at their first visit and although the colposcopy demonstrated CIN 2 in both cases, follow-up biopsies after pregnancy showed HPV only.

Three women had evidence of microinvasion or invasion on histology. All of these women had CIN 3 on presenting smear.

Follow-up status and days in study

When the audit of each woman's notes was complete her follow-up status was classified into one of the five following categories:

1. discharged during the study period

2. still attending (on 16 August 1991)

3. moved or changed gynaecologist (five women were referred to Sydney for further assessment and treatment)

4. did not attend in the time specified by the gynaecologist

5. unknown.

For the last category, I could not discern from the case notes whether the women were discharged, had moved, or did not attend. Women were classified as not attending if they did not attend in the time period specified by the gynaecologist (eg six months) provided the specified period elapsed before 16 August 1991. The women whose next appointment was due after this date were classified as still attending, since there was no further clinical information after that date. This decision may have overstated the number still attending. The time period during which I recorded data is the number of days between each woman's first visit and her last clinic visit. I have called this 'days in study'. (Women attending only once are recorded as having one day in the study.)

Follow-up status is important both for the cost analysis and analysis of non-attendance presented in the following two chapters. Only women in the discharged group completed treatment. Women in the non-attending group

do not incur any further costs for this episode. Therefore, only women in the discharged and did not attend groups can be used to calculate the cost of this episode of treatment. In the case of the analysis of the predictors of non-attendance, women in any other follow-up status category, other than the did not attend group, were no longer at risk of non-attendance after their last clinic visit. The details of how the the follow-up status codes were used in the different analyses of cost and non-attendance are detailed in the relevant chapters. They are mentioned here to draw attention to the significance of the variable 'follow-up status'.

Table 8.4 shows the various follow-up status groups and the distributions of their length of time in the study.

Table 8.4 Follow-up status and days in study (n=502)

Follow-up status	No. of women	Frequency (%)	Median (days in study)	25th percentile, 75th percentile (days in study)
Discharged	273	54.4	297	141, 442
Still attending	51	10.2	453	369, 580
Moved or changed gynaecologists	34	6.8	99	13, 173
Did not attend	102	20.3	125	41, 229
Unknown	42	8.4	307	123, 414

The length of time in the study varied with the women's follow-up status (Medians test, χ^2=97, df=4, p<0.0001, Table 8.4). The women still attending or who had an unknown follow-up status were in the study for the longest periods of time. Those who did not attend or who moved or changed gynaecologist had the fewest days in the study.

The level of the women's presenting smear did not vary significantly between the follow-up status groups (χ^2=5.7, df=4, p=0.22). Similarly, the women's initial histology did not vary significantly between the groups (χ^2=4.6, df=4, p=0.33).

Twenty per cent of the women in this sample did not attend a clinic appointment recommended by their gynaecologist. Inadequate follow-up may place women at greater risk of cervical cancer. In Chapter Ten I explore which factors are associated with women's non-attendance.

Concordance between cytology, colposcopy and histology

I assessed the relationship between the three assessment modalities — cytology, colposcopy and histology — by computing the degree of agreement between each of these measures and the predictive value of cytology and colposcopy. When a woman is referred she has her cytology result. In most cases at the initial visit a colposcopy is performed. Target punch biopsies are taken from the abnormal staining areas of the cervix, seen by the colposcopist, and then examined microscopically to yield a histological diagnosis.

The negative predictive value is the likelihood that an individual with a negative screening test does not have disease and the positive predictive value is the likelihood that an individual with a positive screening test does have the disease. For the purposes of the following analysis, disease was defined as CIN 2 or 3. CIN 1 or less was considered to be a negative result.

The histological diagnosis was taken to be the gold standard for defining the presence or absence of disease. I therefore computed the negative predictive value of Pap smears and colposcopy demonstrating CIN 1 or less and the positive predictive value of Pap smears and colposcopies demonstrating CIN 2 or 3.

To assess the relationship between cytology and colposcopy I define colposcopy as the gold standard. In this situation the negative predictive value of Pap smears demonstrating CIN 1 or less, and the positive predictive value of Pap smears demonstrating CIN 2 or 3 were calculated.

For the following analysis I have combined all presenting smears that were normal, inflammatory, inconclusive, atypia and HPV to form one category called 'No CIN'.

To measure the degree of agreement between the three investigative modalities (cytology, colposcopy and histology) I have used a weighted kappa. The weighted kappa takes into account the amount of disagreement between the different tests, whereas an ordinary kappa only measures the degree of perfect agreement between the different measures and hence is more suited to the analysis of nominal rather than ordinal variables. (Altman 1991).

The results from this analysis should be viewed with caution. Many women in this sample reported having had previous smears demonstrating an

abnormality; women who have had two smears demonstrating minor abnormalities are more likely to have major abnormalities than those who have never previously had an abnormality. In this study pathologists or gynaecologists were aware of the results of other tests. Therefore the correlation between the different assessment modalities is likely to be biased. There are also problems with defining any test as the gold standard. Colposcopy may give a false negative report if the lesion is located high in the endocervical canal. And, histology may be falsely negative if target punch biopsies miss the affected area.

Presenting smear and colposcopy (Table 8.5)

Table 8.5 demonstrates the relationship between presenting smear and initial colposcopy.

Table 8.5 Concordance between cytology and colposcopy (n=492)

		Initial colposcopy				
		No CIN	CIN 1	CIN 2	CIN 3	
Presenting smear number % of row	No CIN	126	75	27	1	229
		55%	32.8%	11.8%	0.4%	100%
	CIN 1	16	37	15	3	71
		22.5%	52.1%	21.1%	4.2%	100%
	CIN 2	32	43	58	6	139
		23.0%	30.9%	41.7%	4.3%	100%
	CIN 3	6	5	13	29	53
		11.3%	9.4%	24.5%	54.7%	100%

For the purposes of this analysis disease is defined as CIN 2 or 3 on colposcopy.

The negative predictive value of cytology showing no CIN and CIN 1 was 88 per cent and 75 per cent respectively. Excluding women who had had previous abnormalities, the negative predictive value of smears showing no CIN increases to 94 per cent. Excluding women who report previous abnormalities does not increase the negative predictive value of smears showing CIN 1.

Of the 109 women who had no history of prior abnormalities, and without CIN on Pap smear, none had CIN 3 on colposcopy. One woman out of 43

women with CIN 1 on Pap smear and no previous abnormalities, had evidence of CIN 3 on colposcopy.

The positive predictive value of smears showing CIN 2 and CIN 3 was 46 per cent and 79 per cent respectively.

Women with CIN 1 or less on presenting smear comprised 61 per cent of the total sample. They constitute 30 per cent of those who had CIN 2 or 3 on colposcopy, and ten per cent of those who had CIN 3 on colposcopy.

The weighted kappa for colposcopy and presenting cytology was 0.41. This represents only moderate agreement between the two measures. (Altman 1991).

Presenting smear and histology (Table 8.6)

Disease is defined as CIN 2 or 3 on histology. If no biopsy was performed the initial colposcopy result was used.

The negative predictive values for smears with no CIN and CIN 1 were 83 per cent and 63 per cent respectively.

Table 8.6 Concordance between histology and cytology (n=490)

		Initial histology				
		No CIN	CIN 1	CIN 2	CIN 3	
Presenting smear number (% of row)	No CIN	122	66	32	7	227
		53.7%	29.1%	14.1%	3.1%	100%
	CIN 1	19	26	16	11	72
		26.4%	36.1%	22.2%	15.3%	100%
	CIN 2	28	40	47	24	139
		20.1%	28.8%	33.8%	17.3%	100%
	CIN 3	6	7	5	34	52
		11.5%	13.5%	9.6%	65.4%	100%

The positive predictive value of smears showing CIN 2 was only 51 per cent. In contrast the positive predictive value of smears showing CIN 3 was 75 per

The weighted kappa for the relationship between presenting smear and histology was only 0.37 which is rated as only fair agreement.

Initial colposcopy and initial histology (Table 8.7)

To calculate the predictive values for this comparison, disease was defined as CIN 2 or 3 on histology.

Table 8.7 Concordance between histology and colposcopy (n=420)

		Initial histology				
		No CIN	CIN 1	CIN 2	CIN 3	
Initial colposcopy number (% of row)	No CIN	53	36	16	8	113
		46.9%	31.9%	14.2%	7.1%	100%
	CIN 1	41	65	40	13	159
		25.8%	40.9%	25.2%	8.2%	100%
	CIN 2	13	34	38	26	111
		11.7%	30.6%	34.2%	23.4%	100%
	CIN 3	3	2	4	28	37
		8.1%	5.4%	10.8%	75.7%	100%

Seventy-nine per cent and 67 per cent were the negative predictive values of colposcopies with No CIN and CIN 1 respectively. Again, if those women with no CIN on colposcopy had had biopsies the above results may have increased. CIN 2 had a positive predictive value of 58 per cent and CIN 3 had a predictive value of 86 per cent.

The weighted kappa between colposcopy and histology was 0.35 which is classified as fair agreement. The concordance between colposcopy and histology may have improved if those women with normal colposcopies had had biopsies.

Conclusion

In Chapter Two I discussed published studies on the reliability of cytology, colposcopy and histology. I established that the intra- and inter-test reliability of these tests is low. I have now shown that in this sample the inter-test reliability is also low.

Despite clinicians having the benefit of the results of other tests the agreement between the three tests was poor. This may be due, in part, to the lack of consistent reporting criteria for the different laboratories. The introduction of a consistent set of guidelines for reporting cervical abnormalities may improve the agreement between the assessment

modalities (Commonwealth Department of Human Services and Health 1994).

A significant proportion of women with CIN 1 or less on presenting Pap smears were found to have CIN 2 or 3 on colposcopy and histology because of the poor agreement between the tests and the high prevalence of disease in this study population. Because many of the women had had previous abnormalities the prevalence of major abnormalities in this sample may be higher than women with CIN 1 or less in the population. However, there were no cases of invasive cancer or microinvasive cancer in women who had Pap smears with CIN 2 or less.

The poor inter-test reliability has implications for women who have abnormal Pap smears, as well as for clinicians and public health practitioners. During my time collecting data, the gynaecologists working at the CLC frequently told me of women presenting with Pap smears showing only minor changes, but who on colposcopy or biopsy were found to have high-grade lesions. The gynaecologists were concerned that if they did not investigate all women with minor lesions, then some women with high grade lesions would not be treated and might develop cervical cancer. They accepted a low criterion of positivity in order to detect all women with high grade lesions.

The results reported in this section show that there is some basis for their concerns. However, to investigate every woman who has minor changes of CIN 1 or less would result in many orders of magnitude more women having colposcopy, biopsy and treatment than would ever develop cervical cancer. Although the program sensitivity may be high its specificity would be low. Such a situation concerns the public health practitioner.

For individual women, knowledge of the positive or negative predictive value may be a useful guide in making decisions about their own gynaecological care. If they had a minor grade lesion the negative predictive value tells them how likely they are to have a major lesion on histology or colposcopy. Based on this knowledge they could make a decision about whether or not to have a colposcopy.

These results cannot be considered representative of women who have CIN 1 or less on Pap smear in the general population; rather, they represent the experience of one colposcopy service. Further studies are needed to explore the relationship between cytology, colposcopy and histology in the clinical

setting. An ACT centralised cytology service that collects details of the gynaecological assessment of women who have abnormal Pap smears is ideally suited to explore this further.

Assessing the generalisability of the findings

In order to assess the relevance of the findings of this study to other clinical situations the age distributions and assessment and treatment practices of the CLC sample are compared with ACT and Australian Medicare samples.

ACT and Australian Medicare samples (Table 8.8)

The Medicare Estimates and Statistics Section of the Commonwealth Department of Human Services and Health (DHSH) extracted two samples of women who claimed on Medicare for a colposcopy[2] over the period 1 January 1989 to 30 April 1990 (the same time period for which women were eligible for the CLC study) who had not claimed for colposcopy in the previous two years. One sample was of women with an ACT postcode, the other was of all Australian women. The two-year criterion was used so that only women commencing treatment were included in the samples. However, it is likely that the Medicare samples include some women who had had a cervical abnormality more than two years previously. In contrast, my sample only includes women who, as far as I can ascertain, have never previously been referred to a gynaecologist for the assessment and treatment of a cervical abnormality.

To convert the sample numbers to a population estimate, the number of women in the Medicare samples was multiplied by ten. Table 8.8 shows the total estimated number of women in the ACT and Australia billed for colposcopy during the time period of the study, who had not claimed in the two previous years.

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[2] I used the item number 35614 (formerly 6415) which is defined as: "examination of the lower female genital tract by a Hinselmann-type colposcope" (p179, Medicare Benefits Schedule Book, AGPS, Canberra, 1993). Benefits for this item are limited to the following circumstances: "(1) where a patient has had an abnormal cervical smear; (2) where there is a history of maternal ingestion of oestrogen by the patient's mother during her pregnancy; or (3) where the patient has been referred by another medical practitioner because of suspicious signs of genital cancer.

Table 8.8 Total Number ('000) of Medicare patients claiming for colposcopy (item 35614)

	Estimated number*	Standard error**	95% Confidence Interval
ACT	1.88	0.12	1.64 - 2.12
Australia	64.8	0.71	63.4 - 66.2

* The estimates of the population totals were obtained by multiplying the number of women in each sample by ten as the Medicare samples were obtained from the ten percent sample of Medicare enrollees.

** See Appendix A for details of how the standard errors were calculated.

Sampling fraction

The sample of 502 women included in this study make up 27 per cent of the estimated total number of women claiming for the first time during the study period. The total estimated number of ACT women billed for colposcopy during the study period was used as a denominator for this calculation (Table 8.8). The estimate of 27 per cent is a lot lower than expected because, as stated earlier, only six gynaecologists regularly practise colposcopy and laser in Canberra and only four of these work from the CLC. However, the ACT estimate is likely to be a biased estimate of the population from which the CLC sample was derived, for the following reasons:

1. The ACT sample includes women who claimed for colposcopy more than two years earlier, and therefore may have had a previous abnormality, whereas the clinic sample excludes women who have previously been investigated for an abnormal Pap smear by a gynaecologist;

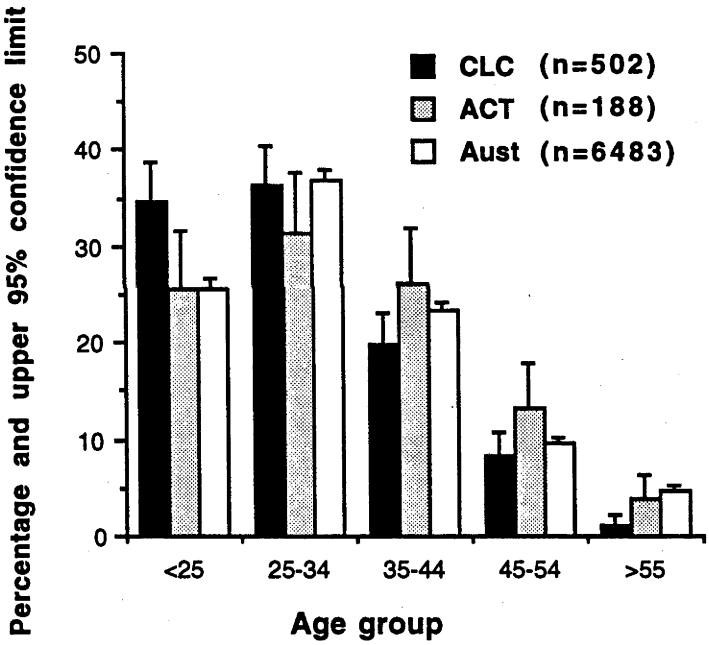
2. The ACT sample includes women who claim for colposcopy because of another genital tract abnormality (for example, vulval warts), whereas the CLC sample only includes women who have been referred with an abnormal Pap smear;

3. The ACT sample only covers women who have a colposcopy and who are resident in the ACT, whereas the CLC sample includes women from outside Canberra. (As the postcode of women in the sample was not collected I do not know the proportion of women who attended the CLC from outside the ACT.) There is no way of estimating the population of women who would come to the ACT for treatment if they had an abnormal Pap smear. Some ACT women seek investigation interstate and some women from interstate seek investigation in the ACT.

Reasons 1 and 2 are likely to result in an overestimation of the true denominator and therefore reduce the estimate of the proportion of the total population represented by the CLC sample. The inclusion of ACT women who seek investigation interstate in the denominator of the sampling fraction, underestimates the proportion the CLC sample represents of women having colposcopy in the ACT. Interstate women seeking investigation in the ACT are not included in the ACT total estimate, resulting in an overestimate of the proportion represented by the CLC sample. Nonetheless it is evident that this clinic sees a reasonably large proportion of women who are referred for the investigation of an abnormal Pap smear in the ACT.

Age distribution (Figure 8.1)

Figure 8.1 Age distribution of CLC and Medicare samples



The CLC sample was slightly younger than the ACT and Australian Medicare samples. Thirty-four per cent of the women in the clinic sample were under 25 years of age, while in both the ACT and Australian Medicare samples only 26 per cent were under 25. The CLC sample had a smaller proportion of women in the age group 45 to 54 and over 55 than both the ACT and Australian populations. The ACT has a greater proportion of people in the younger age groups than elsewhere in Australia, which might explain the age differences between the CLC and the Australian Medicare

samples. The age differences between the clinic and ACT sample are less easily explained. However, the age differences are modest and are unlikely to produce large biases in the cost estimates.

Distribution of abnormalities

It has not been possible to compare the distribution of cytological abnormalities seen at this clinic with an ACT sample because there was no cervical cytology register operating in the ACT at the time of the study. There are no published Australian data on the distribution and frequency of women with different abnormalities referred for gynaecological assessment. Because there is a larger proportion of younger women in the CLC sample, and younger women have a higher prevalence of minor abnormalities, it is likely that the CLC sample has a higher proportion of women with minor abnormalities than the Medicare samples.

Assessment and treatment practices

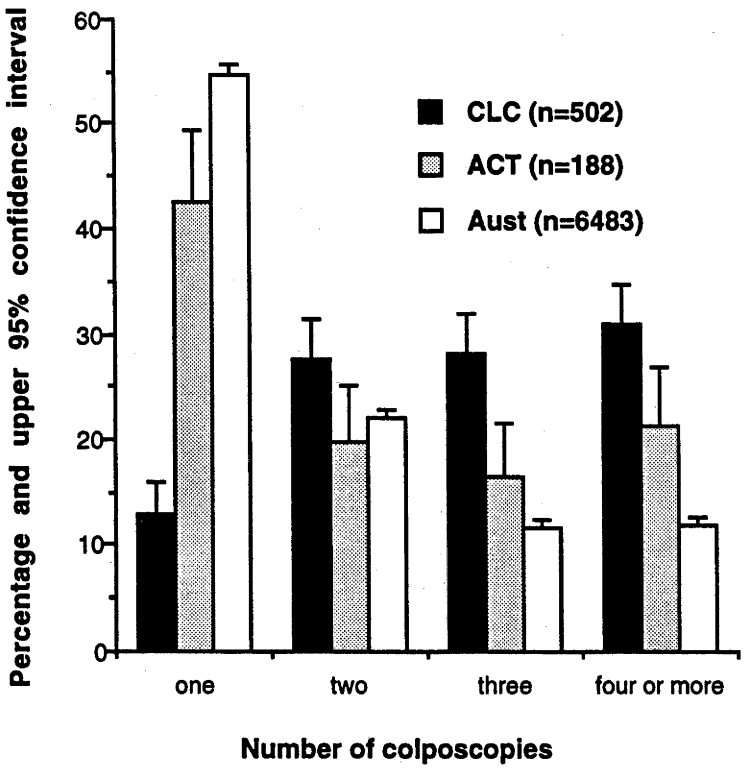
It is not possible to compare the assessment and treatment practices of this clinic with other services without conducting a case note audit on other services. There has been no published research in Australia examining gynaecological practice in relation to abnormal Pap smears. I have therefore again relied on the Medicare data to make my comparisons, despite several limitations. Although the Medicare file contains individual rather than aggregate data, I did not have direct access to Medicare data and it was impossible for me therefore to trace the experience of individual women or to know the follow-up status of women in the Medicare samples. Instead, the Health Insurance Commission provided me with aggregate totals. Many of the differences in assessment and treatment practices may be explained by differences in the prevalence of women with minor abnormalities and major abnormalities at the different services. Medicare data do not contain information about diagnosis.

Comparisons have been limited to claims for colposcopy, biopsy and laser treatment since other treatment methods such as diathermy, cone biopsy and hysterectomy require that women be admitted as inpatients to hospital. Large loop excision of the transformation zone (LLETZ) can also be performed as an outpatient procedure. Its use was infrequent in Australia until after 1992 (after this study was conducted). Inpatient services are only rebated on Medicare if a woman is admitted as private patient.

Consequently, although I have details for inpatient procedures for the clinic sample, I do not have comparable data for the ACT and Australian Medicare samples.

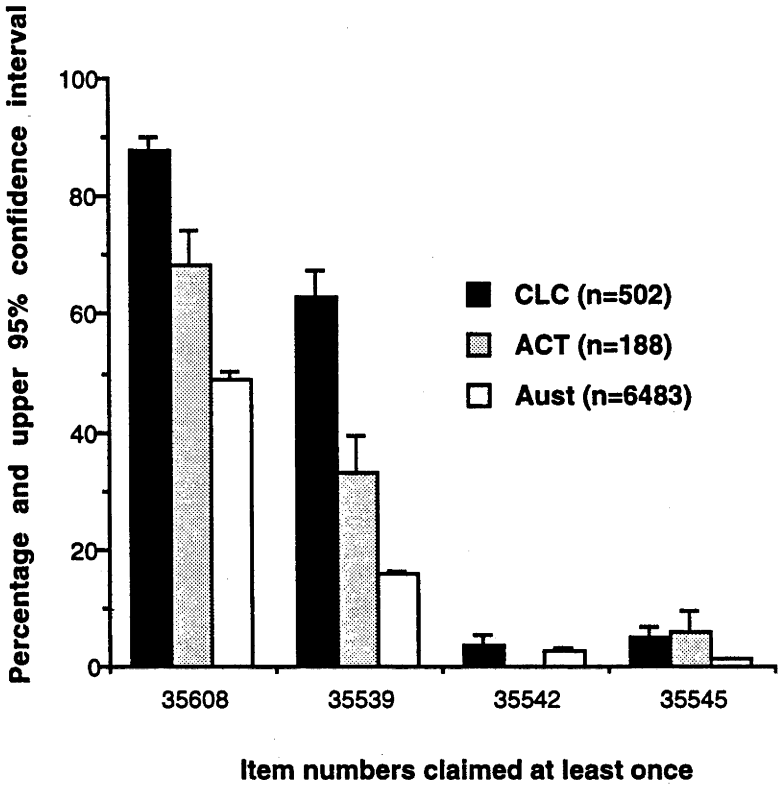
Figure 8.2 shows the obvious differences in the numbers of colposcopies claimed by the three different samples. A large proportion of the ACT and Australian samples had only one colposcopy (43 per cent and 55 per cent respectively). In contrast, only 14 per cent of the clinic sample were billed only once for colposcopy. The clinic sample has higher proportions of women having two, three and four or more colposcopies than the ACT and Australian Medicare samples. The new Commonwealth protocol recommends that women referred for the assessment and treatment of CIN should have a colposcopy to assess the lesion, plus a biopsy, and that after treatment they should have at least one follow-up colposcopy (Commonwealth Department of Human Services and Health 1994). The differences in colposcopy claims may be a reflection of inadequate assessment and treatment elsewhere in Australia and at other services in the ACT.

Figure 8.2 Proportion of women billed for colposcopies



A much greater proportion of women in the clinic sample were billed for laser treatment (item number 35539) (Figure 8.3). Only a small proportion of women in each sample claimed for laser to one or more anatomical sites (item 35542) or for laser to condylomata (item 35545).

Figure 8.3 Proportion of women billed for biopsy, diathermy and laser treatment



No data on the number of women in the ACT sample who claimed for item number 35542 were available because of the small numbers and the need to protect privacy.

The item numbers are described as follows:

35608 - CERVIX, cauterisation (other than by chemical means), ionisation, diathermy or biopsy of, with or without dilatation of the cervix

35539 - COLPOSCOPICALLY DIRECTED CO2 LASER THERAPY for previously confirmed intraepithelial neoplastic changes of the cervix, vagina, vulva, urethra and anal canal, including any associated biopsies - one anatomical site

35542 - COLPOSCOPICALLY DIRECTED CO2 LASER THERAPY for previously confirmed intraepithelial neoplastic changes of the cervix, vagina, vulva, urethra and anal canal, including any associated biopsies - two or more anatomical sites

35545 - COLPOSCOPICALLY DIRECTED CO2 LASER THERAPY for condylomata, unsuccessfully treated by other methods

Not all gynaecologists have a colposcope and CO_2 laser in their rooms. Because CLC has a CO_2 laser, a much higher proportion of women in this sample will have laser treatment than women in the ACT and Australian population samples. It is likely that many of the women in the other samples had inpatient treatment for abnormal Pap smears. The differences in the

proportion of women in the clinic sample claiming for one or more colposcopies may also mean that this colposcopy clinic offers more intensive assessment and treatment than services elsewhere. For both these findings mean that the applicability of the research findings of the CLC sample elsewhere may be limited. The differences in outpatient versus inpatient treatment is likely to result in a lower estimate of financial costs to government than would ap ply to a total population, while the more intensive assessment and treatment may overestimate the population costs.

Methods of costing

In the CLC sample, the cost of each woman's assessment and treatment was costed for the duration she was in the study. All outpatient and inpatient episodes were costed because the aim of the study was to cost current gynaecological care as it relates to women who have abnormal Pap smears.

Two costs were calculated — costs to government (Appendix E), and costs to women (Appendix F). These costs were calculated for the financial year in which they occurred, as well as for 1991/92, the latest financial year for which costs from the Health Insurance Commission were provided[3].

The financial costs to women and government only included the direct costs of medical care. Indirect costs such as loss of work time, child care and transport expenses were not included.

Most of the cost estimates used in this study are based on the charges (the price paid for a service) to government and to women. Finkler (1982) argues that charges are often poor proxies for the economic cost because the 'real' cost of a good or service may be different from its charge. However, while Medicare benefits do not represent the cost to the service provider they are the economic cost to government and women. Because this study is not estimating the cost to society, but rather the separate costs to government and women, charges are a legitimate measure of the cost of a service.

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[3] No discounting of costs was performed since the costs were incurred over such a short time period. Most health economic studies use discounting on the premise that people have a time preference for costs. That is, they would rather delay costs. Discounting enables present costs to be given greater weight than future costs.

The remainder of this chapter outlines how I calculate the costs under the headings of outpatient treatment, public hospital inpatient treatment and private hospital treatment.

Outpatient treatment

All visits to the CLC were outpatient visits. Medicare item numbers detailed in the patients' accounting records were used to determine the costs to government and to women for outpatient care. Rather than calculating the costs of treatment using the costs charged by the clinic, I have used a Medicare sample of ten per cent of Australians[4] enrolled in Medicare to calculate the costs. I did this for two reasons: using Medicare cost estimates improves the transferability of the cost findings of this study to other situations, and because it was difficult to obtain charges from the clinic.

Multiple items were billed at most visits. When multiple *therapeutic* services are performed (as was often the case for example, colposcopy and biopsy) then the scheduled fee is reduced and the Medicare rebate is 85 per cent of the reduced scheduled fee[5]. Items for consultation and local anaesthetic were not subject to the multiple operation formula.

Because most outpatient visits result in accounts with more than one item number, I determined the costs of treatment by using the item combinations for each visit as the units of costing. However, many combinations were not found frequently (less than 20 in the ten per cent Medicare sample). In this situation costs were calculated using charging bands. There are three charging bands (a to c). Charging bands are relevant for items subject to the multiple operation formula described in footnote 5. When items are rebated at 100 per cent of the scheduled fee they are on band a; when rebated at 50 per cent they are on band b; and at 25 per cent they are on band c.

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[4] An Australian rather than an ACT sample was used because the ACT sample would have been too small. Many item combinations would not occur with sufficient frequency to yield reliable estimates.

[5] For therapeutic procedures there is a multiple operation formula which states that: 'The fees for two or more operations, other than amputations, performed on a patient on one occasion are calculated by the following rules - 100% for the item with the greatest scheduled fee plus 50% for the item with the next greatest scheduled fee plus 25% for each other item.' The rule goes on to state that if two items have the same scheduled fee, one of the items will be treated as greater. (Section 8.5, p82, Medicare Benefits Schedule Book, AGPS, Canberra, 1992)

The average cost to government and to women for all item combinations charged by the clinic was calculated using a ten per cent sample of female Medicare enrollees for the financial years 1988/89, 1989/90, 1990/91 and 1991/92. The costs of cytology and histology were also calculated in this way. As the costs were based on a ten per cent sample of Medicare enrollees, they are subject to sampling variation (except in the case of pathology services where cost was calculated using the total population). The Medical Estimates and Statistics Section of the Department of Human Services and Health (DHSH) examined the distribution of costs to government and women and calculated the mean, median and variance for each item and item combination. Below I describe the methods for calculating costs and give a brief description of the DHSH analysis. Due to privacy restrictions of the DHSH, I was unable to examine the distribution of costs personally. Descriptions of the items billed and used for costing are in Appendix D.

Cost to government

The government pays the Medicare rebate for a particular item or item combination in an outpatient setting. Therefore, the average cost incurred by government is given by formula 8.1:

Formula 8.1

$$\text{Average cost to government} = \frac{\text{total benefits paid (Medicare rebate)}}{\text{total number of services}}$$

Tables E.1 to E.4 in Appendix E detail the costs to government of outpatient services for financial years 1988/89 through 1991/92.

The average and median costs to government are almost identical for the item mix table (E.1), abatement table (E.2) and consultation table (E.4). The median is always between 97 per cent and 102 per cent of the mean. The distributions tended to modal with very few outliers. This is because the rebate is set by government. The interquartile range was zero in most cases and was never more than seven per cent of the average cost to government. Therefore, although costs to government were not normally distributed, the average cost to government appears to be representative of the costs to government in all instances. This is because the only source of variation in these costs comes from changes in the scheduled fee. The standard errors are

included in Appendix E, Tables E.1, E.2, E.4 and E.6. These are extremely small relative to the mean.

Cost to women

Women pay the difference between the fees charged by gynaecologists and the Medicare rebate. Therefore, the average cost paid by women is given by formula 8.2.

Formula 8.2

$$\text{Average cost to women} = \frac{\text{total amount charged - total benefits paid}}{\text{total number of services}}$$

Tables F.1 to F.4 in Appendix F detail the costs to women of outpatient services for the financial years 1988/89 through 1991/92.

For the item mix Table F.1 and the abatement Table F.2 the median ranges from between 61 per cent to 129 per cent of the average cost to women. The distributions of cost tended to be positively skewed. That is, there is a greater range of cost above the median than below. The standard errors of costs to women, based on the ten per cent Medicare sample, were much greater than the standard errors for the costs to government. The use of the mean to calculate costs to women may overestimate costs incurred. For the consultation items the cost to women resembled more closely a normal distribution (Table F.3). In addition, the mean and the median were almost identical and the standard errors were low.

Inpatient services

There were 86 hospital inpatient services provided to women attending this clinic — 78 women were admitted to hospital, and eight women had two hospital admissions. I did not have access to the hospital case notes of any of these women, which made it more difficult to cost inpatient treatment than outpatient.

Cost to government for inpatient public hospital services

Most of the admissions (69) were to a public hospital (Table 8.9). Six women were admitted on two occasions. The four women in the 'other' category on Table 8.9 include one who had a secondary haemorrhage, another who had a hymenectomy, and two for whom the type of treatment was unclear.

Table 8.9 Public hospital treatment

Type of Service	No. of services
Laser	1
Diathermy	34
Cone biopsy	20
Vaginal hysterectomy	1
Total abdominal hysterectomy	9
Other	4
Total	69

I could not discern from clinic records whether the women admitted to public hospitals were private or public patients. I have therefore costed each woman's inpatient public hospital treatment as if she were a public patient. Private patients are charged by medical practitioners for the services provided in hospital and are eligible for a Medicare rebate. Costing all patients admitted to public hospitals as public patients may underestimate the cost to women and overestimate the cost to government. Women admitted as private patients may have out-of-pocket expenses.

Public hospitals are managed by the relevant State and Territory governments and are subsidised by Medicare grants from the Commonwealth. However, despite the different sources of financing for public hospital care, care such as outpatient treatment, for example, still involves a cost to one government or another. There is no cost to women for inpatient public hospital services.

To estimate the cost to government for inpatient public hospital treatment I multiplied the diagnostic related groups (DRG) cost per bed-day for the relevant procedure by the length of hospital stay (in days) for that procedure.

The DRG costs per bed-day were calculated for laser, diathermy, cone biopsy and vaginal and abdominal hysterectomy. These costs were determined for the financial years 1989/90 through 1991/92 for the relevant diagnostic related groups [6] using the casemix data at Woden Valley Hospital (WVH).

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[6] Diagnostic Related Groups (DRGs) are used to describe the casemix of hospitals for resource allocation purposes. Therefore, each DRG includes patients who are similar both in terms of their resource intensity and clinical features. I used the Australian National Diagnostic Related Groups as a means of classification. It contains 23 major diagnostic categories. Within each category, DRGs are defined as medical or surgical. A patient is considered as surgical if they have an operating room procedure during their hospital stay. (Australian National Diagnosis Related Groups, Definitions Manual, Version 1; 1992, Health Information Systems (Australia)).

The costs included WVH and Royal Canberra Hospital, the two major public hospitals operating in Canberra at the time of the expenditure study. There are no DRG cost data prior to 1989. I therefore used 1989/90 costs for 88/89. The DRG costs relate to the costs incurred by the hospital in the delivery of services both to public and private patients. Hence the DRG estimates provide some measure of the cost to government both for private and public patients. (The DRG estimates do not take into account the revenue that public hospitals receive from private health insurance companies for private patients.) The DRG codes used are detailed in Appendix D, Table D.2.

To estimate the length of stay for the procedures performed in public hospitals, the ACT hospital separation data were used. These data are coded according to the International Classifications for Disease 9-CM procedure classification (World Health Organization 1992). The procedural ICD-9 codes were used to examine the length of stay for various procedures. When no procedural code existed or if it was not relevant, the ICD-9 disease codes were used. The ICD-9 codes used are shown in Appendix D, Table D.3.

All records of inpatient stay, for the relevant ICD-9-CM and ICD-9 disease codes and during the time period of the CLC study (1 January 1989 to 16 August 1991), were extracted from the ACT hospital separation data base. This data base includes any patient admitted to one of Canberra's three public hospitals as a private or public patient. The average length of stay for each of the relevant codes was calculated. Women admitted as day patients were assigned a length of stay of one day. The cost of each procedure was calculated by multiplying the average length of stay (ICD-9 or ICD-9-CM code) by the average cost per bed-day (DRG code).

Each DRG code includes a variety of procedures or diagnoses. The ICD-9 or ICD-9-CM codes are more specific for particular episodes of inpatient stay. Cost estimates are not routinely made for specific ICD-9 or ICD-9-CM codes. Use of the ICD-9 and ICD-9-CM codes to estimate length of stay and the DRG per diem costs enables a more precise estimate of the cost of public hospital inpatient treatment than the DRG episode cost.

Hence the cost to government for an inpatient episode is given by formula 8.3.

Formula 8.3

Cost to government = mean DRG cost / day x mean LOS for procedure

Private hospital

Fifteen women had treatment at John James Hospital (JJH), the only exclusively private hospital in Canberra. Table 8.10 shows the distribution of cases.

Table 8.10 Private hospital treatment

Type of Service	No. of Services
Diathermy	6
Cone biopsy	9
Total abdominal hysterectomy	2
Total	17

Three components of treatment were used to calculate costs: cost of medical services, theatre costs and accommodation costs.

When women are admitted to private hospitals, the only costs government incurs are for inpatient services. The government does not contribute to the theatre or accommodation costs in a private hospital.

Because individual doctors, rather than the private hospital, issued bills to patients, the private hospital inpatient treatment was costed through the ten per cent Medicare sample. All records of women who claimed for the item numbers describing diathermy (35646), cone biopsy (35618) and total abdominal hysterectomy (TAH) (35653) as inpatients during the financial years 1988/89, 1989/90, 1990/91, 1991/92 were extracted from the ten per cent Medicare file. The relevant item number above and all other items referring to services provided on the same date were used to calculate the costs to government and women. This method ensured that items covering anaesthetic and pathology services were included in the cost calculations.

The cost to government is the Medicare benefit for inpatient services. The Medicare benefit falls to 75 per cent of the Medicare scheduled fee for private inpatient services. The costs to government of private hospital inpatient services were calculated using Formula 8.1.

Because the average cost is computed from a wide range of items the costs tended to be more variable outpatient costs to government, and approximated a normal distribution; the interquartile range was between 19 and 35 per cent of the mean. The median was between 90 per cent and 101

per cent of the mean. Table E.6 in Appendix E shows the average costs and standard errors of the surgical procedures.

Private health insurance covers women for the difference in cost between the Medicare benefit and the Medicare scheduled fee. All women admitted to the private hospital had private health insurance. Therefore the cost to women for medical services in a private hospital is given by Formula 8.4 below.

Formula 8.4

$$\text{Average cost to women} = \frac{\text{total amount charged - total scheduled fee}}{\text{total number of services}}$$

Although the costs to women of private inpatient services were distributed more normally than outpatient services, they still tended to be positively skewed. The median was between 73 per cent and 87 per cent of the mean. Table F.5 in Appendix F details the costs and standard errors of private inpatient treatment for women.

Government does not pay anything towards the theatre costs of private hospital treatment. Therefore, only the cost to women is outlined below.

The cost paid by women for theatre expenses was calculated by subtracting the private health insurance rebate from the costs charged by the private hospital.

John James Hospital supplied their schedule of theatre fees, and the dates of any changes in theatre fees, for the financial years 1988/89 through 1991/92 for diathermy, cone biopsy and TAH.

Medibank Private made available the schedule of benefits paid to women who claimed for the theatre expenses for specific procedures. They also provided the dates of any changes in benefits for theatre procedures. (Medibank Private is one of the four major private health insurance companies in the ACT, (Private Health Insurance Administration Council 1992).) The other three major insurance companies operating in Canberra would not provide their benefits schedule.

During the time of the study, the private health insurance rebate from Medibank Private always covered the theatre costs for the relevant

procedures at JJH; therefore women did not incur any costs for theatre charges.

Government does not pay anything for the accommodation costs of patients admitted to private hospitals.

The cost to women for accommodation expenses is given by Formula 8.5:

Formula 8.5

Cost to woman = n x (charge / bed day - private health insurance rebate / bed day)
where n = no. of bed days

Women were assumed to be in a shared ward for the purposes of the costs of accommodation.

ACT Hospital Separation Data were used to calculate the number of bed days for each procedure. Unfortunately, JJH was not part of this data collection during the study period. Again, ICD-9-CM codes were used to identify women who underwent the same procedures as the women who were admitted to JJH. All women who underwent the relevant procedures during the time period of the study (1/1/89 through 16/8/91) were extracted from the ACT Hospital separation data base. Only women who were admitted as private patients to the public hospitals in the ACT were used for this bed-day calculation. Women admitted as day patients were assigned a value of one for the number of bed-days. The median number of bed-days is used as the indicator of length of stay because the distribution of bed-day stays is positively skewed.

During most of the study period the private health insurance bed-day rebate covered the private hospital charges, resulting in no accommodation costs for women. Details of the costs paid by women for accommodation expenses in private hospitals during the time period of the study are to be found in Appendix F, Table F.6.

Costing each woman's treatment

Using the methods described in this section, the tables of financial costs to government and women outlined in Appendices E and F were generated. Each woman's gynaecological treatment was costed using these tables. According to the date of women's inpatient and outpatient treatment the

costs of treatment to government and to women were calculated using the relevant tables. When the date of hospital treatment was not known it was estimated to be the midpoint between the clinic visit before and the clinic visit after hospital treatment.

Perusal of the tables for costs to government and women shown in Appendices E and F, reveals that cost of services increased during the time period of the study.

Summary

In this chapter I have described the methods of data collection employed during this study as well as the sample characteristics. I have also compared the CLC sample with ACT and Australian samples obtained through Medicare. The CLC sample has a greater proportion of younger women and shows more frequent investigation and treatment than the ACT or national Medicare samples. The CLC sample is also likely to be biased towards more frequent outpatient rather than inpatient services. Also, this study is predominantly located in a private outpatient service. A different allocation of costs to government and women would occur had this study been performed in a public hospital outpatient service. Such differences limit the transferability of the cost estimates derived in this study to other clinical situations. Nonetheless, this is the first study in Australia to calculate costs based on real rather than hypothetical data, and to assess the cost of treatment on the basis of women's presenting Pap smear results.

I have shown that the concordance between cytology, colposcopy and histology was poor. I suggest that the poor inter-test reliability has different implications for women with abnormal Pap smears, for clinicians and public health practitioners. I return to these implications in Chapter Eleven.

The following two chapters report the analyses of costs and describe the patterns of attendance for follow-up in the CLC sample.

Chapter Nine

The financial costs of abnormal Pap smears

In this chapter I examine the cost to government and women for the gynaecological care of women who have abnormal Pap smears. I compare the cost of care on the basis of presenting smear, compute the potential savings of new Commonwealth policy recommendations for the care of women who have abnormal Pap smears, and examine what factors predict cost in this sample. Both current and alternative approaches are examined.

Two measures of cost are used. First, cost was calculated on the basis of the financial year in which the service was provided. For the remainder of the thesis I refer to these costs as 'current costs'. Second, cost was calculated using the financial year 1991/92 (the latest financial year for which the relevant Medicare data were available). These are referred to as 'constant costs'. The second calculation of cost gives a better approximation of the present costs of treatment. I refer to the cost of women's entire episode of care, from their first to last clinic visit, as the 'episode cost'. In this chapter, presenting smear is divided into four categories: No CIN, CIN 1, CIN 2, and CIN 3.

Cost to government of current approaches

In this section I compare the costs of care borne by government according to the category of presenting smear (No CIN, CIN 1, CIN 2, CIN 3).

Geometric mean cost to government and presenting smear

Because the costs to government in this sample of 502 women were positively skewed, the average cost is not an appropriate measure to compare costs for the different categories of presenting smear. The average cost is influenced by the individual cost estimates. Therefore, the geometric mean cost is used. This gives less weight to the large estimates. The natural logarithm of cost to government approximates a normal distribution. The entire episode cost is

compared for the different levels of abnormality. Cost estimates over the time periods three, six and 12 months are also compared for different levels of abnormality.

Women were included in the analysis of each time period if they were in the not-attending or discharged category (permitting the costing for their entire treatment episode), or if they were in another follow-up group and attended for the relevant time period (for example, 183 days for the six month category). In theory, if women in the other follow-up status codes (still attending, moved, or changed gynaecologists and unknown) were excluded from the analysis, biased estimates of costs would be obtained. For example, women in the 'still attending' category may have had more intensive treatment, or may have had recurrences or persistence of abnormalities, explaining why they had more 'days in study' than any other group (see Table 8.4 p174). If these women were dropped from the analysis, costs to government may be underestimated.

Tables 9.1 and 9.2 detail the geometric mean current and constant costs for different levels of presenting smear.

Table 9.1 Geometric mean current costs to government by level of presenting smear

	No CIN	CIN 1	CIN 2	CIN 3	All	One way ANOVA
0 - 3 months						
(n=481)						
Geometric mean	272.35	320.41	367.31	553.36	328.09	p<0.0001
(95% CI)	(248.93, 298.57)	(285.26, 360.00)	(337.14 , 400.21)	(472.23, 640.28)	(309.95, 347.23)	
0 - 6 months						
(n=459)						
Geometric mean	330.83	412.61	453.18	646.78	403.51	p<0.0001
(95% CI)	(300.76, 363.91)	(362.02, 420.27)	(418.34, 490.93)	(557.52, 750.17)	(380..77, 427.61)	
0 - 12 months						
(n=432)						
Geometric mean	390.52	481.11	543.48	776.50	477.47	p<0.0001
(95% CI)	(355.70, 428.80)	(419.26, 552.08)	(502.90, 587.34)	(663.22, 909.23)	(450.52, 505.98)	
0 - last visit						
(n=374)						
Geometric mean	404.03	497.70	571.00	768.32	486.34	p<0.0001
(95% CI)	(365.07, 447.20	(430.92, 582.37)	(527.05, 618.69)	(623.10, 947.38)	(456.41, 518.27)	

Table 9.2 Geometric mean constant costs to government by level of presenting smear

	No CIN	CIN 1	CIN 2	CIN 3	All	One way ANOVA
0 - 3 months						
(n=481)						
Geometric mean	295.57	345.40	403.27	634.54	358.99	p<0.0001
(95% CI)	(265.53, 325.75)	(305.88, 389.98)	(367.45, 442.61)	(535.34, 752.12)	(337.92, 381.42)	
0 - 6 months						
(n=459)						
Geometric mean	357.77	447.33	496.31	740.48	440.89	p<0.0001
(95% CI)	(324.18, 394.85)	(389.51, 513.73)	(454.96, 541.42)	(526.47, 875.24)	(414.51, 468.95)	
0 - 12 months						
(n=432)						
Geometric mean	420.99	520.19	594.90	889.36	520.19	p<0.0001
(95% CI)	(382.22, 463.68)	(449.80, 601.60)	(546.15, 648.01)	(746.42, 1059.66)	(489.31, 553.70)	
0 - last visit						
(n=374)						
Geometric mean	436.33	540.29	621.29	861.35	527.95	p<0.001
(95% CI)	(392.80, 484.69)	(460.95, 633.27)	(569.18, 677.83)	(690.90, 1073.84)	(493.74, 564.53)	

Cost increases with the level of abnormality. The significance of these differences was tested using a one-way analysis of variance. This was highly significant for both constant and current costs, for all time periods. The means for each group were compared using the least significance differences test in SPSS (SPSS-X Inc 1988). A five per cent significance level was used. This test showed that the costs to government for CIN 1, CIN 2, and CIN 3 were statistically significantly different from No CIN for both constant and current costs, for all time periods. The costs to government for the No CIN, CIN 1, and CIN 2 groups were also statistically different from the CIN 3 group over all time periods and for both current and constant costs. That is, the cost to government for the gynaecological care of women in the No CIN group was less expensive than for women with CIN. And, the cost to government of the CIN 3 group was greater than CIN 2 or less. The CIN 1 and 2 groups were not statistically different in terms of costs to government.

It is the magnitude of the differences between the groups that is important for policy, however. The cost of treating CIN 3 is much greater than any of the other abnormalities at each time interval.

The majority of costs occur in the first three months when women are likely to have both an assessment and treatment visit.

If the discharged and not-attending groups only are used to calculate costs, then the geometric mean cost is underestimated when compared with the geometric mean cost calculated when women who attended (from the other follow-up status groups) for the relevant time period are also included. For No CIN, CIN 1 and CIN 2 the magnitude of this underestimation is small. However, for CIN 3 this bias is much greater, particularly at longer time intervals. At 12 months (using constant costs), if the discharged and not-attending groups only are used, the geometric mean cost to government for CIN 3 is $791.13 (95% confidence intervals 649.43, 964.20), which is less than the estimated $889.36 (95% confidence intervals 742.71, 1064.86) using all women who attended for 12 months as well as women in the discharged and not-attending groups.

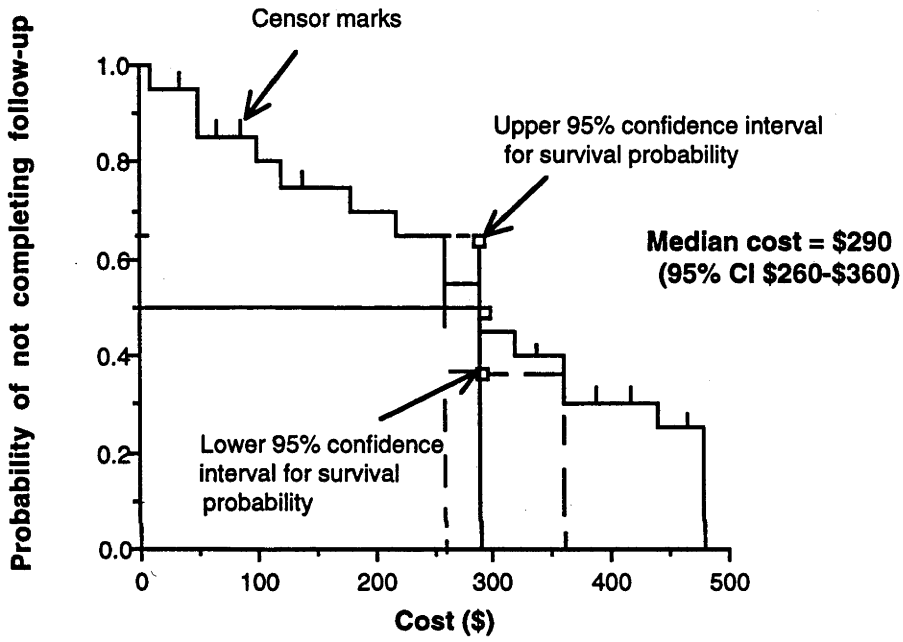
One explanation for the tendency to underestimate costs for CIN 3 when using not-attenders and discharged categories alone is that 21 per cent of women with CIN 3 were in the 'still attending' category, and these women are likely to incur larger costs because they were followed for a longer period of time. Between six and 12 per cent of women with No CIN, CIN 1 and CIN 2 were in the 'still attending' follow-up category. Over three quarters of women in the No CIN, CIN 1 and CIN 2 groups on presenting smear were in the 'did not attend' and 'discharged groups'; however, only 55 per cent of women who had CIN 3 on presenting smear were in these groups.

Twelve-month costs and episode costs are similar for all categories of presenting smear. Episode costs are likely to be underestimated by this technique because only women in the did not attend and discharged categories were included in the estimation of the geometric mean episode cost. Only these women could be assumed to cost no more to government for this episode of care. This underestimation is likely to be more evident for CIN 3 for the reasons stated earlier. Indeed, both current and constant geometric mean episode costs are less than the geometric mean twelve-month costs for CIN 3.

Median cost to government and presenting smear

One way to adjust for the likely biases resulting from estimates based on women at different stages of follow-up is to use survival analysis. Survival analysis enables the calculation of median cost of treatment which has been adjusted for censoring. Figure 9.1 illustrates how the calculation of median cost was made.

Figure 9.1 Illustration of procedure used to calculate median cost



In this section the median cost of treatment is estimated using the Kaplan-Meir curve. Cost is on the X axis instead of time. Cost, like time, is a continuous variable that consistently increases (i.e. is monotonic) and hence can be used in the same manner as time. For the purposes of this analysis, women who are discharged and who do not attend are 'failures' in the traditional survival sense. The Y axis is the cumulative survival probability and in this instance is the cumulative probability of continuing treatment. This 'failure' occurs at the cost of this episode of treatment because cost, rather than time, is on the X axis. All other cases were censored, but contribute to the calculation of cost until they were censored. Because survival analysis allows for censoring, an unbiased estimate of median cost is obtained. This analysis was performed in EGRET (Statistics and Epidemiology Research Corporation 1990).

The median cost is the cost at the point at which 50 per cent of women have completed follow-up. In the illustration, 45 per cent of women had completed at a cost of $260 (i.e., only 55 per cent had not completed treatment). At $290, 55 per cent had completed follow-up (i.e., 55 per cent had not completed follow-up). The median cost is defined as $290 because the line crosses the 50 per cent mark at this cost. EGRET estimates 95 per cent confidence intervals around the different survival probabilities (i.e. around points on the Y axis). To calculate the 95 per cent confidence intervals around the median cost estimates, the confidence intervals for the survival probabilities were used. This is shown in Figure 9.1. In the illustration, the upper and lower confidence intervals of the survival probability (probability of not completing follow-up) are approximately 0.65 and 0.35. Then, the cost at which the survival probability is equal to, or crosses this survival probability, is identified from the graph. These costs are $360 and $260. This method enables an approximation of 95 per cent confidence interval around the cost estimate to be made. Figure 9.1 also has censor marks which illustrate the observations of the follow-up status groups moved or changed gynaecologists, still attending and unknown. The costs for women in these groups contribute to the calculation of cost, at different survival probabilities, up until their last visit, when their observations are censored.

Table 9.3 Median cost to government by level of presenting smear ($)

	No CIN (n=230)	CIN 1 (n=73)	CIN 2 (n=142)	CIN 3 (n=56)	Total (n=502)
Current cost					
Median	511.77	488.50	601.66	1036.44	540.70
(95% CI)	(470.36, 537.35)	464.57, 548.30)	(540.70, 673.48)	(751.84, 1781.83)	(537.35, 601.66)
Constant cost					
Median	541.05	529.28	642.20	1372.73	580.69
(95% CI)	(504.85, 562.27)	(504.85, 580.69)	(580.69, 713.95)	(866.80, 2146.22)	(562.27, 640.25)

Table 9.3 shows the median costs to government for each category of presenting smear. Similar median costs are obtained for No CIN and CIN 1. The median cost of treatment is greater for CIN 2 than lower levels of abnormality. However, the median cost of treatment of CIN 3 is much greater than for any of the other groups and might reflect the increased chance of hospitalisation and prolonged follow-up in this group.

Proportion of the cost of total care to government and presenting smear

In this section I show the contribution of each abnormality to the total costs of gynaecological care for the sample at three, six and 12 months and for the entire treatment episode. In these calculations, women in the discharged and not attending categories are included for all time periods and women in other categories are included if they attended for the relevant time period. Only women in the discharged and did not attend categories are used to calculate episode costs. (These are the same inclusion criteria as those used for the calculation of the geometric mean cost to government.)

At all time periods the No CIN and CIN 1 categories combined constitute more than 50 per cent of the costs of treatment to government for this sample. Therefore, a substantial proportion of the costs to government come from minor abnormalities. This is because more women were referred with CIN 1 or less than CIN 2 or CIN 3. Recent policy regarding the gynaecological care of women with screen-detected abnormalities proposes more conservative treatment for these minor abnormalities (Commonwealth Department of Human Services and Health 1994).

Figure 9.2 Proportion of total constant costs to government at three months

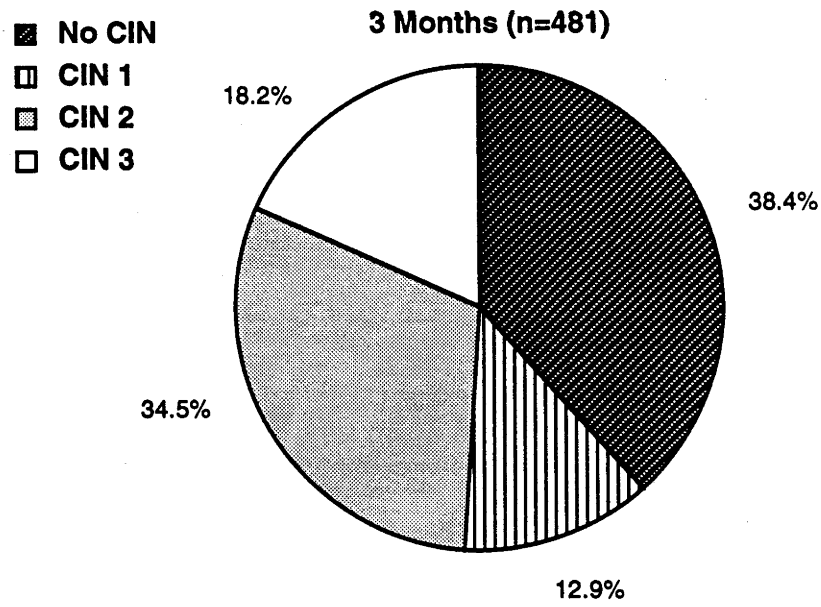


Figure 9.3 Proportion of total constant costs to government at six months

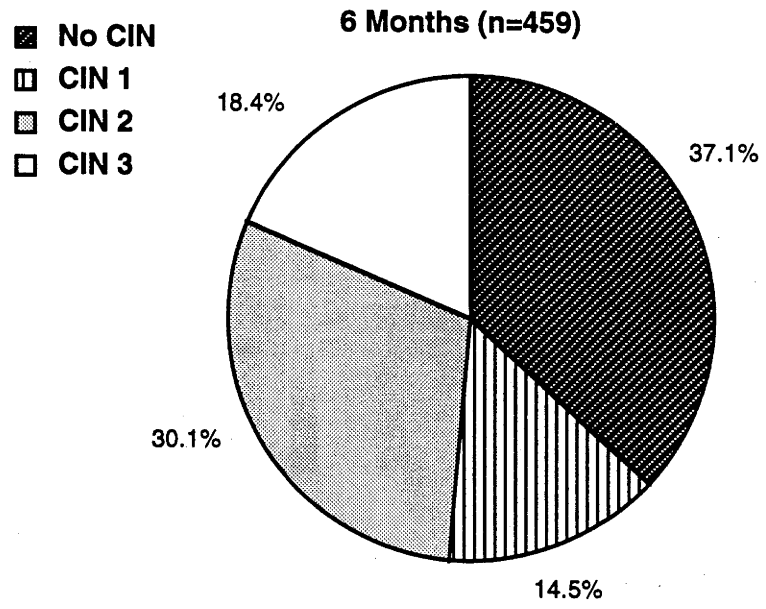


Figure 9.4 Proportion of total constant costs to government at 12 months

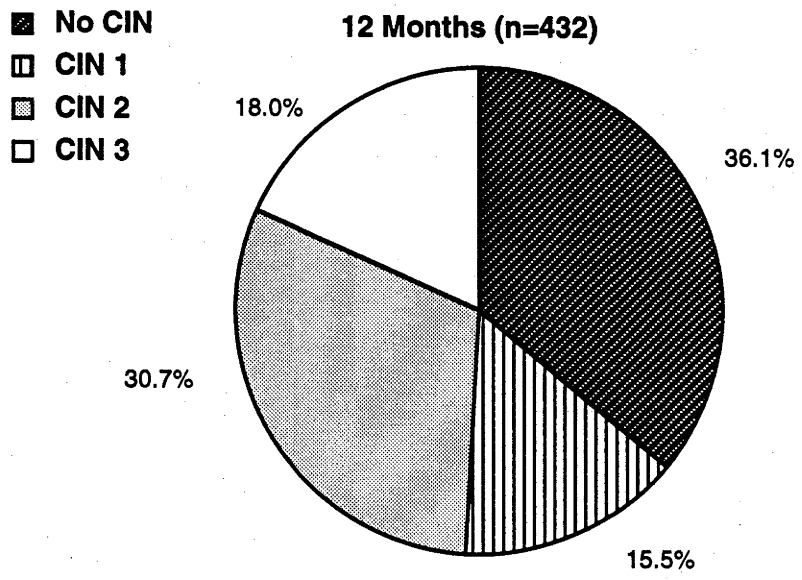
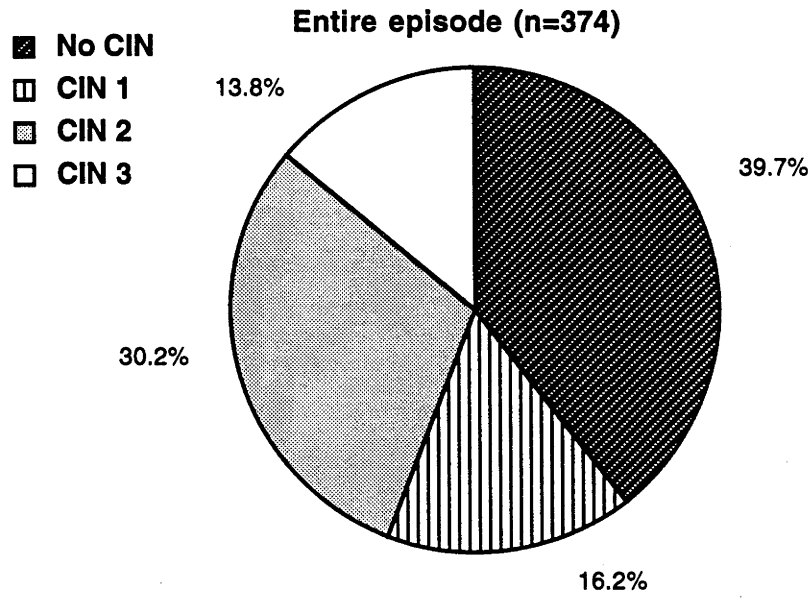


Figure 9.5 Proportion of the total constant costs to government for entire episode



Cost to women of current approaches

The costs to women of gynaecological care according to the severity of their presenting smear are described in this section.

Arithmetic mean cost to women

The estimated costs to women approximate a normal distribution, hence the arithmetic mean costs are compared for each category of presenting smear. Current costs are shown in Table 9.4 and constant costs are shown in Table 9.5.

In Chapter Eight I discussed the distribution of costs to women that were calculated using the ten per cent Medicare file. (The relevant data are in Tables F.1, F.2, F.3 and F.5 in Appendix F.) I discussed how these costs to women tend to be positively skewed and there were large variances in the estimates of the mean. Cost estimates for each woman in the clinic sample were obtained, in part, from the ten per cent Medicare file cost estimates. Therefore, the cost estimates for each woman's treatment are subject to error. To describe this error I include, for each category of presenting smear, the mean variance of the individual cost to women estimates. This gives an indication of the variability of individual cost to women estimates. I have

called this the mean intra-individual variance[1]. These were not included in the cost to government because the variance in the estimates of the individual cost to government estimates was very small.

Tables 9.4 and 9.5 show the mean costs to women at three, six, 12 months and total costs using both current and constant costs respectively.

Women were included in the relevant time period calculation if they attended for that time period or were in the discharged or not attending category. Only women in the discharged and not-attending category were used to calculated the mean episode costs of treatment for each category of presenting smear. Similar results are obtained when only the discharged and not attending categories are used to calculate average costs over all the time periods.

One-way analysis of variance showed statistically significant differences in the costs to women between the groups for all time periods and for both current and constant costs. However, using the least significant differences test described earlier, only the CIN 2 and No CIN group are statistically significantly different, at the five per cent level, for all time periods. At three months, all CIN groups have statistically significant different costs compared with the No CIN group.

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[1] The variance of each woman's cost estimate was calculated by summing the variance of all the components of the cost estimates. For example, the cost at one clinic visit might consist of a consultation fee as well as cost of colposcopy. The variance in the estimate for consultation would be added to the variance for the cost in colposcopy and would constitute the variance in cost for this visit. This variance would be added to the variance in cost for all other visits and inpatient procedures (if relevant). In this way the total variance in cost is obtained for each woman's treatment. The variances can be summed because it is known that the variance of a sum is equal to the sum of the variances, assuming that the components are independent.

An average variance for each category of presenting smear is produced by the adding variance of each woman's cost estimate and dividing by the number of women in the category.

When estimates with large variance are combined, a popular way of addressing the problem of their variances is to weight each observation by the inverse of its variance. It is not appropriate to use this procedure in this situation, however. To do this would result in a bias towards those cases with lower costs because they have the smallest variances.

Table 9.4 Average current costs to women by level of presenting smear ($)

	No CIN	CIN 1	CIN 2	CIN 3	Total	One way ANOVA
0 - 3 months						
(n=481)						
Average cost	89.83	102.74	106.09	102.74	97.84	p=0.008
(95% CI)	(84.16, 95.48)	(94.98, 110.59)	(100.19, 112.00)	(89.88, 115.63)	(94.23 101.44)	
Mean intraindividual variance	*6.07*	*8.31*	*8.57*	*9.14*	*7.46*	
0 - 6 months						
(n=459)						
Average cost	109.82	124.76	131.18	120.46	119.41	p=0.007
(95% CI)	(102.74, 116.89)	(114.79, 134.73)	(123.58, 138.78)	(106.95, 133.97)	(114.96, 123.87)	
Mean intraindividual variance	*6.21*	*8.66*	*9.41*	*10.58*	*7.99*	
0 - 12 months						
(n=432)						
Average cost	130.30	141.75	151.85	45.45	139.91	p=0.009
(95% CI)	(121.33, 139.60)	(130.40, 153.09)	(143.66, 160.04)	(127.91, 163.99)	(134.53, 145.30)	
Mean intraindividual variance	*6.73*	*9.08*	*9.69*	*12.77*	*8.59*	
0 - last visit						
(n=374)						
Average cost	135.46	150.87	167.19	151.74	148.36	p=0.001
(95% CI)	(124.83, 146.04)	(136.55, 165.19)	(155.93, 178.45)	(128.30, 177.17)	(141.60, 155.12)	
Mean intraindividual variance	*6.85*	*9.73*	*10.27*	*13.31*	*8.81*	

There is less variation in cost to women by level of presenting smear than variation in costs to government. In fact, CIN 2 costs more to women, on average, than CIN 3 for all time periods (although these differences were not statistically significant in the multiple comparisons test). This is probably because women with CIN 3 were more likely to have inpatient treatment. Most of these women were admitted to a public hospital which did not entail out-of-pocket expenses to them. Therefore, some women with CIN 3 would have paid less for their treatment than women who had outpatient treatment. Most of the costs are in the first three months of treatment. This analysis shows that women had significant out-of-pocket expenses.

Table 9.5 Average constant costs to women by level of presenting smear ($)

	No CIN	CIN 1	CIN 2	CIN 3	Total	One way ANOVA
0 - 3 months						
(n=481)						
Average cost	109.77	126.10	133.36	127.89	120.97	p=0.002
(95% CI)	(102.54, 117.01)	(115.97, 136.23)	(125.47, 141.25)	(110.81, 194.98)	(116.27, 125.97)	
Mean intraindividual variance	*12.99*	*13.81*	*13.27*	*12.79*	*12.80*	
0 - 6 months						
(n=459)						
Average cost	131.72	150.70	162.65	147.92	145.32	p=0.001
(95% CI)	(122.78, 140.66)	(138.42, 162.99)	(152.66, 172.64)	(130.05, 169.78)	(139.60, 151.04)	
Mean intraindividual variance	*13.29*	*14.65*	*12.93*	*17.15*	*13.82*	
0 - 12 months						
(n=432)						
Average cost	153.67	169.35	185.10	175.53	167.53	p=0.001
(95% CI)	(142.88, 164.46)	(155.49, 183.22)	(174.28, 195.93)	(152.53, 198.54)	(160.84, 174.21)	
Mean intraindividual variance	*14.58*	*15.31*	*12.51*	*18.98*	*14.56*	
0 - last visit						
(n=374)						
Average cost	158.84	179.73	202.04	184.76	176.59	p=0.002
(95% CI)	(146.18, 171.50)	(162.42, 197.04)	(187.95, 216.12)	(154.60, 214.93)	(168.35, 184.82)	
Mean intraindividual variance	*14.49*	*16.61*	*13.72*	*18.98*	*14.97*	

There is considerable intra-individual variation in the cost estimates particularly for the constant costs to women estimates.

Median cost to women

The median costs to women were calculated using survival analysis in the same way as discussed for costs to government.

The median costs to women are similar for the categories No CIN and CIN 1. CIN 2 appears to cost women more than CIN 1 or less. CIN 3 is slightly more expensive again. However, the magnitude of the differences between the costs of the various presenting smear categories is much less for women than

for government. This is probably because unless women are admitted to a private hospital they have no out-of-pocket expenses for hospital treatment. However, because most women had no out-of-pocket expenses for their hospital treatment, differences in costs to them for each category of presenting smear were less evident.

Table 9.6 Median cost to women by level of presenting smear ($)

	No CIN (n=230)	CIN 1 (n=73)	CIN 2 (n=142)	CIN 3 (n=56)	Total (n=502))
Current costs					
Median	151.02	152.09	178.10	184.86	164.52
(95% CI)	(149.78, 167.21)	(138.60, 173.95)	(175.79, 194.87)	(164.52, 252.65)	(156.15, 174.72)
Constant costs					
Median	180.84	180.84	207.25	226.49	196.97
(95% CI)	(173.67, 200.08)	(180.84, 196.97)	(200.08, 232.10)	(207.25, 321.79)	(189.27, 200.08)

Proportion of the cost to women and presenting smear

In this section I calculate the costs to women on the basis of their presenting smear. Total costs are the estimated costs paid by all women in this sample. At each time period the total costs paid by women in each category of presenting smear were computed and was divided by the total costs paid by women for that time period to give the proportion of total costs for that time period. These results are presented in Figures 9.5, 9.6, 9.7 and 9.8 and are based on constant costs.

The inclusion and exclusion criteria are the same as those used when calculating the average costs paid by women for each time period.

Costs paid by women with CIN 1 or less on presenting smear constituted over 55 per cent of the total costs paid by women for each time period. Over 40 per cent of the total costs paid at each time period were from women with no evidence of CIN on presenting smear. Clearly, minor abnormalities comprise much of the costs paid by women. The new Commowealth protocols attempt to rationalise the clinical care of women who have minor abnormalities. Below, I outline the projected savings in these costs if the new approaches were implemented in this clinic.

Figure 9.6 Proportion of total constant costs to women at three months

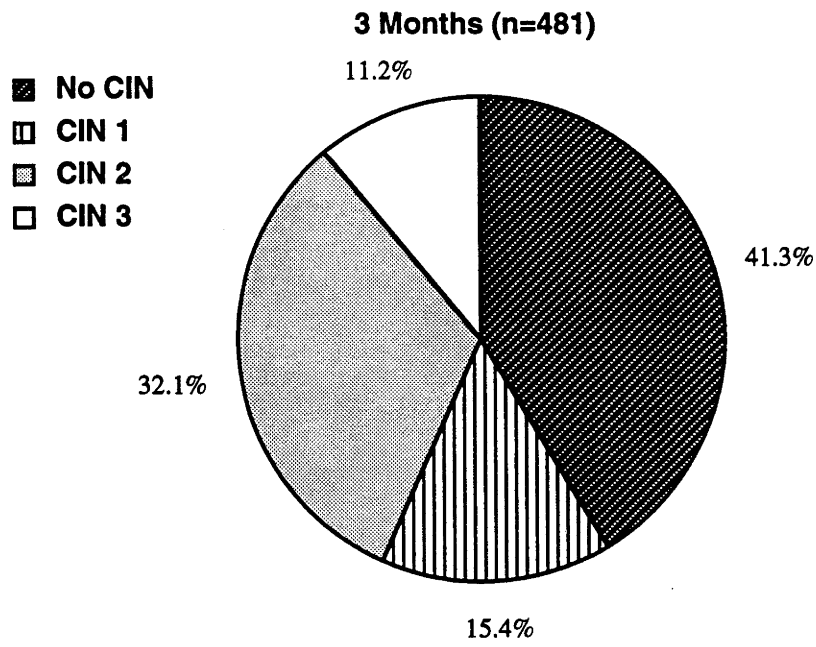


Figure 9.7 Proportion of total constant costs to women at six months

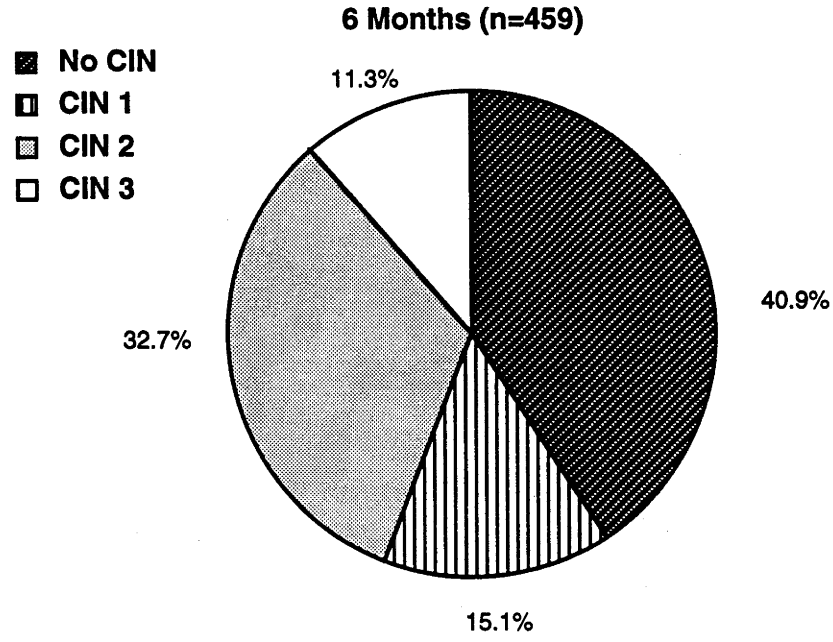


Figure 9.8 Proportion of total constant costs to women at 12 months

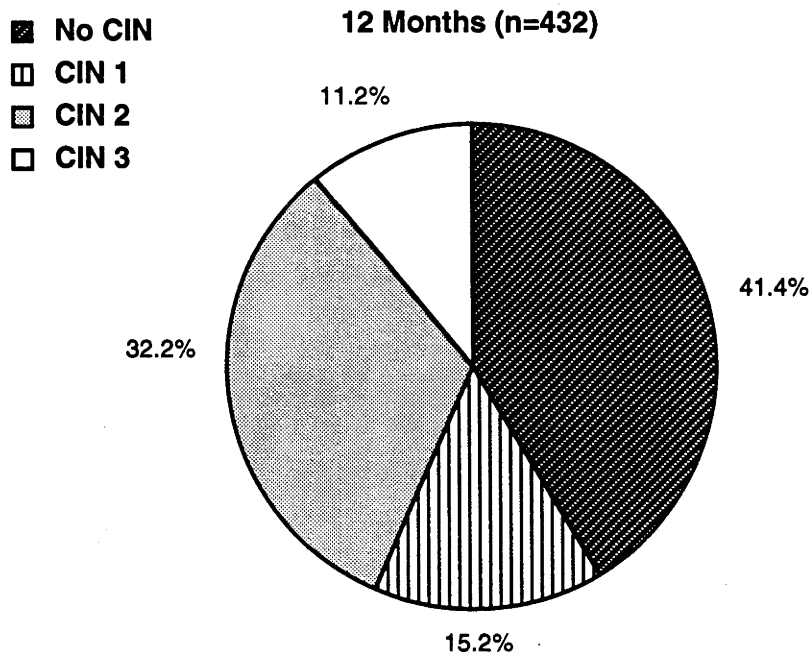
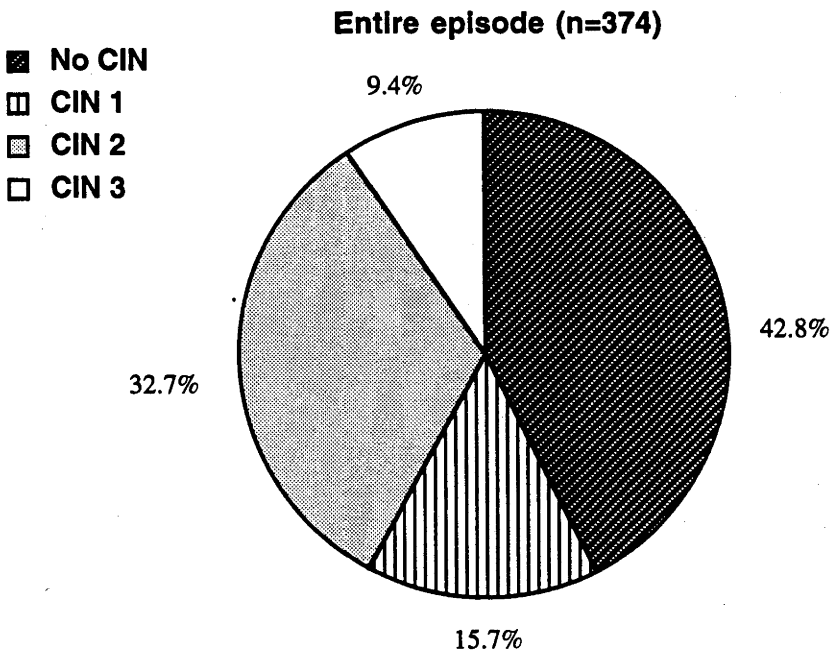


Figure 9.9 Proportion of total constant costs to women for entire episode



Comparing the costs to government of current and alternative approaches

In this section I estimate the proportion of the costs to government (due to the current approach of the clinic) that would be saved if the new Commonwealth policy (Commonwealth Department of Human Services and Health 1994) produced by the NHMRC Working Party for the Management of Women with Screen Detected Abnormalities, were instituted in this clinic. Constant costs are used for this analysis.

The new Commonwealth policy was summarised in Chapter Two. In the policy two clinical protocols for CIN 1 were proposed. These different protocols were referred to as "active" and "observational". The observational approach entails the assessment of all women who have CIN 1 with colposcopy and, if appropriate, biopsy. According to this approach, if a high-grade lesion (CIN 2 or greater) is demonstrated then treatment is undertaken. If assessment confirms a diagnosis of CIN 1, then it is recommended that women have Pap smears at six-monthly intervals until regression occurs. In contrast, the active approach entails the treatment of all women who have CIN confirmed on histology. Women with a diagnosis of HPV are recommended to have follow-up Pap smears rather than gynaecological assessment and treatment in the first instance.

I estimate the proportion of constant costs — resulting from the current approach of this clinic — that would be saved if these different approaches, active and observational, were introduced. In both cases it is assumed the newly recommended approach to HPV is also adopted. Table 9.7 details the assumptions used to construct the constant costs of the active and observational approach.

Table 9.7 Assumptions used to compare the costs of current and alternative approaches

	Current approach	Active approach	Observational approach
Who is referred for colposcopy and biopsy?	All women in the CLC sample	All women with CIN 1 or greater or women who have had previous abnormalities	All women with CIN 1 or greater or women who have had previous abnormalities
Who is discharged following colposcopy and biopsy?	All women in the CLC sample	All women with no evidence of CIN on biopsy	All women with no evidence of CIN 2 or greater on biopsy
Who is treated following colposcopy and biopsy?	All women in the CLC sample	All women with CIN on biopsy	All women with CIN 2 or 3 on biopsy

First, I describe the potential savings of the 'active' approach over the current approach of the clinic. It is assumed that women with No CIN and no past history of abnormalities are not referred to the clinic. Therefore the cost of their treatment is saved. I have assumed that all women who have a persistent abnormality, whatever the level of severity, are still referred for a gynaecological assessment. Only those with histological evidence of CIN have treatment. It is assumed that women without evidence of CIN are discharged and have their follow-up Pap smears with their general practitioners or other primary health care providers. They do not incur further costs for their gynaecological care once they are discharged.

Second, I describe the potential savings of the observational approach over the current approach. Like the active approach, it is assumed that women with no previous abnormalities and no CIN are not referred to the clinic. In this model, only women with CIN 2 or greater on histology have further treatment. For both the active and observational approach women with CIN 2 or CIN 3 are still referred for gynaecological assessment.

The assumptions do not entirely correspond with the policy recommendations. However, the models are useful approximations of the active and observational approaches outlined in the recent Commonwealth policy. In each case the results are presented as the proportion of the costs of the current approach that is saved for each of the time intervals.

Table 9.8 Costs to government saved from alternative approaches

	Savings of active approach compared with current approach (%)	Savings of observational approach compared with current approach(%)
3 months (n=481)	40.0	51.1
6 months (n=459)	40.8	53.3
12 months (n=432)	40.7	52.3
Entire episode (n=374)	43.4	55.5

About 40 per cent of the cost of the entire episode of clinical treatment could be saved in this clinic if the active approach was adopted. These savings are a result of a more conservative approach to the care of women who have no evidence of CIN. The observational approach would bring a further ten per cent savings on top of the active approach. The potential savings are slightly greater when episode costs, rather than costs of the time intervals three, six and 12 months, are used. These differences reflect the fact that the estimated

episode costs only include women who were discharged or non-attenders. As discussed earlier, women with a presenting smear of CIN 3 are more likely to be in the still-attending category. These women are likely to cost more to government. Their exclusion means that the total costs to government are underestimated and the potential savings of the new approaches overestimated.

These costs savings cannot be generalised to the population. As this modelling was done using the clinic data it only includes women who had been referred for colposcopy. Currently, some women with minor abnormalities may not be referred for colposcopy. There is no cost to government for the gynaecological care of these women currently, or under the active or observational options. The potential savings of the active and observational approaches could be estimated if the proportion of women who are currently referred with minor abnormalities such as atypia, HPV and CIN 1 was known. As there is no population data-base for cytology in the ACT it was not possible to estimate these referral rates.

Nonetheless, it appears that both the active and observational approaches, coupled with other recommendations regarding HPV, would produce substantial savings if introduced in this clinic. The potential savings of these strategies Australia-wide depends on the profile of abnormalities in the population that are referred to gynaecologists. Unfortunately, no estimate of the range and prevalence of the different grades of cytological abnormalities referred to gynaecologists in Australia is available. A high proportion of women referred to this clinic had CIN 1 or less. Another clinic with a less active approach to the management of minor abnormalities would result in fewer savings for women.

Under the active and observational approaches, some women who would not have treatment might need it in the future because their lesion progresses. If their lesions progressed to CIN 3 this may entail a greater expense to government. The marginal cost-effectiveness of the observational approach over the active approach depends on the probability of progression of minor lesions, particularly CIN 1. As discussed in Chapter Two, the studies on the natural history of minor lesions are poor. However, in Chapter Three I showed that many more women will be referred for colposcopy than would ever develop cervical cancer. Most women who are currently referred are unlikely to develop CIN 3. Therefore, most of the cost savings from a more

conservative approach to the gynaecological care of women who have smears showing CIN 1 or less, would be long term.

Earlier in the chapter I discussed the geometric mean and median costs to government of different levels of presenting smear. Assuming that the relationships between the costs of care remained the same, if even half the women with CIN 1 or less subsequently developed CIN 3 (which is much higher than would be expected from natural history studies), long-term savings from the active and observational approaches over the current approaches would still occur. Progression and regression rates for CIN 1 based on recently adopted reporting criteria (Commonwealth Department of Human Services and Health 1994) are needed before the cost-effectiveness of these two approaches can be evaluated further.

The new approaches to gynaecological care of women with abnormal Pap smears are likely to produce substantial cost savings in the short term. Much of the savings will result from the more judicious referral of women whose Pap smears show abnormalities with no evidence of CIN. However, the long-term impact of these new approaches depends on the natural history of minor abnormalities.

Comparing the costs to women of current and alternative approaches

In this section the costs savings for women of the new Commonwealth policy are outlined. The approaches are the same as those outlined in the previous section and are summarised in Table 9.7. Again, constant costs were used for this analysis.

The potential savings realised by government and women with the institution of the new Commonwealth policy recommendations have quite different meanings. Government can be considered a single entity. Thus new clinical protocols change the amount that government, as a single entity, pays. While new clinical protocols will decrease the total amount paid by women as a whole, the overall result achieved by the policies will have different impacts on different women. Some women will pay the same, some will pay less and others will have no out-of-pocket expenses.

In Table 9.9 the proportion of the savings of the costs of the current approach are shown for the active and observational approaches.

About 40 per cent of the costs to women of the current approach would be saved if the active approach were implemented. The cost savings are greater at the longer time periods. This is because I assumed that all women who had a previous abnormality were still referred. These women would receive a colposcopic assessment visit. In the case of the active approach, if their colposcopy was normal or there was no histological evidence of CIN these women were then discharged. This means they still incur a cost for their initial consultation which happens in the first three months.

Table 9.9 Cost savings to women under alternative approaches

	Savings of active approach compared with current approach (%)	Savings of observational approach compared with current approach (%)
3 months (n=481)	38.8	52.2
6 months (n=459)	39.2	53.9
12 months (n=432)	41.0	56.7
Entire episode (n=374)	42.1	57.8

Over 50 per cent of the costs to women of the current approach would be saved if the observational approach were implemented in this clinic. Again, the proportion saved is greater as the time period increases. This is because women with CIN and recurrent minor abnormalities are still assessed but only receive treatment if CIN 2 or greater is confirmed on biopsy. Like costs to government, these savings cannot be generalised to the population because they are based on women who have already been referred for colposcopy.

In sum, these are short-term savings. The savings in cost to women in the long term are contingent upon knowledge of the natural history of these minor lesions.

Substantial short-term savings in costs to women would be realised if either the observational or active approach were instituted in this clinic. However, this relates to the finding that over half of the costs paid by women in this sample are from women with CIN 1 or less. At a clinic with a lower proportion of women with minor abnormalities the cost savings to women of these new approaches would be less.

Predicting the cost to government

Throughout the chapter I have compared costs on the basis of the presenting smear. Government policy is formulated in the same way. That is, clinical protocols are based on pathological tests. However, the differences in cost to government for each level of presenting smear may be confounded by other factors, such as insurance status or a woman's age. The comparative costs I have shown depend on the distribution of possible confounders such as age and health insurance status.

In this section I therefore explore which factors predict costs to government in the Canberra Laser Clinic, using multiple linear regression. This enables the examination of the association between cost and presenting smear while controlling for possible confounders.

Methods

Costs for 1991/92 financial year were used for this analysis. That is, constant costs were used for the entire episode. The natural logarithm of cost was used as the outcome measure to achieve a constant variance of the residuals (homoscedasticity). Therefore, the antilog of the beta coefficient provides an estimate of the multiplicative effect on cost of moving from the baseline category of an explanatory variable to another category, while holding the other explanatory variables constant.

The normality of residuals assumption, which was tested by graphical means, was met by these models.

Only women in the 'did not attend category' or 'discharged category', who had no missing values on any of the explanatory variables, were included in this analysis (n= 328). Women who did not attend were included on the assumption that they would not consume any more resources for this treatment episode. (They may, of course, consume more resources in the future.) Similar results were obtained when the analysis was restricted to women who were discharged. A five per cent significance level was used.

Table 9.10 shows the frequency of variables used in this analysis. Two variables that have not been previously described were constructed for this analysis. The first variable describes whether or not there was evidence of HPV on the presenting smear (+/- CIN). The second describes whether there was cytologic, colposcopic or histologic evidence of persistent abnormalities following treatment at any of the visits following treatment.

Table 9.10 Frequencies of variables used in the multivariate analyses of costs to government and women

Variable	No. of women	Percentage (%)*
Presenting smear (1 unknown)		
No CIN	178	47.5
CIN 1	58	15.5
CIN 2	107	28.5
CIN 3	31	8.3
Age		
<25	129	34.4
25-34	136	36.3
>35	110	29.3
Health insurance status (46 unknown)		
No private health insurance	159	48.3
Private health insurance	170	51.7
Marital status (67 unknown)		
Ever married	229	74.4
Single	79	25.6
Parity (9 unknown)		
Nulliparous	177	49.7
Parous	179	50.3
HPV on presenting smear (1 unknown)		
No HPV	157	42.0
HPV	217	58.0
Persistence of abnormalities		
No persistent abnormalities	351	93.6
Minor abnormalities < CIN	10	2.7
CIN following treatment	14	3.7

* Cases with missing values on the variable were not included in the calculation of frequency per cent.

Age and insurance status were entered into the initial model because they may confound the relationship between presenting smear and cost. Presenting smear was then entered into the model. This significantly improved the fit of the model ($F(3,322)= 12.78, p < 0.0001$). This model details of which are given in Table 9.11 below — explained 12.8 per cent of the variation in costs.

Table 9.11 Cost to government and age, presenting smear and health insurance status

Variable	$e\beta$	95% CI	P value
Age			
<25	1.0		
25 - 34	0.91	0.78, 1.08	0.29
>35	0.84	0.71, 1.00	0.05
Health insurance status			
No private health insurance	1.0		
Private health insurance	0.95	0.82, 1.08	0.41
Presenting smear			
No CIN	1.0		
CIN 1	1.21	0.99, 1.47	0.06
CIN 2	1.41	1.20, 1.65	< 0.0001
CIN 3	2.05	1.58, 2.67	< 0.0001

$R^2=0.128$

$F(6,322)=7.94, p <0.0001$

In this model (Table 9.11) the cost of gynaecological care increases with the more severe levels of abnormality. After controlling for age and health insurance status, women with CIN 1 to CIN 3 cost government more than women with No CIN. This is statistically significant, at the five per cent level, for CIN 2 and 3. Women with CIN 3 cost approximately twice as much to government as women with no evidence of CIN. The relationship between diagnosis and cost is likely to be mediated by in-hospital treatment and through more clinic visits. More serious abnormalities may result in hospital admission and more costly inpatient procedures. Similarly, more serious abnormalities may result in more clinic visits. The increasing costs of treatment with level of abnormality may be related to the finding that women with more severe abnormalities are more likely to be admitted to hospital ($\chi^2=14.92$, df=3, p=0.002). However, although there appears to be an

association between the severity of the presenting smear and hospitalisation, the strength of this association is weak (phi=0.203, p=0.002). Also, women with higher levels of abnormalities appear to have more clinic visits (medians test, χ^2=15.64, df=3, p=0.0013).

Cost decreased with age. Women older than 35 cost 16 per cent less to government than women under 25.

An interaction between age and presenting smear was incorporated into the model to examine whether presenting smear is an effect modifier of age. The addition of this variable addresses the question: is the effect of age different for the different categories of presenting smear? Ten women had persistent minor abnormalities such as atypia or CIN following ablative or excisional treatment. Fourteen women had persistent evidence of CIN after treatment. A variable describing persistence of abnormalities was also added to the model. Adding the variables describing the age/presenting smear interaction and persistence of abnormalities significantly improved the fit of the model (F (8, 314)=3.73, p=0.003). Table 9.12 details this model.

Women who have persistent abnormalities with evidence of CIN cost the government approximately 60 per cent more than women with no persistent abnormalities after treatment.

For CIN 1 or less, women over age 35 cost government less than women under 25. When there is no evidence of CIN, women older than 35 cost government 63 per cent of the cost of treating women younger than 25 with no evidence of CIN. However, in the case of CIN 3, women over 35 cost the government 2.43 times more than women younger than 25.

In contrast, the costs of treating women in the 25 to 34 year old age group did not vary significantly from women under 25 for all levels of abnormality.

Table 9.12 Final model for predicting costs to government

Variable	e^{β}	95% CI	P value
Age			
< 25	1.0		
25 - 34	0.83	0.65, 1.05	0.13
>35	0.63	0.49, 0.80	0.0002
Health insurance status			
No private health insurance	1.0		
Private health insurance	0.95	0.83, 1.08	0.43
Presenting smear			
No CIN	1.0		
CIN 1	0.97	0.71, 1.33	0.86
CIN 2	1.05	0.81, 1.37	0.68
CIN 3	1.38	0.83, 2.31	0.22
Age/Presenting smear interactions			
Age 25-34 X CIN 1	1.14	0.73, 1.77	0.57
Age 25-34 X CIN 2	1.27	0.87, 1.85	0.21
Age 25-34 X CIN 3	1.25	0.68, 2.31	0.48
Age > 35 X CIN 1	1.73	1.05, 2.85	0.03
Age > 35 x CIN 2	1.74	1.20, 2.53	0.004
Age > 35 x CIN 3	3.86	1.74, 8.56	0.001
Persistence of abnormalities			
No recurrence	1.0		
No CIN	1.35	0.92, 1.99	0.12
Evidence of CIN	1.58	1.14, 2.20	0.006

R^2=0.226

F =5.77, df=16,312, p < 0.0001

On the other hand, for minor levels of abnormality, women younger than 25 cost government more than women older than 35. Further exploration of the data revealed more intensive outpatient follow-up of younger women with minor abnormalities. The Mann-Whitney test was used to compare the number of visits for women less than 25 and women 35 or older. Younger women had significantly more visits than women older than 35 (n=239, z=-2.37, 2 tailed p=0.018). However, after stratifying by category of presenting smear, it was found that there was only a statistically significant difference in the number of visits between women younger than 25 and women 35 or older if the presenting smear did not show any evidence of CIN (M-W test, n=116,

z=-3.09, 2 tailed p=0.0021). For presenting smears showing CIN 1 or greater there was not a statistically significant difference (at the five per cent level) in the number of visits between younger and older women.

Marital status and parity did not predict costs to government and were not confounders of other variables.

Conclusion

This multivariate analysis has demonstrated that there are associations between costs to government and presenting smear, age and persistence of abnormalities following treatment.

There are two problems with the analysis. First, only women in the discharged and not-attending categories were included, since it is not possible to account easily for censoring when there is a continuous outcome variable. The exclusion of women in the other follow-up status categories may bias the results. Second, I assumed that women who had private health insurance and were admitted to a public hospital (n= 8) were admitted as public patients. If these women were admitted as private patients the government receives some revenue. Hence the cost to government of these women's treatment would be overestimated. It could be argued that presenting smear is not a good measure of the severity of the abnormality since there was such poor correlation between presenting smear, colposcopy and histology. However, when this analysis was performed using histology instead of cytology, similar results were obtained (also including the interaction between age and level of abnormality).

The increasing costs of treatment for more severe levels of abnormality may be related to the increased chance of hospitalisation. Many gynaecologists in the ACT cannot treat women as an outpatient (for example, they do not have a CO_2 laser). These gynaecologists admit all women who require treatment to hospital. Such practices are likely to result in greater costs to government.

There is a suggestion that clinical practices may vary with different levels of abnormality for women of different ages. Women at younger ages appear to receive more intensive follow-up if they have minor abnormalities, while older women are more likely to have intensive treatment if they have severe abnormalities.

The increased cost of treating women older than 35 with CIN 3 may reflect the tendency for gynaecologists to undertake more radical treatment in the older age group. Four of the five women in this sample who had a hysterectomy were in the older age group. Conservation of reproductive function may be the rationale for less intensive treatment in the younger age groups. A sociological study based in an American hospital outpatient service which saw women with abnormal Pap smears, showed that clinicians were more likely to suggest hysterectomy to older women (Fisher 1986).

Explaining these differences requires further understanding of the world of the clinician. If an explanation for the increasing cost of treatment for women over 35 with CIN 3 is that they have radical treatment while younger women have more conservative treatment, why is this so? One answer might be that doctors think women over 35 are less likely to have further children and therefore use more radical treatment in the older age group. As discussed earlier, other studies have demonstrated that the treatment practices of clinicians vary with women's socio-demographic variables. For example, one Australian study showed that women with private health insurance were more likely to have a hysterectomy than women who only had public health insurance (Renwick 1991).

Why do younger women cost more when they have minor abnormalities? Younger women with no evidence of CIN have more visits than older women. Do the gynaecologists respond differentially to young women with minor lesions? If so, why? Are they more fearful of missing a significant lesion in a younger woman?

It is clear that the heterogeneity in the costs of treatment to government can not be adequately explained by clinicians making decisions on the basis of diagnosis alone. Other factors, such as a woman's age, influence clinical decision-making.

Containing the costs of current treatment could be improved if we had a better understanding of how diagnosis and other variables relating to both clinician and patient influenced cost. Clearly, factors other than diagnosis (as measured by presenting smear) explain the variation in costs.

Predicting costs to women

Like costs to government, the relationship between costs to women and presenting smear may be confounded by other factors such as age and health insurance status. Therefore, using multiple linear regression I examine the relationship between presenting smear and costs to women (after controlling for possible confounders), and explore other factors that may be associated with costs to women in this sample.

Methods

Cost to women is the outcome measure of interest. The assumptions of normality and constant variance of residuals were met by the following models. These assumptions were tested graphically.

In this analysis 328 cases were used. Only women in the discharged and not-attending categories were included. Women with missing values on any of the explanatory variables were not included in this analysis. A five per cent significance level was used.

Results

The frequencies of the categories for each of the variables used in this analysis were shown in Table 9.10.

Age and insurance status were entered into the model first. When presenting smear was added to this model it improved the predictive power of the model ($F=4.94$, $df=3,322$, $p=0.002$). The variable describing persistence of abnormalities was entered into the model next. This improved the model further ($F=29.4$, $df=2,320$, $P<0.0001$). The interaction between age and presenting smear, which was significant in the cost to government model, was not an important predictor of cost to women.

Another variable describing whether or not women had HPV of presenting smear was added to the model. This variable enhanced the model's predictive power a small amount ($F=4.48$, $df=2,319$, $p=0.04$). Parity and marital status did not explain the variation in costs to women in this sample.

Age, health insurance status, presenting smear and presence of HPV explained 24 per cent of the variation of the costs to women in this sample. Table 9.13 shows this model.

Whether or not women have persistent abnormalities after ablative or excisional treatment seems to exert influence over the costs women pay. Women with persistent abnormalities less than CIN pay, on average, $84 more than other women, after controlling for the other variables. If a woman has persistent CIN after treatment then she pays $130 more. These women will be followed for longer, and may receive further treatment, because of their persistent abnormalities. The Mann-Whitney test shows that women with persistent minor abnormalities (no evidence of CIN) tended to have more visits than women who had normal smears and colposcopy following treatment (M-W Test, n=361, z=-3.23, p=0.0012). Women with CIN following treatment also attended a greater number of visits than women who had normal cytology or colposcopy following treatment (M-W test, n=366, z=-4.96, p<0.0001).

Table 9.13 Predicting costs to women

Variable	β ($)	95% CI	P value
Age			
< 25	0.0		
25 - 34	-3.64	-23.59,16.31	0.71
>35	-29.15	-50.57, -7.73	0.008
Health insurance status			
Public health insurance only	0.0		
Private health insurance	3.46	-12.94, 19.84	0.68
Presenting smear			
No CIN	0.0		
CIN 1	8.30	-10.35, 26.95	0.49
CIN 2	30.50	11.84, 49.16	0.0015
CIN 3	20.95	-9.67, 51.57	0.18
HPV on presenting smear			
No HPV	0.00		
HPV	18.48	1.39, 35.57	0.035
Persistence of abnormalities			
No recurrence	0.0		
No CIN	83.95	37.97, 129.93	0.004
Evidence of CIN	130.26	90.96, 169.56	<0.0001

R^2=0.244

F=11.46, df=9, 319 p < 0.0001

Women older than 35 appear to pay less than younger women. There is no statistically significant difference in the effect of age for different categories of presenting smear. In the costs to government analysis women over 35 paid more for major abnormalities and less for minor abnormalities. However, most of the effect for major abnormalities may have been explained by an increasing risk of hospitalisation and more radical treatment in this age group. Because public hospital inpatient treatment does not cost women anything, the interaction between age and presenting smear is not important even though older women had more radical treatment than younger women for higher levels of abnormality. Instead, because younger women have more clinic visits, younger women had slightly greater out-of-pocket expenses than women over 35.

Women with HPV paid on average about $18 more than other women after controlling for other variables. However, there was not a statistically significant difference in the number of visits that women with HPV on presenting smear had compared with women with no evidence of HPV (M-W test, n=374, z=-1.58, p=0.11).

Women with CIN 2 and CIN 3 appear to pay about $30 more than other women after controlling for other variables. Compared with women with no evidence of CIN, women with CIN 2 have more clinic visits (M-W test, n=285, z=-4.00, p=0.0001). Women with CIN 3 also have more visits than women with no CIN (M-W test, n=209, z=-2.02, p=0.04). There was no statistically significant difference in the number of visits between women with CIN 1 and women with no evidence of CIN.

Conclusion

More severe abnormalities appear to cost women slightly more. A woman's age also influences how much she pays. Further exploration of how clinical practices differ in relation to age is required. Once such differences have been identified then possible explanations for such differences should be examined.

Factors which influence the number of visits (for example, age, presenting smear, persistent abnormalities and presence of HPV infection) are significant predictors of costs to women. Women who have persistent abnormalities appear to be followed longer, explaining why they pay more than other women in the study. Women with CIN 2 and CIN 3 on presenting smear

have more visits, and hence have greater out-of-pocket expenses, than other women. If more were known about what factors are associated with increased length of follow-up, policy formulation could be more cognisant of such factors and, possibly, save women out-of-pocket expense.

Costs to women were more homogeneous with respect to category of presenting smear than costs to government. This is because most women had no out-of-pocket expenses for hospitalisation. Hence most of the costs to women were for outpatient treatment. The assumption that 15 women (in the multivariate analysis) with private health insurance were admitted to the public hospital as public patients may have biased these results considerably. If their expenses as private patients in a public hospital were included, this may have increased the cost estimates for the more severe levels of presenting smear.

However, this regression analysis of cost only included women who 'completed treatment' (i.e. were discharged or did not attend). Because women in other follow-up status groups were not included these results may be biased in unknown ways.

Discussion

CIN 1 or less made up over half the cost to government and women for this sample. There is no doubt that consistent recommendations regarding the appropriate approach to these minor abnormalities are necessary. If the Commonwealth recommendations are implemented they are likely to result in substantial cost savings in the short term. In the long term, the cost savings depend on the natural history of minor lesions. If the progression rates are low then substantial savings will also be realised in the long term. Whether the observational approach would realise savings over and above the active approach also rests on knowledge of the natural history of CIN 1. In Chapter Three I suggest that, based on current diagnostic and referral practices, very few women who are referred for colposcopy currently would ever develop cervical cancer. Therefore, the new Commonwealth approach is also likely to result in savings in the long term.

There does appear to be a relationship between presenting smear and cost both to government and to women. With increasing severity the cost increases. This relationship is stronger for costs to government than costs to women. CIN 3 appears to cost government substantially more than any other

lesion. This has implications for policy. If conservative approaches to the care of women who have minor lesions are adopted they may cost more to government in the future because they may progress to CIN 3 which is more expensive to treat. Again, whether this would negate the cost savings of the approaches advocated by Commonwealth requires further knowledge of the natural history of minor lesions.

However, the relationship between costs and presenting smear is not straightforward. The multivariate analyses of costs to government and costs to women suggest that factors other than diagnosis influence clinical practice. Age was an important factor in relation to costs. Women over 35 cost more to government when they had CIN 3 than other women, whereas women younger than 35 cost more to government when they had minor abnormalities. Women over 35 had fewer out-of-pocket expenses than other women.

This study only considered direct costs to women. The indirect costs of time off work, childcare and transportation also entail expense for women.

As this study was located in a private outpatient service, the findings in terms of costs to government and women are not relevant to the experience of women who attend public hospital outpatient colposcopy services which do not involve a direct cost to women.

However, at the clinic studied, women with any level of abnormality had significant out-of-pocket expenses. Indeed, many women commented on the expense of treatment in my interviews with them. In the next chapter, I examine what factors predict non-attendance for colposcopy clinic follow-up, and explore how the financial costs to women may constitute a barrier to some continuing participation in follow-up.

Unfortunately, few socio-demographic variables were collected in this study. Further exploration of the relationship between women's socio-demographic variables and cost might reveal more about the process of clinical decision-making in relation to women who have abnormal Pap smears. A population data base linking women's screening history and clinical data would enable examination of these relationships.

Policy is couched in terms that assume clinical decision-making is based on biomedical evidence alone. Instead, clinical decision-making is likely to be based on the world views of clinicians, which is partly based on clinical

findings. It would be useful to know how the world views of gynaecologists shape the recommendations they make about each woman's care. This suggests that what constitutes rational policy may be different from what constitutes rational clinical practice. Therefore, there may be difficulty in applying the simplified protocols of policy to the clinical situation. I return to the dissonances between public health policy-making and clinical practice in Chapter Eleven.

The multivariate analyses demonstrate the need to examine cost with real rather than hypothetical data. Hypothetical models, used to simulate the cost of various clinical practices, rely on simplistic assumptions about the nature of clinical decision-making. Such models reduce decision-making to a few variables, usually related to diagnosis, and fail to capture the complexity of the process.

This analysis suggests that substantial savings may be realised by instituting current policy initiatives. However, further cost savings might be achieved if policy was cognisant of the process of clinical decision-making. Recognition in policy of the ways clinicians make recommendations might also enable further accountability of clinicians as well as facilitate the delivery of a better service for women.

Chapter Ten

Attendance for colposcopy clinic follow-up after referral for an abnormal Pap smear

Not completing gynaecological follow-up may place women at greater risk of cervical cancer in the future. In this chapter I examine which categories of women are least likely to attend for colposcopy clinic follow-up. Twenty per cent of women in the CLC sample did not complete the follow-up recommended by their clinicians. By drawing on the findings of Part B and Chapter Nine of this thesis, I explore possible explanations for the different pattern of attendance.

Methods

The CLC sample was used for this study. Presenting smear was used as an indicator of the severity of the abnormality. For this analysis the women's presenting smear was divided into two groups: minor abnormalities (CIN 1 or less including smears with HPV effect, minor atypia and inflammation), and major abnormalities (CIN 2 or 3).

Several proportions are calculated. First, the proportions of women who did not attend after one and two assessment visits are calculated. Second, I calculate the proportions of women who did not attend for one follow-up visit after they had ablative or excisional treatment and who did not attend after one or more follow-up visits after treatment. For these calculations the denominator was all women who were at risk of not attending at the subsequent visit. For example, for the first assessment visit the denominator included all those women who were not classified into any of the follow-up groups, other than 'did not attend', on the date of their assessment visit. That is, the denominator is comprised of all women who are at risk of being non-attenders for the second visit.

Unfortunately, no variables which indicate the sample group's socio-economic status could be collected in this study. However, income has a

strong relationship to private health insurance status. Although fewer younger people have private health insurance, the relationship between income and private health insurance is strong across all age groups (Australian Bureau of Statistics 1993b). Young single-parent families are least likely to have private health insurance, whereas families where the major contributor is between 35 and 54 have the highest levels of insurance (Australian Bureau of Statistics 1993b).

Only those women who, after their first visit to their gynaecologist, were recommended for further gynaecological assessment or treatment, were included in this analysis. (Nine women were excluded because they were discharged after one visit.) Using Cox proportional hazards modelling I examine how socio-demographic and clinical variables relate to non-attendance (Anderson, Auquier et al. 1980). This is a multivariate analytical technique, which is appropriate for follow-up data with a dichotomous outcome and censoring, and which provides estimates of relative risk.

Cox proportional hazards modelling produces unbiased estimates of the association between the variables recorded and women's non-attendance because it accounts for the time-dependent nature of women's follow-up status. The follow-up states — moved, discharged, still attending, and unknown — preclude women being categorised as 'not attending' at a later date. The frequency and distribution of days for each of the five follow-up states are shown on Table 8.4, p174. For this analysis the outcome of interest is non-attendance. Women in the other discharge groups are censored on the date they receive their follow-up status code. This means that women not classified as non-attenders contribute to the analysis until they are discharged, move, change gynaecologists, or their follow-up status becomes unknown. Those still attending at the end of the case note audit contribute to the analysis for the time period they attend the clinic.

An underlying assumption of the method is that the relative risk or hazard for the outcome between the different covariate groups is constant over time. The models satisfied the assumptions of the proportional hazards analysis. Graphical techniques were used to test the proportional hazards assumption.

Treatment was entered into the model as a time-dependent variable. The women were assigned to the treatment category when they had ablative or excisional treatment to their cervix. Until they had treatment, they were in the 'no treatment' category.

Using the likelihood ratio test, which produces a chi-square statistic, new models are compared with previous models in the Cox proportional hazards analysis. In the multivariate analysis only cases for which there were no missing values on any of the variables were used. This means that comparisons between the different models could be made. A five per cent significance level was used. SPSS and EGRET were used for these analyses. (SPSS-X Inc 1988; Statistics and Epidemiology Research Corporation 1990).

Results

Twenty per cent of the women in this study did not continue to attend the clinic as recommended by their gynaecologist. This is a non-attendance rate of 2.2 women per 100 women months. Some of the women of unknown follow-up status may have been non-attenders. If these are reclassified as non-attenders, 29 per cent of the sample is lost to follow-up and the non-attendance rate is 3.1 per 100 women months. Only two women who had a major abnormality and evidence of persistent disease did not have appropriate treatment. Of the 102 women who were classified as non-attenders, 49 had a normal colposcopy and Pap smear on their last visit. After one clinic visit, 1.4 per cent of women did not attend the subsequent visit (n=485). Of the women who had treatment, 6.1 per cent did not attend for the next follow-up visit (n=395). Reclassifying as non-attenders those women who were of unknown follow-up status on their assessment or treatment visit changes the proportion not attending after the first assessment and treatment visits to 1.9 and 6.3 per cent respectively. For those who did not have treatment, the proportion who did not attend after one follow-up visit was 21.7 per cent (n=297); if those women in the unknown category are reclassified as non-attenders, the proportion is then 30.9 per cent (n=307). Irrespective of whether a woman had treatment, the proportion who did not attend for subsequent visits after their second and third visits was 17.7 and 23.5 per cent, respectively.

Predictors of non-attendance

The distribution of variables used in this analysis is detailed in Table 10.1.

Table 10.1 Socio-demographic characteristics and clinical details of sample

Variable	No. of women	Percentage (%)	No. not attending	Percentage not attending (%)
Presenting smear (n=492)				
Minor abnormality	294	59.8	62	21.1
Major abnormality	198	40.2	40	20.2
Age (n=493)				
< 25	173	32.0	48	27.7
25- 34	179	37.3	33	18.4
>35	141	30.7	21	14.9
Health insurance status (n=439)				
No private health insurance	213	43.8	59	27.7
Private health insurance	226	56.3	28	12.4
Marital status (n=446)				
Ever married	348	77.8	68	19.5
Single	98	22.2	18	20.9
Parity (n=468)				
Nulliparous	234	50.0	47	20.1
Parous	234	50.0	47	20.1
Previous Pap smear history (n=457)				
Normal or never*	287	60.4	69	24.0
Abnormal	170	39.6	27	15.9
Self-reported Pap smear frequency (n=442)				
At least biennial	336	76.0	67	19.9
Less than biennial	106	24.0	26	24.5
Treatment (n=493)**				
No treatment	91	18.5	22	24.2
Treatment	402	81.5	80	19.9

* This group includes 32 women who had never previously had a smear as well as women who reported previously normal smears only

** Women were in the treatment group if they had treatment at any time during the study period. Because treatment is a time dependent co-variate those in the treatment category contributed to the estimates of the hazard ratio for the treatment category until they had treatment.

Bivariate analyses of the relationship between women's socio-demographic variables, treatment and presenting cytology, and non-attendance, produce estimates of the unadjusted relative risk for each of the variables. The results of the bivariate analyses are shown in Table 10.2.

Table 10.2 Bivariate analyses of socio-demographic and clinical variables and non-attendance

Variable	Relative risk	95% confidence intervals
Age (n=493)*		
< 25	1.00	0.39, 0.96
25-34	0.62	0.30, 0.85
> 35	0.51	
Insurance status (n=439)*		
No private health insurance	1.00	
Private health insurance	0.46	0.30, 0.73
Parity (n=468)		
Nulliparous	1.00	
Parous	0.96	0.64, 1.45
Marital status (n=446)		
Ever married	1.00	
Single	1.06	0.63, 1.79
Self -reported Pap smear frequency (n=442)		
Annual/Biennial	1.00	
Less than biennial	1.18	0.75, 1.85
Previous Pap smear history (n=457)		
Normal or never	1.00	
Abnormal	0.66	0.43, 1.04
Presenting smear (n=492)		
Minor abnormality	1.00	
Major abnormality	0.78	0.52, 1.17
Treatment (n=493)**		
No treatment	1.00	
Treatment	2.30	1.25, 4.21

*Log rank test significant at the five per cent level.

**Treatment is a time-dependent co-variate which is coded zero before treatment and one after treatment. Since treatment is a time-dependent the significance of the co-variate can only be assessed by using the Wald statistic (p=0.007) or the Log likelihood ratio test ($\Delta\chi^2$=8.32, df=1, p=0.004).

On the bivariate analyses, women with private health insurance were less likely to discontinue attending (relative risk 0.47, 95% confidence intervals 0.30 - 0.73, log rank test, χ^2=11.82, df=1, p <0.001). Women were more likely to discontinue attending after treatment compared with before treatment (relative risk 2.30, 95% confidence intervals 1.25-4.21, df=1, p=0.007). Non-attendance was also associated with age. Women between 25 and 34 (relative

risk 0.62, 95 confidence intervals 0.39 - 0.96, p=0.03) and women 35 and older (relative risk 0.51, 95% confidence intervals 0.31 - 0.85, p=0.01) were at less risk of not attending than women less than 25 years of age.

However, the effect of private health insurance is likely to be confounded by other variables. In her Health Strategy paper, Sharon Willcox reports on the findings of an unpublished health insurance survey. (Willcox 1991). This survey showed that the factors people use to explain whether or not they have private health insurance include cost, beliefs about the adequacy of Medicare and their health status. Age, marital status and parity are also related to private health insurance status. (Australian Bureau of Statistics 1993b). Presenting smear is also likely to be a confounder of women's treatment status.

To assess the associations between variables collected in this study and non-attendance, and to enable control of confounding, the approach outlined by Kleinbaum et al. was used. (Kleinbaum, Kupper et al. 1982). All the variables were entered into the model (χ^2=23.61, df=9, p =0.005). Using the forward selection procedure outlined by Kleinbaum et al. (1982), the significance of two-way interactions between the variables was then tested. Only an interaction between private health insurance and previous Pap smear history improved the model fit (χ^2=10.34, df=1, p=0.001). Those women who had never had an abnormal Pap smear prior to the smear which resulted in their referral to the clinic, were less likely to attend if they did not have private health insurance. In contrast, the association between private health insurance status and non-attendance was not significant for women who had had abnormalities prior to referral. Neither marital status nor self-reported Pap smear frequency was a significant predictor of non-attendance, and did not change the estimates of the effects of any of the other variables. These were consequently dropped from the final model. Table 10.3 details the final model.

Table 10.3 Multivariate Cox proportional hazards model and non-attendance (n=337)

Variable	Relative risk	95% confidence Intervals
Age		
< 25	1.00	
25-34 *	0.49	0.26, 0.91
>35	0.47	0.21, 1.06
Parity		
Nulliparous	1.00	
Parous *	1.99	1.07, 3.69
Presenting smear		
Minor abnormality	1.00	
Major abnormality *	0.57	0.33, 0.97
Treatment		
No treatment	1.00	
Treatment *	3.13	1.42, 6.90
Previously normal Pap smears		
No private health insurance	1.00	0.17, 0.66
Private health insurance *	0.34	
Previously abnormal Pap smears		
No private health insurance	1.00	0.84, 6.55
Private health insurance	2.34	

	Deviance	**df**
Initial Model	690.3	336
Final Model	657.5	328
$\Delta\chi^2$	32.8	8

* Wald statistic significant at the five per cent level.

Unfortunately, many case notes were incomplete. Any case with missing values on any of the variables was excluded from the multivariate analyses so that comparisons between various models could be made. In the overall sample, 56 women (11%) did not have their private health insurance status recorded. Women for whom private health insurance status was recorded tended to be slightly younger (geometric mean age 26, 95% confidence intervals 24.0-28.0) compared to the balance of the sample (geometric mean age 29, 95% confidence intervals 28-30, t=2.78, p=0.006). These women were also less likely to have children (odds ratio 0.49, 95% confidence intervals 0.27-0.90, χ^2=5.52, df=1, p=0.02).

Discussion

This study has demonstrated that a significant proportion of women do not complete the follow-up recommended by their clinicians after treatment. In a sample of women attending a private colposcopy clinic, I have shown that non-attendance was associated with age, parity, severity of smear and private health insurance status for women who had not previously had an abnormal Pap smear. In this sample, women who had had treatment were three times more likely not to attend than women who had not had treatment.

Most women attended the visit subsequent to their initial assessment visit. Most women who had treatment also attended a follow-up visit. For women who had treatment, most of the losses to follow-up occurred after the first follow-up visit after treatment. The new Australian guidelines recommend at least one colposcopy and Pap smear following treatment. It is suggested that a woman has a Pap smear 12 months after treatment. A colposcopy may also be performed 12 months following treatment. (Commonwealth Department of Human Services and Health 1994). However, this study was conducted before such guidelines were in place.

This study could only investigate the predictors of subsequent non-attendance for women who attend at least one clinic appointment. Also, some women may have attended other gynaecologists. However, as there are no public hospital clinics in Canberra, there is no financial reason to change gynaecologists unless other gynaecologists have different billing practices. If some women attended other clinics this study may overestimate the proportion of non-attenders. Some women in the 'unknown' follow-up status group are probably non-attenders. Censoring their observations at the time they receive their 'unknown' follow-up code would only bias the estimates obtained if the censoring was associated both with the explanatory variables and non-attendance. If censoring was only related to non-attendance, estimates of relative risk might lack precision but would still be unbiased.

Barriers to participation?

One way of considering possible explanations for non-attendance is to think in terms of structural or cultural barriers. Factors such as financial cost, travel and childcare might be considered structural barriers. Cultural barriers include the beliefs and understandings of women and their medical

practitioners towards their abnormal Pap smear. Below I discuss possible barriers and propose how they may operate to produce the pattern of attendance I have described in this chapter.

Structural barriers

I have shown that women with abnormal Pap smears face significant out-of-pocket of expenses for their gynaecological care. As discussed previously private health insurance status is related to income (Australian Bureau of Statistics 1993b). Young women and women with children may also experience economic disadvantage. Because most care is undertaken on an outpatient basis all women, insured or uninsured, face similar expenses. The clinic where this study was conducted has a policy of direct billing (charging at the same level as the Medicare benefit) women they perceive to be economically disadvantaged. But these women probably comprise only a small proportion of women who find cost a barrier to access.

Women who are admitted to hospital as private patients also face significant expense. To test whether cost might be an important explanation for non-attendance for these women, one would have to examine whether they were at greater risk of non-attendance prior to their admission to hospital.

If financial cost is an important barrier to follow-up for women in this study, the associations between private health insurance status, age and parity and attendance may be particularly strong in the ACT because there are no public hospital clinics. In other Australian cities, women have the option of attending public hospital clinics which do not entail a financial cost to them.

Lack of transport and child care may be barriers to participation in follow-up for some women. American women without private health insurance who had abnormal Pap smears were more likely to attend for follow-up if they were sent bus tickets to get to the clinic. In contrast, a health education intervention did not increase the attendance of uninsured women (Marcus 1992).

In the multivariate analysis, women who had treatment were three times more likely to discontinue attending than women who had not had treatment. In Chapter Five I discussed how some women's perceptions of their risk of cervical cancer and even death shifted after having treatment. After treatment, some women perceived themselves to be at similar risk of cervical cancer as other women. Many regarded themselves to be 'cured' of their abnormality after treatment. Hence, some women may have considered continued follow-up after treatment unnecessary because they were no longer at risk of cervical cancer or death. A longitudinal study that explored how women's perception of their risk of cervical cancer changed over the course of their diagnosis, treatment and follow-up may have thrown more light on this matter. Certainly, an indepth study with women who did not attend after treatment could explore this proposition further.

Socio-cultural differences between women patients and their gynaecologists may produce barriers to continuing attendance. Could socio-cultural differences explain the pattern of attendance described in this chapter? It may be that the categories of women described as non-attenders have less in common with their doctors than other women.

In Chapter Six I also explored how women made sense of their abnormality. Many sought explanations such as stress and lifestyle factors which were rooted in their own life circumstances. Some women considered that their gynaecologists were not cognisant of the meanings their abnormality held for them. Therefore, the high non-attendance rate could be partly attributable to the conflicts women experience between their own way of understanding their abnormal Pap smear and the gynaecological care they received.

Anthropologist, Emily Martin, found that middle class women tended to describe menstruation in the scientific terms of failed production. On the other hand, working class women's accounts of menstruation were phenomenologically based. Working class women's descriptions dealt with their own experiences as menstruators (Martin 1987). Similarly, in reporting a study with Italo-Australian women, Gifford (1994) suggests participants' ways of understanding cancer and menopause may constitute barriers to their attendance in cancer screening services (Gifford 1994). Basker (1983) demonstrated how conflicting meaning systems between lay women and the

medical mediators for abortion and contraception resulted in communication difficulties.

Women may explain and understand their condition differently from their gynaecologists. These differences may be more obvious when the women do not share similar social positions or cultural backgrounds as their doctor. As the qualitative study was based on a small Canberra sample which was relatively homogeneous in terms of class and ethnicity, these differences could not be explored.

The way gynaecologists regard their patients may depend on the patients' social and cultural background. In a participant observation study based in hospital clinics for women with precancerous cervical lesions, Fischer (1986) found that poorer women and older women were more frequently recommended for hysterectomy than other women with similar complaints. Medical practitioners' recommendations were based on their feelings about individual patient and less on biomedical evidence. Sociological analysis suggests that the social order of society is reflected in and produced by medical interactions. For example, a participant observation study of some Canberra general practitioners and their clients revealed that the gender order of society also manifests in general practice medical encounters (Broom-Darroch 1978).

In the above discussion I have considered non-attendance in terms of barriers to participation rather than poor compliance. Compliance focuses attention on the individual. In doing so the problem is located in the individual and attention is directed towards developing strategies that encourage individuals to follow medical advice. Zola (1980) argues that patients should be allies in their own management plans.

In Chapter Six I proposed that if greater cognisance were given to women's understanding and meanings systems for cervical abnormalities, management plans more satisfactory both to gynaecologists and their women patients might be negotiated which would improve the experience for women.

In Chapter Seven I discussed how some women experienced pain or discomfort with their biopsy or treatment. Such experiences may explain why some did not attend subsequent visits. Women required further information about treatment and its after-effects.

In Part B I argued that their was a need for greater information exchange between gynaecologists and women. In this chapter I suggest that this information exchange is not only necessary in terms of reducing the personal burden of this condition but may also improve attendance.

Screening history data

An effective cervical cancer screening program requires attention to all steps along the 'screening pathway'. The screening pathway is a concept used to describe six elements: screening of an identified population at designated intervals; the recruitment of women; provision of appropriate services for taking and processing Pap smears; ensuring the adequate follow-up of women who have abnormal Pap smears and continuing evaluation of the screening program; policy support; and co-ordination to ensure communication between all steps.

In Australia, we do not know which groups of women are at risk of not completing the screening pathway. This is partly because there is no population data base from which to examine this issue.

If screening and clinical data were linked, we could examine at what points along the screening pathway specific women were more at risk of being lost to follow-up. The report of the Steering Group on Quality Assurance in Screening for the Prevention of Cancer of the Cervix recommends that cervical cytology registries carry details of women's treatment as well as their colposcopy, cytology and histology findings. (Commonwealth Department of Human Services and Health 1993). If cervical cytology registries carried such details we could, using the methods used in this study, examine which categories of women are at risk of not completing at various points in the screening pathway, using a population data base. However, such data would be difficult to collect. Whether it is possible for cytology registries to gather data on the follow-up and treatment received by women who have abnormal Pap smears is currently being debated.

Summary

In this chapter I have examined which groups of women were at risk of not attending colposcopy follow-up. I showed that age, parity, previous Pap smear history, health insurance status and treatment status were associated with non-attendance in this sample. I explored possible structural and cultural barriers to continued attendance. In doing so, I drew on the results of Part B of this thesis to suggest that dissonance between the meaning systems of gynaecologists and women patients may contribute to the low attendance rate. I suggested that the financial cost of treatment to women described in Chapter Nine may constitute a structural barrier to attendance.

Part D

Closing and balancing accounts

Chapter Eleven

Conclusion

This chapter considers the findings of the thesis in terms of the individual and aggregate costs of abnormal Pap smears. I propose a framework for interpreting these costs and suggest possible ways of reducing them. The thesis concludes with a discussion of future research directions.

The costs of current practice

Aggregate costs are the economic, social, and cultural consequences of abnormal Pap smears experienced by the community. Individual costs are the economic, personal and social costs that individuals with abnormal Pap smears experience. In this section the research findings of the thesis are considered in terms of these two costs.

In the colposcopy clinic studied for this research, a significant proportion of the economic costs to government come from investigating women who have CIN 1 or less. These costs would not be incurred in countries where colposcopy is only recommended for women with CIN 2 or 3. Women with CIN 1 or less paid over half the total out-of-pocket expenses paid by all women in the CLC sample.

How do aggregate social or cultural costs occur? Social practices shape how we understand ourselves and our world. For example, Metcalfe (1993) argues that health promotion strategies, designed to address high rates of cardiovascular morbidity and mortality among coalminers in the Cessnock region of New South Wales, transformed miners from being perceived as '...bad to being fat'. Coalfields people had been identified as suffering higher rates of cardiovascular morbidity and mortality than the rest of the Hunter region. They were shown to have a higher prevalence of cardiovascular risk factors such as obesity, smoking and high serum fats. A community-wide heart disease prevention program was launched. Metcalfe claims that the campaigns were developed within a healthist discourse which promotes

maximising one's own health. He argues that in the past coalfields people had been construed as bad, 'unable to train their minds', delinquent. Now they were defined as fat and lacking in willpower. 'Within the healthist discourse, they lack self-control which is demanded before people are granted the full rights to dignity' p40. Hence the health promotion campaigns, designed to address the poor health experiences of the coalfields people, had been 'used to reproduce miners and their inadequacy' p38. These definitions of the coalfields people might be considered a cultural cost of the health promotion campaign.

What do the research findings of this thesis tell us about how contemporary clinical and public health practice might construct women? And, how might abnormal Pap smears result in cultural costs?

The prevention of cervical cancer depends upon medical surveillance of women's cervices. In Chapter Three I suggest that if current referral patterns for colposcopy continue, most women will have a colposcopy in their lifetime. This means that more women may have colposcopy than is necessary to reduce the incidence of cervical cancer. What are the consequences of this intensive colposcopic investigation?

In Chapters Five and Six, I show that some women consider that their abnormality reflects the inherent disorderliness of women's reproductive systems. Their cervices require medical surveillance; women's reproductive organs are constitutionally deranged. This surveillance is necessary because of the troublesome nature of their cervix. Surveillance also reinforces its disorderly quality. This is a significant cultural cost. It might also be considered a personal or social cost for individual women.

Individual women also bear costs. This thesis has shown that individual women attending a private outpatient colposcopy service have significant out-of-pocket expenses. These are significant for all levels of their abnormality. In Chapter Ten, I advance the proposition that these out-of-pocket expenses may deter some women from completing the recommended follow-up.

In this thesis I have identified many possible personal and social costs for women. Individual women feel vulnerable and experience embarrassment, discomfort and pain because of examination and treatment. They feel stigmatised and anxious, and experience changes in their intimate

relationships. The event redefines who they are. They have a different sense of their physical integrity. Their abnormality redefines them as having a cervix that is life-threatening. Some women feel out of control of their own health. Their attempts to re-assert control, evident in their narratives about stress and lifestyle, are not part of the clinical encounter. The marginalisation of women's accounts of what is happening to them exacerbates their distress.

No-one would want these costs to occur, so how do they come about?

A framework for understanding the costs

I suggest that two dynamics contribute to the high costs identified in this research: the clinician's concern to reduce clinical uncertainty, and the weak representation of women's perspectives in clinical and public policy decision-making.

In this section I explore these dynamics and suggest that clinical protocols, developed within a policy framework, may not achieve the changes necessary in clinical practice to reduce costs. In making these arguments, I return to the notion, developed throughout the thesis, that abnormal Pap smears have three major stakeholders: clinicians, public health practitioners[1] and women who have abnormalities. Decisions about abnormal Pap smears occur in two settings: the clinical encounter and the formulation of public health policy. What is each stakeholder's perspective and what choices are available to them in the two settings?

The role of clinical uncertainty

The clinician's concerns to reduce her or his uncertainty is well illustrated in the deliberations that went into the formulation of the document "Guidelines for the Management of Women with Screen Detected Abnormalities". (Commonwealth Department of Human Services and Health 1994). This document was produced after research for this thesis was conducted, and therefore had no influence on the activities studied in this research. However, reviewing the development of the clinical protocols presented in the document reveals the differences between the perspectives of the clinicians and public health practitioners.

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[1] I use the term public health practitioner to encapsulate those working from a public health perspective, including the health economist, the epidemiologist and the health bureaucrat.

A working party was formed with the aim of achieving consensus about appropriate clinical recommendations for women who have abnormal Pap smears. To do this, a protocol was developed. The working party included three gynaecological oncologists, an epidemiologist, a cytopathologist, a medical educator, a consumer representative and a general practitioner. The working party was dominated numerically by practitioners working in clinical settings. The epidemiologist was the only public health practitioner (although some of the members with clinical expertise may have shared some of her perspectives). One woman — the 'consumer representative' — was to represent all women!

During the development of the Commonwealth guidelines, there was debate between members of the working party with population perspectives and those adopting a clinical perspective. Most of the disagreement concerned the approach to care of women with CIN 1.[2] From a population perspective, the concern was that referral and treatment of women with cytological evidence of CIN 1 would incur financial costs with little reduction in population morbidity or mortality.

Clinicians were concerned that some women with CIN 1 might have either a high-grade lesion or a rapidly-growing lesion, or that they might develop cervical cancer because of inadequate follow-up. The clinicians' view prevailed and the guidelines recommend referral of all women with CIN 1 for colposcopy and treatment if CIN 1 is confirmed.

This policy might be viewed as irrational by a public health practitioner because the financial costs are too high. Referring and treating all women with CIN 1 might reduce the incidence of cervical cancer slightly but would result in substantially higher financial costs to the community. This is confirmed again in the research findings of this thesis.

At the clinical level, the clinician is also conscious of the uncertainties with which she or he is working. How might the clinician decide whether to refer a woman for colposcopy? They are aware of the ambiguity of scientific knowledge, the incompleteness of their own knowledge, and the difficulty of

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[2] For example, draft protocols were discussed at the Annual Scientific Meeting of the Australian Society of Colposcopy and Cervical Pathology in Adelaide, in 1992, which I attended. Members of the working party were keen to obtain the support from the society for their position, which was to recommend colposcopic investigation and treatment for all women with cytological evidence of CIN 1. I also discussed the deliberations with employees of the Department of Human Services and Health.

transferring general knowledge to a specific situation. Research has not defined clearly the natural history of cervical cancer. The role of various risk factors such as HPV is controversial, and the accuracy and comparability of pathology tests is poor, even in the best of circumstances.

What might clinicians consider when they make decisions about whether to refer a woman with an abnormal Pap smear for colposcopy? If a woman has a colposcopy and treatment is undertaken then her risk of future cancer is reduced. Alternatively, if the colposcopy reveals no abnormality, a higher degree of diagnostic certainty is achieved and the doctor and the woman may be reassured.

What are the costs of not referring? The individual woman may develop cancer. This would be a tragedy for the individual woman and the clinician would be distressed that they have failed to protect the woman's health. If the woman developed cancer they may also be at risk of litigation. The decision may be considered an error and the professional integrity and self-respect of the clinician might be undermined. A clinician who refers can be guaranteed that she or he will not be considered negligent in professional or legal terms. Katz (1984) argues that in clinical practice 'errors of commission are less reprehensible than errors of omission'. From the clinician's perspective, referring a woman with an abnormal Pap smear for colposcopy is likely to be conceived as the safest approach.

It is possible that gynaecologists are predisposed towards treatment after they have established that a woman has a low-grade lesion. Their reasons may be similar to the rationale for referring women with low-grade lesions for colposcopy in the first place. To treat ensures that an individual's risk of future cancer is minimised. One of the gynaecologists contacted during the course of the study told me that he was aware that treating women with minor abnormalities was of dubious value. Nevertheless he felt that omitting treatment was not an acceptable alternative.

The pathologist who reads the cytology and histology slides also requires consideration. What do they do when faced with a slide which is ambiguous? Do they call it abnormal? If they are unsure how to grade an abnormality are they likely to report it as a higher grade? Like the clinician who sees an individual patient, the pathologist who reports on cytology or histology specimens carries heavy responsibility, like the clinician, the pathologist might feel that it is best to be cautious. They may decide to call

an ambiguous slide a higher grade and therefore ensure that the woman is investigated further, rather than risk misdiagnosing a high-grade lesion or cancer.

Contemporary clinical and pathology practices are resulting in large disparities between the population-based risks of cervical cancer and risk of referral for colposcopy. How might a change in clinical practice be accomplished? Clinical protocols are a possible avenue for modifying practice.

The application of protocols in clinical practice

There is no doubt that consistent recommendations are required for the clinical care of women who have screen-detected abnormalities. The new Commonwealth protocol is a useful first step (Commonwealth Department of Human Services and Health 1994). The research conducted for this thesis suggests that even if all women with CIN 1 or above were referred for colposcopy, and the new guidelines were adopted in the clinic studied, there would still be a reduction in the number of women referred for colposcopy because women with abnormalities less than CIN would not be referred. However, I believe the new guidelines are unlikely to produce substantial changes in clinical practice because the appreciation of the costs and benefits of particular decisions in the clinical setting is different from that in the public health setting.

Previous research has demonstrated that protocols alone do not always change clinical practice. In light of an increasing tendency for Caesarean section in Canada, a consensus statement on Caesarean delivery was produced under the auspices of a specialty organisation. According to Lomas, Anderson et al. (1989), despite widespread acceptance of the statement amongst obstetricians, practices altered only slightly following the release of the guidelines. The authors conclude:

> The results underscore the fact that the practices of physicians are influenced by many things besides research evidence, even when such research evidence is packaged in a set of clear concrete recommendations. In this case, there may have been other barriers to the implementation of the recommendations because of perceived threats of malpractice litigation from potentially dissatisfied patients, inadequate skills for the vaginal delivery of a baby in a breech presentation, economic and socioeconomic incentives to perform Caesarean section as opposed to vaginal

> delivery or even pressure from the women who were offered the opportunity to avoid a potentially painful and prolonged vaginal delivery. p1312

Even when there are no detailed protocols, health service organisations may have different priorities from those of clinicians. It may be difficult, or impossible, for hospital managers, for example, to produce changes in the behaviour of doctors. Fox (1991) found that policy recommendations for the organisation of surgery in the operating theatre (OT) were not implemented by clinicians. This was despite clinicians giving advice to hospital management when the policy was formulated. He suggests that 'any apparent shared interest between management and clinicians at the policy level is in fact illusory, based on differing conceptions and different meanings of the passage of the patient through the OT' p740. The clinicians and hospital managers defined 'success' in ways that represented their professional interests. For the hospital manager, success related to efficiency, while for the clinician, success was clinically defined. Despite the clinicians and management agreeing on policy regarding the workings of the operating theatre these were not realised in the OT where the clinician retained autonomy and could subvert the decisions of management. (Fox 1991).

This brings us back to the argument about how clinicians and public health practitioners conceptualise the costs and benefits of particular decisions. For the public health practitioner the relevant costs are the aggregate financial costs to government and to women, and the benefits are the total number of cancers averted. As discussed previously, for the clinician assessment of the costs and benefits of specific decisions relate to an individual. These might be considered micro-costs and -benefits. The public health policy discourses are concerned about cost efficiency. Within this discourse the clinicians managed to achieve a greater investment of resources for a given number of cancers prevented than the public health practitioner might regard as optimal. However, the clinician's concern for individual costs and benefits is not part of the policy making, just as the public health practitioner's concern for macro-level costs and benefits is not considered in the clinical encounter.

The clinical decision does not consider how much referring or treating a woman with a low-grade lesion contributes to aggregate costs and benefits. Instead it revolves around how treatment or referral might reduce an individual's risk and therefore benefit the individual. From this perspective, it might even be considered appropriate to recommend referral or treatment

for women with mild atypia or HPV. The protocol developed in the committee room, agreed to by all members of the committee who apparently share a common interest in maximising aggregate benefits and minimising aggregate costs, becomes more or less irrelevant in the clinic.

There is another problem with the Commonwealth guidelines. They reduce clinical decision-making to a mechanical process with a few distinct steps: a woman is found to have a particular abnormality, the abnormality is investigated further and, if necessary, treatment is undertaken. Such a protocol implies that clinical decision-making is driven by diagnosis alone. But, as we have seen in this thesis, other pressures and the clinician's concern about uncertainty — not identified in the policy document — may influence how clinicians make decisions and provide clinical care.

Marginalising women's accounts

Whatever the effect of protocols on clinical practice, one voice is silent. Women's perspectives have not been considered in the clinical or policy framework.

The title of the policy document released recently is revealing. It refers to women with screen-detected abnormalities being 'managed'. A woman can hardly be an autonomous agent within this construction. At the public health policy-making level the financial costs are the dominant consideration. The benefits are lives saved or cancer averted. What of the cultural consequences of naming and referring for colposcopy a large proportion of the female population with cervical abnormalities? How can accounts of these cultural costs be represented within the policy-making process?

It may be argued that the working party included a consumer representative whose responsibility was to articulate women's concerns in the committee room. Such an expectation is unrealistic, however. Let us compare the resources of the single consumer representative on the working party committee with those of the three gynaecological oncologists. As members of a professional college they have access to resources to consult and lobby. They can draw upon an abundance of research and have extensive personal experience which they can legitimately bring to the working party. On the other hand, the consumer representative is meant to represent the views of *all* women who have abnormalities. She has a limited capacity to consult with other women and there is very little literature on women's experiences of

abnormalities. She must imagine what it is like for other women. Furthermore her lack of resources limits her capacity to speak with confidence and authority on the working party.

The policy attempts to incorporate women into the clinical decision-making process but it is the clinician's responsibility to achieve this. The policy suggests that women with abnormal Pap smears make decisions about the appropriate course of action in particular circumstances. It is proposed that the clinicians present the information to women and that the clinician and the woman with the abnormality take responsibility for ensuring adequate follow-up after referral and treatment of a screen-detected abnormality. The document does not address the question of litigation if a woman who is not referred or treated develops cervical cancer. The clinician still carries the responsibility for providing the information and for cancers missed under the current approach. This maintains their position of power and responsibility in the clinical decision-making process.

In the clinical setting, GPs and gynaecologists were important sources of medical information. Many women found this information unsatisfactory because it did not address the significance of their abnormality, the rationale for treatment or the reasons for the after-effects many experienced. A couple of women said they may not have had treatment if they had had fuller knowledge of the natural history of cervical abnormalities. Leslie stopped having medical treatment when she continued to have abnormalities despite treatment. Referral and treatment had not reduced her risk. Most women apparently did not make active decisions about whether referral or treatment should proceed.

A series of visits establishes the cervix as a possibly disordered organ and signals that medical treatment and surveillance are the only way to manage this unpredictable organ. Women did not have full access to the gynaecological accounts, they could not see their cervix (although most would have liked to), and they were not told enough about their abnormality.

When they were first informed of their Pap smear result, most women feared that they had or would get cancer. How was their anxiety about developing cancer experienced by clinicians? Perhaps one way was by referring and treating the women.

Finally, women's ways of making sense of their abnormality could not be heard within the clinical encounter. For example, some women's ways of managing their risk, through changes in their diet and lifestyle, could not be incorporated into their overall clinical care. In the clinical situation, medical treatment and surveillance were the only legitimate ways of approaching the abnormality and one's future risk of cervical cancer. I have previously proposed that such marginalising of women's experiences may contribute to some women's non-attendance for follow-up.

Clinicians and women with abnormalities might agree that the benefit of referral and treatment is the reduction of individual risk, but is either aware of the likely costs to the individual of referral and treatment? That is, are the out-of-pocket expenses to women and the emotional costs of having an abnormality considered?

Summary

Clinicians' ethical concern for the reduction in individual risk has meant that a large proportion of the female population will be diagnosed as having an abnormal Pap smear and will be referred for a colposcopy. This results in significant personal and cultural costs. Protocols for clinical practice may not achieve a change in practice because the costs and benefits of particular decisions are thought of differently in the committee room, where policy is made, and in clinical practice, where clinicians retain responsibility for decisions. Finally, women's experiences have remained peripheral both to clinical practice and public health policy. I maintain that having clinicians as the key players in this program results in significant costs, both aggregate and individual. So, how might this be different?

Women playing a more active role in decision-making

As stated previously, clinicians have the responsibility for making the decisions about the appropriate course of action in a particular situation or a particular category of situations. They manage the clinical uncertainty. If this responsibility was shared with the women who have abnormal Pap smears, the program might be more effective and result in lower costs. If individual women were better informed about the likely costs and benefits of particular courses of action, and consequently contributed more knowledgeably to decisions made about their care, things might change. The

responsibility for preventing future cancer would then be shared between clinicians and individual women with an abnormality. In this scenario, the fully informed woman could decide whether she wanted a colposcopy or treatment for her abnormality based on her appreciation of the probable costs and benefits of these options.

How might such a process be achieved? How could individual women with abnormalities become knowledgeable about the pros and cons of particular decisions? Although clinicians are an important source of such information they might present it in a way that preserves the status quo. Which costs would they discount and which would they emphasise? Other ways of providing the information might be developed. Resourcing workers in the women's health community to provide written and verbal information might be an alternative. The booklet "When a Pap smear isn't all clear", produced by the Women's Health Information Resource Collective in 1988, is an example of the written information that might be produced. It combines clinical information with accounts of several women's experiences of treatment. I gave this booklet to some of the women I interviewed, who found it useful. None of them had seen the booklet before. Clearly, such publications require wider circulation. Information provided by community organisations might create a greater scepticism among women about the value of medical intervention. Individual women could then make informed decisions about their care. By shifting the politics of clinical decisions, individual women's ways of making sense of their abnormality would become central rather than silenced. This might improve the follow-up rate.

How could the women's health community become more influential in policy development? Better documentation of women's experiences is required. This would mean that the costs and benefits considered in the formulation of policy would not be only the dollar costs and cancers prevented. For example, the cultural consequences of particular forms of clinical practice such as those described in this thesis might be thought of as a cost and considered in the formulation of policy. Like the gynaecologists with their professional college which has in-built structures and resources to consult with colleagues, women's health advocates need the resources to develop a structure to consult. Such a structure was developed for consultation leading to the National Women's Health Policy. It is also available in small, poorly resourced, volunteer non-government organisations.

Women have not been given a full account of how screening prevents cancer of the cervix. Health promotion messages have not addressed the mechanisms of prevention. Women are recruited into the cervical cancer screening program, but they are not informed about how it works and do not know the costs and benefits of making particular decisions about their care. I suggest that this should be changed and that this change might facilitate a reduction in both the individual and aggregate costs of the cervical cancer screening program.

Directions for future research

Two questions that arise from the analysis of costs could be subjects of further research. I have maintained that in the clinic and public health policy, women's accounts of what is happening to them individually and as a collective are not heard or are considered irrelevant. Future research might usefully document how this silencing occurs.

The second question that arises from this analysis is, how do some options become obvious courses of action?

Further investigation of these two issues would reveal the structures of current practices that uphold certain accounts and silence others. Such an approach would illuminate how clinical practice and public health policy currently operate and would enable the development of alternatives.

Individual interviews with clinicians and public health policy makers may help answer these questions. A study that observed clinical interactions and the public health policy-making process may also shed light on these queries.

Some of the research findings of the thesis also require further development.

The health economic study was based in one private outpatient service. Similar studies in public services and other private services would enable further elucidation of the distribution of economic costs according to level of abnormality and other variables such as age and socio-economic status. If cytology registries collect data on the follow-up and treatment of women who have abnormal Pap smears, future research could examine which categories of women do not complete the appropriate follow-up. Such information could then inform the delivery of services. Women and service providers could develop services that are more cognisant of women's needs.

My interviews with women were conducted after the diagnosis of an abnormal Pap smear. These women came to experience their risk as part of themselves. Interviews with women before as well as after a diagnosis of an abnormal Pap smear might disentangle how the diagnosis *per se* shaped women's perception of their risk. Such research could explore how cervical cancer screening constructs women's perceptions of their risk of cervical cancer and clarify some of the non-dollar costs of abnormal Pap smears.

I have suggested that there are cultural consequences of current forms of practice; that cervical screening and the identification of women with cervical abnormalities perpetuates the construction of women as having reproductive organs that are inherently troublesome. This finding requires further elaboration. A qualitative study involving women who have had abnormalities as well as those who have not, could disentangle how cervical abnormalities shape this construction.

Concluding remark

It is now thirty years since cervical cancer screening was introduced in Australia. While there have been benefits, there have also been significant costs. When Phillipa was told that she had a positive Pap smear, she said:

> You felt very demeaned by it all — and you think how could one little slip of paper make you feel so rotten?

Hopefully, in another thirty years the cervical screening program can produce the benefits without the burden of costs that women such as Phillipa experience today.

Appendix A

Standard errors of Medicare estimates

Total number estimates

The standard errors of the total population estimates were calculated using the following formula:

$$\text{standard error} = \frac{Ns}{\sqrt{n}} \times \sqrt{1-f}$$

where s, the sample standard deviation, is given by:

$$s = \sqrt{\frac{\sum_{i=1}^{n} yi^2 - \frac{(\sum_{i=1}^{n} yi)^2}{n}}{n-1}}$$

and n = sample size, yi = the sample values, and since yi = 0 or 1,

$$\sum_{i=1}^{n} yi^2 = \sum_{i=1}^{n} yi$$

$\bar{y}$ = the sample mean, N = total population.(Cochran 1977) p24

1 - f, the finite population

correction, is given by:

$$1 - f = 1 - \frac{n}{N}$$

The finite population correction (fpc) is 0.9 for the Medicare Samples. A fpc is only necessary if the sample fraction is equal to or above ten per cent (Kirkwood 1988).

N was calculated by determining the number of female Medicare enrollees for ACT and Australia for the financial year 1989/90. N was adjusted for the proportion of women who had had a hysterectomy in each age group.

Proportion estimates

$$\text{se(proportion)} = \sqrt{(1-f)\cdot \frac{p(1-p)}{n-1}}$$

where p = sample estimate of the proportion. (Cochran 1977) p52

Ratio estimates

To calculate the variance of the ratio estimate the following formula was used:

Given that the estimated ratio $\hat{R} = \frac{\sum_{i=1}^{n} yi}{\sum_{i=1}^{n} xi}$

the standard error of $(\hat{R}) = \frac{\sqrt{1-f}}{\bar{x}\sqrt{n}} \sqrt{\frac{\sum_{i=1}^{n} y_i^2 - 2\hat{R}\sum_{i=1}^{n} y_i x_i + \hat{R}^2 \sum_{i=1}^{n} x_i^2}{n-1}}$

When yi and xi are equal to 0 or 1 then $\sum_{i=1}^{n} yi^2 = \sum_{i=1}^{n} yi$ and $\sum_{i=1}^{n} xi^2 = \sum_{i=1}^{n} xi$.

When yi and xi have values other than 0 or 1 then $\sum_{i=1}^{n} yi^2$ and $\sum_{i=1}^{n} xi^2$ cannot be calculated because I only had access to aggregate Medicare data.

The term $2\hat{R}\sum_{i=1}^{n} yixi$ estimates the covariance of x and y. This is assumed to be zero because it cannot be estimated without access to the individual data from the Medicare sample. This is a conservative assumption. In large samples, the normal distribution can be used to calculate the confidence limits of a ratio. (Cochran 1977) p31-32

Appendix B

Interview schedule

Part A

Understanding of the condition

Meaning of precancer

Progression/regression

Probability of cure

Severity/Risk of invasive disease

Commonness

Role of viruses/sexual transmission

Possible complications/Interpretation of meaning of complications

Meaning of cancer

Development of current understanding

Education/reading

Contact with health care system

Other women/family/friends

GP/Gynaecologist/Primary health practitioner

Health promotion/Health education messages

Recommendations

Part B

Explanations for condition

Relevance of life context

Role of chance

Explanations for other illnesses

Relevance of cervix/genitalia

Description of cervix

Attitudes/feelings/beliefs about cervix

Effect of removal of cervix

Relationship between this experience and their life context

Effect on rest of life

Effect of life context on experience

Relationship to issues about control

Appendix C

Pseudonyms

Adrienne: aged 41, lives with her male partner and works in the public service. She suffers from a chronic illness which she linked to her abnormality. At the time of interview Adrienne felt well. Adrienne had CIN 3 which was treated with laser.

Amanda: aged 30, lives with her husband and children. She works in the insurance industry. Amanda had CIN 3 which was treated with laser. At the time of interview Amanda still thought she had had cancer. Amanda found that the abnormality had made her more aware of her own mortality and the possibility that she may develop cancer. Unfortunately the tape recorder did not work for Amanda's interview so I wrote some quotes verbatim but I mainly noted the content of her answers.

Amy: aged 21, works in the public service and lives with her male partner. She had wart virus found on her smear six years previously. Recently she had CIN 2 and HPV and had laser treatment. One of Amy's main concerns was her mother's reaction to her wart virus infection. Her mother believed that wart virus was sexually transmitted and Amy felt her mother was angry at her for developing a sexually transmitted infection. Her mother worked in the health area.

Anna: aged 29, lives with her partner and works as a curator. She had CIN 3 on cervical biopsy and had laser treatment. Anna wanted much greater involvement in decisions about her gynaecological care.

Brenda: aged 34, works in a library and lives alone. She had CIN 2 on Pap smear and had laser treatment. After a recurrence she had further laser treatment. She has recently divorced. Her partner had been unsupportive when she had the abnormality diagnosed and had treatment. Brenda was adamant that she should have much more information about the medical approach to abnormal Pap smears. She appreciated doctors who expressed their uncertainty and she questioned categorical statements about abnormal Pap smears and treatment. She was angered, and not reassured by, clinical staff who told her "not to worry".

Bronwyn: aged 22, works in marketing and lives with her male partner. She has HPV affecting her vulva and on Pap smear. She had had two laser treatments and various topical treatments. Although her Pap smears no longer demonstrated HPV she has persistent wart virus infection of her vulva. Bronwyn felt a lot of pain with any sexual activity involving her genitals. She was concerned that she had "invented" her pain and that this was affecting her relationship.

Carmel: aged 37, lives with her husband and children. She works with preschool children. Carmel had CIN treated five years previously with a cone biopsy and it had recurred. She had laser treatment following the second abnormality. Her abnormality caused her to reflect upon her own mortality. Although she still feared her own death she appeared to feel more comfortable thinking about it than she had prior to the abnormality.

Gladys: aged 50, lives with her husband. Gladys has had abnormal Pap smears for 26 years. Her Pap smears have demonstrated inflammatory and atypical changes. She had diathermy 11 years ago and is currently deciding whether to have further ablative treatments. Gladys desired more information about her abnormality and her treatment options. She brought her case notes to the interview for me to read. These documented her Pap smear results and the treatments over many years.

Gloria: aged 65, lives on her own. She retired from community nursing several years ago. Gloria is a keen gardener and bush walker. Several years ago Gloria suffered from a lump in her breast and at the time she was concerned that it was malignant. Gloria had CIN 3 and a cone biopsy under general anaesthetic.

Heather: aged 24, is married and works in the public service. She studies part-time. She had CIN 2 and had laser treatment. Heather was initially concerned that she had cancer. However, overall she felt her abnormal Pap smear was only a minor problem.

Jenny: aged 46, lives with her husband and children. She trained as a nurse. Jenny had CIN 2 found on her Pap smear and had laser treatment. Because of her abnormality Jenny thought more about her own death. She felt it had changed her approach to nursing, making her more sensitive to her patients' needs.

Judith: aged 53, works with books and lives with her husband. She had HPV found on her Pap smear and had had laser treatment. The main issue for Judith was how the diagnosis affected her relationship with her husband. Her husband felt she blamed him for her abnormality and she felt uncertain about why she developed the abnormality and was reluctant about sexual relations.

Julie: aged 29, lives with her husband and two children. Julie was studying for an arts degree part-time. She suffered from a chronic gastrointestinal disorder which she considered to be a much greater problem than her cervical abnormality. Julie had a minor cervical abnormality but was unsure of the grade. Julie thought the abnormality was a fairly insignificant health problem. She had one laser treatment.

Leslie: aged 24, is a university student who has had cervical abnormalities for several years. Initially she had CIN 1 and wart virus but her condition worsened, despite treatment, to CIN 3. Leslie had diathermy under general anaesthetic and when her condition recurred had laser treatment with a different gynaecologist. Following laser treatment she still had CIN 3 and used naturopathic treatment and made lifestyle changes. A colposcopy following her naturopathic treatment did not reveal any evidence of CIN or HPV. Leslie was angry because she felt she had not been fully informed about the various treatment options. She also thought that the possibilities of recurrences after treatment should have been explained.

Lorraine: aged 28, lives with her husband and two children. She had CIN 2-3 on colposcopic biopsy. Initially she tried various herbal treatments but her CIN persisted so she had laser treatment. At the time of her diagnosis Lorraine was experiencing considerable emotional trauma. The abnormality became part of her narrative about how difficult her life was at the time of diagnosis. She had a second treatment with laser six months after her first because her condition still persisted.

Louise: aged 36, lives with her husband and two children and works as an administrator part-time. She had CIN 1 and a diathermy under general anaesthetic. After treatment, a colposcopy revealed a recurrence of her CIN, however when she returned for treatment there was no evidence of CIN. Louise trusted her doctors to act in her best interest.

Maeve: aged 70, lives with her husband. She is retired and used to work as a counsellor. She had CIN 1 and had laser treatment. Maeve had recently had an abdominal operation. Maeve read quite a lot about abnormal Pap smears. However, she felt she did not have adequate information to question clinicians' decisions nor make sense of the after-effects she experienced.

Mary: aged 27, lives with her husband and children. Mary had CIN 2 and diathermy under a general anaesthetic. For some time preceding the abnormal smear Mary had experienced health problems and had sought medical advice from several doctors. She was frustrated by the lack of diagnosis. Her Pap smear was one of the many tests that was done to investigate her symptoms. Initially she considered her abnormality might explain her symptoms. When the symptoms recurred after treatment she was upset that her problems had not been resolved.

Peggy: aged 46, lives with her male partner and works as an administrative clerk. Peggy had CIN 1 and HPV and was treated with laser. She believed that without treatment she would develop cervical cancer and that the frequency of recurrences after treatment was low.

Penny: aged 37, works in the public service. She lives with her children and male partner. On colposcopy her gynaecologist told her she had possible CIN and wart virus infection. Several months later when she returned for another colposcopy there was no evidence of either CIN or wart virus infection. She related her abnormality to an emotionally difficult period in her life.

Phillipa: aged 36, lives with her husband and children and works as a school teacher. She had CIN and HPV on Pap smear and had laser treatment. Phillipa was very embarrassed about having wart virus infection. She felt stigmatised because she had a sexually transmitted infection.

Rosemary: aged 19, looks after her child at home. At the time of the interview Rosemary was living by herself. Her abnormal smear was found when she had a Pap smear at her post-natal visit to her obstetrician. She had not previously had a Pap smear. Rosemary had CIN 3 and laser treatment. Rosemary felt she had had cancer. Her mother, her main support person, also feared she would die. Rosemary felt unable to get support from her friends who she thought considered her abnormality related to sexual transmission and marked her as unclean.

Ruth: aged 30, lives with her male partner and works in an administrative post. She had recently emigrated to Australia from the United Kingdom. CIN 1 was picked on her Pap smear and she had laser treatment. Several years ago Ruth had a cervical abnormality but did not have treatment for it. She feared cancer and linked it to the pressures of modern life. She believed that the chances of her developing cancer in the future were high.

Sally: aged 41, lives with her husband and child and works as a graphic artist. Sally had wart virus infection many years previously. On Pap smear she had CIN 1 and HPV infection and had laser treatment. Sally participated in the study because a health professional had previously told her that little was known about wart virus infection. She thought of her cervical abnormality as part of women's fate to experience reproductive afflictions.

Sarah: aged 27, works in the community sector and studies a health related degree part-time. Sarah shared a house with several other women. She had CIN 2 and a diathermy under general anaesthetic. She connected her abnormal Pap smear with a difficult period in her life and regrets that she did not adopt an expectant approach to the medical treatment for her abnormality. She felt this would have enabled her to address the other aspects of her life that she related to her abnormality.

Sharon: aged 31, lives with her husband and works in the community sector in a health area. Sharon had CIN 1 and HPV and had laser treatment. Sharon's main concern related to the effect of the abnormality and treatment on her capacity to have children.

Valerie: aged 51, is a school teacher who lives with her husband. She had wart virus infection which was treated with laser on two occasions. There were still microscopic signs of wart virus infection after treatment. She felt that wart virus infection was difficult to eliminate. Her husband was also treated for wart virus infection.

Veronica: aged 34, is a public servant who lives with her male partner. Veronica has CIN 3 diagnosed on Pap smear and had laser treatment. Follow-up Pap smears have been normal. Although she initially thought she had cancer and was concerned that she would die, she felt reassured by her GP and gynaecologist. Her partner was also supportive.

Winnie: aged 48, works in the public service and is studying part-time. She had an abnormal Pap smear 15 years ago which was treated with cryotherapy. Three years ago she had diathermy for a further recurrence. Recently she had CIN 1 and HPV found on her Pap smear and had laser treatment. Winnie felt able to ask doctors questions as she had medical friends and had some nursing training.

Appendix D

Definitions of item numbers, DRG and ICD-9 codes

Item numbers

Table D.1 Item numbers*

Item number	Item description
104	Professional attendance at consulting rooms, hospital or nursing home by a specialist in the practice of his or her speciality where the patient is referred to him or her. INITIAL attendance in a course of treatment.
105	Each SUBSEQUENT attendance to the first in a single course of treatment.
35614	Examination of the lower female genital tract by a Hinselmann-type colposcope. Benefits for this item are limited to the following circumstances: "(1) where a patient has had an abnormal cervical smear; (2) where there is a history of maternal ingestion of oestragen by the patient's mother during her pregnancy; or (3) where the patient has been referred by another medical practitioner because of suspicious signs of genital cancer.
35608	CERVIX, cauterisation (other than by chemical means), ionisation, diathermy or biopsy of, with or without dilatation of the cervix.
18200	REGIONAL OR FIELD NERVE BLOCK.
35539	COLPOSCOPICALLY DIRECTED CO2 LASER THERAPY for previously confirmed intraepithelial neoplastic changes of the cervix, vagina, vulva, urethra or anal canal, including associated biopsies - one anatomical site.
35542	As for 35539 except that laser is to two or more anatomical sites.
35545	COLPOSCOPICALLY DIRECTED CO2 LASER THERAPY for condylomata, unsuccessfully treated by other methods.
30071	BIOPSY OF SKIN OR MUCOUS MEMBRANE
30118	TUMOUR, CYST, ULCER OR SCAR, up to 3cm in diameter, removal from cutaneous or subcutaneous tissue or mucous membrane, where removal is by surgical excision and suture.
73806	Pregnancy test by one or more immunochemical methods.

*All number codes were converted to their equivalent in the Medicare Benefits Schedule Book November 1992.

Table D.1 Item numbers* (continued)

Item number	Item description
73806	Pregnancy test by one or more immunochemical methods.
72801	Histopathology examination of biopsy material including all the tissue processing, staining and professional opinion or opinions.
73055	Cytological examination of smears from the cervix in association with the management of previously detected abnormalities including precancerous or cancerous conditions, or the investigation of women with symptoms, signs or recent history suggestive of cervical neoplasia and smears repeated due to an unsatisfactory examination.
35646	CERVIX, colposcopy with radical diathermy of, with or without cervical biopsy, for previously confirmed intraepithelial neoplastic changes of the cervix, where performed in the operating theatre of a hospital or approved day facility.
35653	HYSTERECTOMY, ABDOMINAL, SUB-TOTAL or TOTAL, with or without removal of the uterine adnexae.
35657	HYSTERECTOMY, VAGINAL, with or without uterine curettage.

*All number codes were converted to their equivalent in the Medicare Benefits Schedule Book November 1992.

Diagnostic related groups

Table D.2 DRGs

DRG code	DRG description
360	Vaginal, cervical and vulval procedures
364	D&C, conization except for malignancy
358	Uterine and adnexal procedures for non-malignancy
369	Menstrual and other reproductive system disorders

ICD-9-CM procedure classification codes

Table D.3 ICD-9-CM procedure classification codes

ICD-9 Code	Description of code
67.2	Conization of the cervix
67.32	Destruction of tissue by cauterisation
68.4	Total abdominal hysterectomy
68.5	Vaginal hysterectomy
622.1	Dysplasia of the cervix (diagnostic code)
70.31	Hymenectomy

Appendix E

Cost to government

Cost to government of outpatient treatment

Table E.1 Cost to government: item mix table

	35614, 35608	73806	35545	35542	35539
1988/89					
Estimated Total No.	21510	2570	160	310	3230
Average cost ($)	48.88	7.50	92.13	172.00	143.93
Standard error ($)	0.03	0.02	0.89	0.00	0.10
1989/90					
Estimated Total No.	25530	2510	740	310	5330
Average cost ($)	50.46	8.12	98.32	177.94	150.66
Standard error ($)	0.04	0.02	0.13	0.61	0.24
1990/91					
Estimated Total No.	23320	2320	560	350	5220
Average cost ($)	52.95	8.46	102.05	184.69	155.34
Standard error ($)	0.04	0.01	0.31	0.61	0.27
1991/92					
Estimated Total No.	21360	2010	510	200	4720
Average cost ($)	55.13	8.65	105.57	188.98	159.02
Standard error ($)	0.03	0.00	0.23	1.02	0.13

Table E.2 Cost to government: abatement table

Item	18200**	30071#	30118#	35608			35614		
Abatement level*	A	A	A	A	B	C	A	B	C
1988/89									
Estimated total	60	530	530	28270	1010	380	58310	22680	590
Average cost ($)	47.60	26.75	64.12	32.62	16.35	8.20	32.67	16.36	8.19
Standard error ($)	0.00	0.03	0.03	0.01	0.02	0.00	0.01	0.00	0.01
1989/90									
Estimated total	470	530	530	31800	980	550	66410	26730	760
Average cost ($)	49.12	27.86	67.22	33.78	16.95	8.47	33.81	16.90	8.46
Standard error ($)	0.07	0.06	0.19	0.01	0.04	0.01	0.01	0.00	0.01
1990/91									
Estimated total	610	630	390	29210	740	330	69510	24580	510
Average cost ($)	51.59	28.96	70.27	35.33	17.83	8.97	35.43	17.69	8.92
Standard error ($)	0.20	0.07	0.25	0.02	0.05	0.03	0.01	0.01	0.03
1991/92									
Estimated total	550	540	510	25840	710	250	66790	22370	380
Average cost ($)	53.47	30.07	73.15	36.78	18.40	9.19	36.85	18.42	9.21
Standard error ($)	0.11	0.08	0.16	0.01	0.03	0.03	0.01	0.01	0.02

* Items are rebated at 85 per cent of the 100, 50 and 25 per cent of the scheduled fee for levels A, B and C respectively.

**The multiple operation formula does not apply to 18200 which is always rebated at 100 per cent of the scheduled fee.

Although items 30071 and 30118 were occasionally rebated at levels B and C in my clinic sample there were insufficient numbers in the ten per cent file to calculate costs. Therrefore, the cost to goverment was taken as 50 per cent and 25 per cent of the abatement A cost when they were rebated at levels B and C, respectively.

Table E.3 Cost to government of gynaecological consultations *

Item	104			105		
	Estimated total	Average cost ($)	Standard error ($)	Estimated total	Average cost ($)	Standard error ($)
1988/89	576530	44.00	0.00	693110	22.02	0.00
1989/90	588720	45.56	0.00	715920	22.77	0.00
1990/91	594180	47.50	0.01	691170	23.72	0.00
1991/92	596720	49.34	0.00	682800	24.66	0.00

* Consultation item numbers are not affected, and do not affect, the multiple operation formulae. All consultation item numbers are rebated at 85 per cent of the scheduled fee. Other items charged with the consultation are subject to the multiple operation formula separately from the consultation item.

Table E.4 Costs to government of pathology services*

	Pap Smear**	Biopsy#
1988/89		
Total No.	1,404,324	764,827
Average cost ($)	14.82	67.19
1989/90		
Total No.	1,542,957	938,176
Average cost ($)	16.20	69.77
1990/91		
Total No.	1,687,936	1,020,0863
Average cost ($)	16.98	73.09
1991/92		
Total No.	1,606,427	1,069,780
Average cost ($)	14.33	68.97

* Calculations for Pap smear and biopsy services used a 100% file of pathology services.

** The cost of Pap smear services was calculated using the following item numbers: 2051, 2052, 2053, 2054, 2081, 2082, 2338, 2339, 73053, 73055, 73057. The item numbers for Pap smears changed over the time period of the study. Hence only a few of the above item numbers pertained in any one year.

The cost of cervical biopsies taken as an outpatient was calculated using the following item numbers: 2041, 2042, 72801. The item numbers for biopsies changed during the course of study. Hence not all of the above item numbers were relevant to any one year.

Cost to government of public hospital treatment

Table E.5 Costs to governmennt of inpatient public hospital treatment

	89/90*	90/91	91/92
Cone biopsy (average LOS 1.41 days)			
Average cost per bed day	633.17	736.81	850.56
Total cost	892.77	1038.90	1199.29
Diathermy (average LOS 1.04 days)			
Average cost per bed day	750.98	865.63	1125.63
Total cost	781.02	900.26	1170.97
Total abdominal hysterectomy			
(average LOS 8.31 days)			
Average cost per bed day	323.75	348.07	418.90
Total cost	2691.01	2893.16	3481.90
Vaginal hysterectomy			
(average LOS 10.30 days)			
Average cost per bed day	323.75	348.07	418.90
Total cost	3333.98	3584.42	4313.83
Laser (average LOS 1.14 days)			
Average cost per bed day	750.98	865.63	1125.93
Total cost	856.12	986.82	1283.56
Hymenectomy (average LOS 1.60 days)			
Average cost per bed day	750.98	865.63	1125.83
Total cost	1199.32	1382.41	1798.11
Other** (average LOS 2.19 days)#			
Average cost per bed day	380.13	444.39	404.43
Total cost	832.48	973.21	885.42

LOS = Length of stay in days

* I use 89/90 estimate for 88/89 because there were no DRG cost estimates prior to 89/90

** The other category refers to two women who had unknown treatment in hospital and one woman who had a secondary haemorrhage.

The length of stay in this category was calculated using the diagnostic ICD 9 code 622.1.

Cost to government of private hospital treatment

Table E.6 Cost to government of private hospital inpatient treatment (medical expenses)

	35618	35646	35653	35657
1988/89				
Estimated total	1950	7960	15980	810
Average cost ($)	253.83	235.71	527.52	604.29
Standard error ($)	5.23	2.47	3.14	11.54
1989/90				
Estimated total	2080	6310	14250	2670
Average cost ($)	270.54	252.03	563.36	635.92
Standard error ($)	5.13	2.90	3.60	5.98
1990/91				
Estimated total	2270	5630	12280	3890
Average cost ($)	272.55	271.61	582.06	674.72
Standard error ($)	4.17	3.33	3.98	6.22
1991/92				
Estimated total	1990	3910	10870	4890
Average cost ($)	278.30	279.67	605.15	697.85
Standard error ($)	5.88	4.61	4.29	5.49

Appendix F

Cost to women

Cost to women of outpatient treatment

Table F.1 Cost to women: item mix table

	35614, 35608	73806	35545	35542	35539
1988/89					
Estimated total no.	21510	2570	160	310	3230
Average cost ($)	16.19	2.89	20.41	30.94	38.22
Standard error ($)	0.33	0.03	4.17	5.47	3.07
1989/90					
Estimated Total No.	25530	2510	740	310	5330
Average cost ($)	19.49	2.58	40.07	51.55	42.03
Standard error ($)	0.35	0.02	2.84	8.50	2.37
1990/91					
Estimated Total No.	23320	2320	560	350	5220
Average cost ($)	21.39	2.74	37.27	74.95	49.44
Standard error ($)	0.17	0.03	4.39	11.10	1.72
1991/92					
Estimated Total No.	21360	2010	510	200	4720
Average cost ($)	21.54	2.77	39.92	71.27	49.44
Standard error ($)	0.46	0.21	5.33	14.01	3.83

Table F.2 Cost to women: abatement table

Item	18200**	30071#	30118#	35608			35614		
Abatement level*	A	A	A	A	B	C	A	B	C
1988/89									
Estimated total	60	530	530	28270	1010	380	58310	22680	590
Average cost ($)	16.40	12.95	19.64	10.62	4.73	1.79	11.59	5.50	3.44
Standard error ($)	3.39	1.83	2.55	0.19	0.24	0.39	0.15	0.11	0.36
1989/90									
Estimated total	470	530	530	31800	980	550	66410	26730	760
Average cost ($)	26.88	10.82	18.61	12.07	5.75	4.70	13.41	6.37	3.90
Standard error ($)	1.71	1.74	2.89	0.20	0.59	0.43	0.16	0.11	0.40
1990/91									
Estimated total	610	630	390	29210	740	330	69510	24580	510
Average cost ($)	33.56	17.32	22.50	13.60	6.12	3.56	14.69	7.13	4.03
Standard error ($)	1.16	2.12	3.57	6.12	0.74	0.30	0.18	0.15	0.45
1991/92									
Estimated total	550	540	510	25840	710	250	66790	22370	380
Average cost ($)	34.14	15.00	20.88	13.61	7.81	2.51	14.87	7.17	4.03
Standard error ($)	1.52	2.31	3.49	0.27	0.93	0.53	0.19	0.15	0.51

* Items are rebated at 85 per cent of the 100, 50 and 25 per cent of the scheduled fee for levels A, B and C respectively.

**The multiple operation formula does not apply to 18200 which is always rebated at 100 per cent of the scheduled fee.

Although items 30071 and 30118 were occasionally rebated at levels B and C in my clinic sample there were insufficient numbers in the 10 per cent file to calculate costs. Therefore, the cost to government was taken as 50 per cent and 25 per cent of the abatement A cost when they were rebated at levels B and C respectively.

Table F.3 Cost to women of outpatient gynaecological consultation*

Item	104			105		
	Estimated total	Average cost ($)	Standard error ($)	Estimated total	Average cost ($)	Standard error ($)
1988/89	576530	10.96	0.03	693110	5.83	0.02
1989/90	588720	12.65	0.03	715920	6.74	0.02
1990/91	594180	14.39	0.04	691170	7.77	0.02
1991/92	596720	15.53	0.04	682800	8.43	0.02

* Consultation item numbers are not affected, and do not affect, the multiple operation formulae. All consultation item numbers are rebated at 85 per cent of the scheduled fee. Other items charged with the consultation are subject to the multiple operation formula separately from the consultation item.

Table F.4 Costs of pathology services to women*

	Pap smear**	Biopsy#
1988/89		
Total no.	1,404,324	764,827
Average cost ($)	3.05	18.15
1989/90		
Total no.	1,542,957	938,176
Average cost ($)	3.55	18.29
1990/91		
Total no.	1,687,936	1,020,0863
Average cost ($)	3.55	18.67
1991/92		
Total no.	1,606,427	1,069,780
Average cost ($)	3.10	18.17

* Calculations for Pap smear and biopsy services used a 100 per cent file of pathology services.

** The cost of Pap smear services was calculated using the following item numbers: 2051, 2052, 2053, 2054, 2081, 2082, 2338, 2339, 73053, 73055, 73057. The item numbers for Pap smears changed over the time period of the study. Hence only a few of the above item numbers pertained in any one year.

The cost of cervical biopsies taken as an outpatient was calculated using the following item numbers: 2041, 2042, 72801. The item numbers for biopsies changed during the course of study. Hence not all of the above item numbers were relevant to any one year.

Cost to women of private hospital treatment

Table F.5 Cost to women for private hospital treatment (medical expenses)

	35618	35646	35653	35657
1988/89				
Estimated total	1950	7960	15980	810
Average cost ($)	53.61	46.66	101.90	116.41
Standard error ($)	3.96	1.62	2.26	11.38
1989/90				
Estimated total	2080	6310	14250	2670
Average cost ($)	56.20	60.24	131.52	109.10
Standard error ($)	3.71	2.62	2.97	7.14
1990/91				
Estimated total	2270	5630	12280	3890
Average cost ($)	70.92	9.28	153.18	148.22
Standard error ($)	4.38	2.85	3.56	6.68
1991/92				
Estimated total	1990	3910	10870	4890
Average cost ($)	67.43	85.10	174.33	180.43
Standard error ($)	4.43	4.32	4.00	6.70

Table F.6 Private hospital accommodation costs to women

	1/5/90 to 30/9/90 ($)	1/11/90 ($)
Cone biopsy (median LOS 1 day)	5.00	20.00
Diathermy (median LOS 1 day)	5.00	20.00
Total abdominal hysterectomy (Median LOS 8 days)	25.00	40.00

Women admitted on dates not included in the table did not have any accommodation expenses for their private hospital admission.

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