The ‘lived experience’ of women with a cervical screening detected abnormality: A phenomenological study

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Abstract

This thesis focuses on the stories of thirteen women who had experienced an abnormal Pap test result. A review of the literature demonstrated that, while much research had investigated the biomedical aspects of cervical intraepithelial neoplasia (CIN) and cervical cancer, very few studies in comparison had explored women’s experiences of having a cervical screening abnormality detected. The majority of those studies related to cervical cancer and assumed a homogenous sample of English speaking, heterosexual, middle class and well-educated women.

It is argued that the stories of women whose voices are silent in the literature need to be heard, so that health professionals can learn from women how to enhance their clinical practice to ensure the best possible health outcomes for women with a screening detected cervical abnormality.

The research aimed to answer the question, ‘What is the “lived experience” of women who have had an abnormal Pap test result?’ The thirteen participants were from groups considered at greatest risk of developing CIN/cancer and least likely to access cervical screening services. Each participant was interviewed on between two and five occasions, for one and a half to four hours per interview. At the first interview, participants were asked to respond to two predetermined prompts. The first, ‘Please tell me about yourself as a woman’ was asked in an endeavour to encourage the woman to share her story in a manner that was contextualised, integrated and whole. The second prompt was, ‘Please tell me about your experience when you had an abnormal Pap test result’. At the remaining interviews, an unstructured approach was adopted and the women were asked to clarify any issues that had arisen in previous interviews. Only the first interview was audiotaped, transcribed verbatim and analysed. Analysis and interpretation occurred simultaneously and were in keeping with the principles outlined by the hermeneutic phenomenologist, Gadamer (1975a).

Four major thematic interpretations emerged from the transcript analysis and form the basis of the interpretive chapters. The first represents how the participants defined themselves according to life stressors. These stressors were of a devastating nature...
related to physical violence, sexual trauma and/or profound grief and loss, mostly experienced in their intimate and family relationships. This is the first study to explore how women define themselves within the parameters of violence and how a woman’s previously traumatised self can be further threatened by the experience of having an abnormal Pap test result. This sense of being threatened is referred to as ‘abjection’ and forms the second theme.

Feelings of abjection were accentuated by the disservice, harm and injury the participants experienced within the health system and were identified as the ‘Nocebo Effect’ in the third theme. The fourth and final interpretive chapter explores how women, having felt threatened on multiple occasions, were able to transform and redefine themselves as strong, assertive women, no longer the victims of their circumstances.

The final chapter cautions against generalisations and concludes with a discussion of potential further research avenues.
Chapter 1
Introduction and literature review

Background to and rationale for the study

Everyday, millions of healthy women in industrialised nations attend a health professional, usually a medical practitioner, for a Pap test. They choose to submit themselves to this gynaecological procedure because they wish to be both reassured and insured. Reassurance comes from an objective, scientific test that they are indeed as healthy as they believe themselves to be and they feel insured against the possibility that they might develop cervical cancer.

The majority of women receive their desired reassurance and insurance. However, a significant minority, up to one in twenty women having a Pap test in New South Wales, will be faced with an abnormal Pap test result (NSW Cervical Screening Program 1997). When a woman has an abnormal Pap test result, the previously hidden cervix is not the only part of her to come under medical surveillance. Cervical pathology detected at screening exposes her deeply personal and often times intimate past and present lifestyle choices or impositions, such as a history of sexual abuse, to scrutiny. For a woman with an abnormal Pap test result the past suddenly becomes the present and threatens her future.

Thirteen women who had an abnormal Pap test result shared their stories in this phenomenological research project and chose their own pseudonym. They wished to be known as Ann, Annabelle, Faye, Janette, Jayne, Joyce, Julie, Margaret, Marie, Megan, Melanie, Rita and Terry. The women, almost all of whom were clients of a women’s health nurse clinic in rural Australia at the time the project was initiated, were invited to participate in the study. The women were purposively invited because they identified as being from groups whose voices were silent in the professional nursing/medical journals. They were from the same groups identified as being at greatest risk of cervical intraepithelial neoplasia (CIN) and given priority of access to cervical screening attended by women’s health nurses. In keeping with the nature of phenomenology, the participants were never asked to share instances of trauma. Instead, they were invited to
share their stories in response to two prompts, ‘Please tell me about yourself as a woman’ and ‘Please tell me about your experience when you had an abnormal Pap test result’.

Sixteen women were invited to participate but three women declined. Of the women who declined, one was a sex industry worker with a newborn baby and two were from non-English speaking South East Asian countries. Of those who participated, the youngest woman was eighteen and the oldest seventy years old. Eight were socio-economically disadvantaged and in receipt of social security payments. One had been homeless for eighteen months and two lived in caravan parks. Three women had a disability – one was deaf and communicated by lip reading, one had had paraplegia since childhood and another was mildly developmentally delayed. Three of the women were distressed by their obesity. One woman identified as Aboriginal and spoke Wiradjuri as a second language. Two of the women were from non-English speaking backgrounds. One woman was a refugee and one woman identified as lesbian. Three of the women, having heard of the research project, contacted me and asked if they could also share their stories. Five women shared stories of surviving child sexual assault, two of being raped as adults and one woman described the trauma she felt on discovering that her husband was a paedophile. Six women shared stories of feeling betrayed when they learnt that their partners were having sexual relationships with other women, three of those with a woman they considered to be a close friend. Seven women shared stories of surviving violent intimate relationships. Two women were widows, their husbands having died prematurely under tragic circumstances. Two women shared their grief when describing the death of their babies and four women described their distress at having experienced miscarriages. One woman’s husband, one woman’s daughter and one woman herself had survived life-threatening illnesses. Women were not invited to participate because of their stressful life histories and, prior to the initial interview, the majority of the women’s life stories and contexts were unknown to me. Every woman who participated in this study requested that their stories be shared as widely as possible so that others, especially health professionals, might learn from them.

This thesis, together with the publications, conference presentations, seminars and workshops that arose from the women’s shared experiences, responds to their request.
This introductory chapter has two components: the first provides the background to and the rationale for the study, the second is a detailed and critical review of the literature. Readers are given a very brief overview on how the theoretical perspectives that inform the thesis are used. Reasons for attending the study are then identified and these include the recognition that, while much is known and published about the biomedical aspects of Pap testing, CIN and cervical cancer, very little in comparison has been published that explores the issue from the woman’s perspective (Taylor, Keller & Egan 1997). The nomenclature cervical dysplasia and cervical intraepithelial neoplasia tend to be used synonymously in Australia but, for the purposes of consistency and ease of grading where appropriate, the terminology cervical intraepithelial neoplasia (CIN) will be used in this thesis.

An abnormal Pap test result is a very common phenomenon for women. In Australia in 1996, it was estimated that a 15-year-old woman exposed to current rates of colposcopy usage had a 76.8% lifetime chance of requiring a colposcopy for further investigations of an abnormal Pap test result before she is 75 (Kavanagh, Santow & Mitchell 1996). In the United Kingdom in the mid-1990s, about 7% of women screened required a repeat smear because an inadequate sample was taken, about 5.5% had borderline or minor abnormalities and about 1.6% had more severe abnormalities (NHS Cervical Screening Programme 1995 cited in Summers 1998).

The meaning an abnormal Pap test result has for a woman is seldom taken into account in the literature (Posner 1991). In analysing health education information about Pap testing, Lane and Lawler (1997) found that the Pap test was contextualised as a procedure ‘done to’ women and that their experiences of the encounter and any possible sequelae were silenced. The research reported in this thesis seeks to break this silence.

The women’s life stories and experiences are unique but intertwined with common threads. The theoretical framework on which this study developed reflects the complexity of the women’s stories. The thesis was undergirded and informed by feminist theory and supported by the works of several social critical and feminist theorists. Theoretical perspectives are articulated with the women’s voices in a manner that provides reciprocal recognition and mutual validation between the theorist and the study participant. As a woman-centred study, the women’s voices are always the primary focus. Through their stories, lessons can be learnt that have the potential to
increase health professional understanding and enhance clinical practice. Health professionals will do well to listen to and learn from these women’s experiences.

The nature of this research project demanded that the review of the literature precede the study and continue throughout the data collection and interpretation processes. It was finalised only as the draft of this thesis neared completion. As the review of the literature to follow demonstrates, few of the studies to date focus on either the woman’s experience, her life context or the meaning that she gave to the experience of having had an abnormal Pap test result.

**Literature review**

*Each person comes to an illness with a history relevant to that illness ... her prior experience with and knowledge of the disease may be scant or extensive. The person may invest the disease with particular personal terror or have few preconceptions about it ... This personal history shapes the person’s illness experience during all of its phases ... prior knowledge and experience may lead to vigilance or to denial and avoidance.*

Benner & Wrubel 1989, p. 275

I found myself troubled by this literature search into the effects of an abnormal Pap test result. The balance of available material is heavily slanted towards the microbiological perspective with some limited information available from the psychological standpoint. The voices of women are both silent in and silenced by the scientific literature. The woman’s experience has been largely ignored. This ignorance has led to a tendency for women with an abnormal Pap test result to be blamed and to blame themselves for somehow putting themselves at risk and precludes many sociological impactions from being fully explored. The literature that feeds health professional bias, attitudes, values and worldviews is therefore critiqued in relation to the adverse influence it can have on women experiencing an abnormal Pap test result.

The path this review travels is through the biomedical literature, commencing with the conception of the Pap test and then on to the links established between human papillomavirus (HPV), CIN and cervical cancer. It explores the natural history of cervical pathology and those factors thought to progress the disease process. The psychological literature is examined and the hypothesis that cervical pathology is linked to personality type is critiqued. Sociological factors that create barriers for women receiving necessary follow-up investigations and treatments are discussed. The limited
amount of literature relating to the woman’s experience of having a Pap test and the impact of an abnormal result is reviewed. The paucity of literature relating to women considered marginalised and at greatest risk of developing CIN/cervical cancer is uncovered. The literature review concludes by confirming the need for an in-depth research study that listens to, publishes and learns from the stories of women who have experienced an abnormal Pap test result.

**Biomedical paradigm**

The uterus is the only part of the body that is unique to women; it is the one organ that doesn’t have an anatomical equivalent in the male (Angier 1999) and the cervix is the gateway to and from this structure. Squamous cells line the vagina and columnar cells line the endocervical canal and the two types of cell meet at the squamo-columnar junction (Tortora 2003). Surrounding the squamo-columnar junction is the transformation zone where columnar cells, exposed to the acid environment of the vagina, are transformed into squamous cells and it is this rapid cell division occurring in the cervical transformation zone that increases the possibility of abnormal cellular changes (Tortora 2003). Dr George N. Papanicolaou is traditionally accredited with developing the screening Pap test to detect abnormal cellular changes to the cervix (Loeb 1993).

**The Pap test conceived**

Papanicolaou, a medical researcher, studying the oocytes of guinea pigs and the endocrinology of the menstrual cycle with his wife and medical research partner, Mache Papanicolaou, incidentally discovered that malignant cells from the cervix could be observed in vaginal smears (Barter 1992; Loeb 1993). He presented this observation in May 1928 at a ‘Third Race Betterment Conference’ in the USA (cited in Visser et al. 2000). Papanicolaou was apparently unaware that the Romanian pathologist, Aureli Babes, had used cytological sampling of the cervix for the diagnosis of cancer at least two years earlier and had published a detailed account of his work in April 1928 (Koss 1989). In 1947, J. Ernest Ayre, a Canadian gynaecologist, documented that direct sampling of the cervix with a wooden spatula was more efficient and easily examined than a vaginal smear (Ayre 1947 cited in Koss 1989). What came to be known as the Pap test, was esteemed, and continues to be esteemed, as a tool that could prevent cancer of the cervix when it was discovered that slowly progressive, cellular changes confined to the cervical epithelium could be detected and treated so that invasive
cervical cancer would not develop (Koss 1989; Sevin 1999). There is consensus in the literature, among health professionals and most women in the community, that Pap testing saves lives and that the benefits of cervical screening outweigh any costs (Youngkin & Davis 1998).

Two global problems with Pap testing have been identified in the literature. The first is that, in the developing world where cervical cancer is the most significant female cancer, relative costs of cervical screening prohibit its use (Symonds 1997; Sherman et al. 1998; Varghese et al. 1999). The second is the adverse emotional effects and potential over-treatment of women with CIN in industrialised countries (Austoker 1994). Since the introduction of the Bethesda Classification that combined HPV changes and mild CIN (CIN 1) into the designation of low-grade squamous intraepithelial lesion (LSIL) requiring further investigations, an increasing number of women have been subjected to further investigations. This is due to both the changed nomenclature in the Bethesda Reporting System and the increasing incidence of cervical pathology (Lewis et al. 1999). The result has been considerable anxiety, expense, inconvenience and some morbidity for the women concerned (Jones 1995).

**Links between HPV and CIN/cervical cancer**

Both the clinician and the woman concerned are faced with a dilemma when a Pap test result detects cellular changes suggestive of HPV and/or low-grade CIN. At this stage in the knowledge continuum, HPV has been established as the central causal factor in CIN and cervical cancer (zur Hausen 1987; Munoz et al. 1992; Schiffman et al. 1993; Potischman & Brinton 1996; Schiffman et al. 1998; Bosch et al. 2002). However, the causes of HPV have not been clearly isolated and HPV alone is not considered sufficient to cause cervical cancer (Austoker & McPherson 1992 cited in McKie 1995; Burger et al. 1993; Cothran 1996; Haverkos, Rohrer & Pickworth 2000). Even with the most sensitive methods of detection, HPV is detected in only 90% of cervical cancers and 80–90% of CIN (Tabrizi et al. 1999). Ylitalo et al. (1999) therefore suggested that HPV is a significant but not sufficient cause of cervical cancer. The dilemma is that, while HPV is significantly related to CIN and it is established that CIN can progress to invasive cancer, the majority of lesions detected at the time of cervical screening will either spontaneously regress or persist without progression (NHMRC 1994).
Progression and regression of CIN

It has been estimated by Moscicki et al. (1998) that almost three-quarters (60–75%) of young women who test positive for HPV deoxyribonucleic acid (DNA) become negative for that viral group within 20–30 months. This is a low level of regression compared with the studies by Evander et al. (1995) and Hinchcliffe et al. (1995) who estimated that 93–97% of HPV spontaneously regressed within two years. The discrepancy may have been due to varied sensitivity of testing between the Moscicki et al. (1998) study and the Evander et al. (1995) and Hinchcliffe et al. (1995) studies. It may also represent a variable such as altered immune response or more reinfection in the group of women aged 13–22 in the Moscicki et al. (1998) study.

There is also some discrepancy in progression and regression rates of CIN lesions between European and Brazilian studies. Regression is more likely in the studies conducted in Europe (Syrjanen 1989; Kataja et al. 1992) than in Brazilian studies (Rader et al. 2000). This is possibly related to the fact that HPV 18 is detected in nearly 30% of lesions in Brazilian women (Cavalcanti et al. 1996) but does not exceed 10% in cervical lesions of women in the European studies (Syrjanen 1989). HPV 18 is associated with efficient and fast neoplastic transformation and poor prognosis (Rader et al. 2000).

It is predicted overall that approximately 54–60% of biopsy proven CIN 1 lesions will revert to normal over time, 24% will persist and 21% will be subsequently treated (Lewis et al. 1999; Teale et al. 2000). Both mild and moderate CIN are more likely to regress than progress (Van der Vugt 1994 cited in Visser et al.; Bos et al. 1997; Holowaty et al. 1999), making immediate colposcopy in women with a mild cervical abnormality a seemingly unnecessary procedure that predisposes them to potentially harmful interventions. The predicament remains that approximately 30% of women with minor abnormalities on their Pap smear actually have CIN 3 lesions on their cervix (Mould 1998). The percentage of these CIN 3 lesions that will eventually become invasive malignancies if left untreated may exceed 50% (Schiffman et al. 1998). According to Meijer, Van den Brule & Snijders (1992), most women with CIN 1 or 2 do not develop CIN 3 or worse in many years of follow-up and spontaneous regression is most likely to occur in young women less than 30 years old and those with lower levels of CIN. However, Kavanagh, Santow & Mitchell (1996) argue that it remains
impossible to know which individual women with CIN will develop cervical cancer and which will persist as CIN or spontaneously regress to normal.

As the majority of conditions detected at cervical screening would have regressed or remained asymptomatic throughout life, any emotional trauma that arises from having an abnormal Pap test result must be regarded as a side effect of screening. However, the studies cited here demonstrate that emotional problems associated with screening do not exclude the possibility that for some women screening may have beneficial psychological effects (Summers 1998).

**Risk factors for progression of CIN**

There are many factors proposed in the literature that increase the risk for a woman developing CIN and/or cervical cancer. The most widely reported and accepted link is between a woman’s sexual history, especially the age at coitarche (age of first heterosexual intercourse) and the number of sexual partners she has had. The connections made in both public and professional discourses between sexual risk factors and the woman having an abnormal Pap test result serve to heighten and exacerbate her distress when cervical pathology is detected. As there are so many confounding variables it is impossible to know which risk factors are independent and which may act as cofactors. A cause and effect link cannot be definitively established between any reported risk factor and CIN/cervical cancer. Age at coitarche and number of sexual partners, because of their widespread, unquestioned acceptance as risk factors, will be discussed as separate entities. Other risk factors reported in the literature are listed as follows:

- **Inadequate cervical screening**: Women who have never been screened or have not had a Pap test for a long period of time are at greatest risk of developing cervical cancer (Howard 1987; Day 1989; Brinton et al. 1993; Potischman & Brinton 1996; Hamilton & Bauchman 1999; Sevin 1999; Franco, Duarte-Franco & Ferenczy 2001; Khanna & Phillips 2001; Taylor et al. 2001a).

  The weight of evidence is firmly in favour of cervical screening being a protective strategy for women. However, women at greatest risk of developing cervical pathology are those least likely to attend cervical screening (Griffith-Kenney 1986; Howard 1987; Guest, Mitchell & Plant 1990; Balcombe & Stoden 1991; NSW Health Department 1994; Mak 1995; Anderson 1996 cited in Cooper & Temby
1998; Temby 1996; Firebrace 1998; Wilson 1998; Kahn et al. 1999; Kahn & Emans 1999; Vidler 1999), possibly skewing the effectiveness of the Pap test. The potential harmful effects and risks of cervical screening are rarely considered, or at best minimised in the literature, because of the need to perpetuate the view that Pap tests are universally beneficial. Pap tests have low specificity and sensitivity, with a false-negative rate of 6–58%; and 13–47% of cervical malignancies are in women who had a negative smear in the 3–5 years preceding diagnosis (McCormick 1989; McKie 1994 cited in Milburn & MacAskill 1994; Mould 1998; Schoell, Janicek & Mirhashemi 1999; Renshaw 2001).

- **Cigarette smoking**: Nicotine and cotinine are found in the cervical mucous of women who smoke thus linking CIN/cervical cancer and smoking. The effect is dose dependent and increases with long-term exposure to either their own or their partner’s cigarette smoke (Greenberg et al. 1985; Brinton, Schairer & Haenszel 1986; Schiffman et al. 1987; Slattery et al. 1989; Winkelstein 1990; Fletcher, Neill & Norval 1991; Hulka 1991; Daly et al. 1998; Sevin 1999; Cavalcanti et al. 2000; Deacon et al. 2000; Eppel et al. 2000; Haverkos, Rohrer & Pickworth 2000; Hildesheim et al. 2001; Moore et al. 2001; Moscicki et al. 2001; Santos et al. 2001).

Although both active and passive cigarette smoking is associated with CIN/cervical cancer, it is not clear whether smoking operates independently of other risk factors such as sexual activity, stress levels and socio-economic status (Van der Vugt 1994 cited in Visser et al. 2000; Cothran 1996; Marcus & Crane 1998; Neilson & Jones 1998; Murthy & Mathew 2000; Franco, Duarte-Franco & Ferenczy 2001).


It is not established whether prolonged steroidal contraceptive use is an independent or cofactor as it appears to alter disease progression rather than increase incidence of CIN. The risk for past users is not clear. There are a large number of confounding
variables, such as steroidal contraceptive users being less likely to use barrier type contraceptives that offer cervical protection (Hildesheim et al. 2001; Kataja et al. 1993; Lovejoy 1994; Koutsky 1997; Parazzini et al. 1998; Beral et al. 1999; Schoell, Janicek & Mirhashemi 1999; Murthy & Mathew 2000; Deacon et al. 2000).


Confounding variables, particularly socio-economic standing, may influence nutritional status. Most data linking nutritional status are from observational studies and no definitive cause and effect link can be established, especially from more recent chemoprevention trials (Giuliano & Gapstur 1998; Giovannucci 1999; Kjellberg et al. 2000).

- **Poor personal hygiene**: Women who bath less than once a day or, paradoxically, more than twice a day during menstruation have a slightly increased risk of cervical cancer (Herrero et al. 1990; Lovejoy 1994; Murthy & Mathew 2000). Women are at greater risk of developing cervical cancer if their first coital experience was on the ground (Rotkin 1973) and Lovejoy (1994) suggests that loss of virginity under poor hygienic conditions is a risk factor because the immature traumatised cervix has been exposed to environmental carcinogens or viruses by an unclean condom or penis. She argues that unhygienic conditions or contaminants introduced to the vagina during foreplay may be risk factors for mutually monogamous couples.

Poor personal hygiene may be linked to other variables, in particular, the lack of available clean, running, hot water and other sanitation resources which are restricted for women in developing countries who are homeless and/or with limited financial means.

- **Marital status**: Divorced and widowed women have twice the risk as married women of developing CIN. The particularly high incidence of CIN in divorced women may be associated with either their or their ex-partner’s sexual activity level but this has yet to be established (Visser et al. 2000).
Other confounding variables may include socio-economic status and/or stressful life events that led to the death or separation of a spouse. Bartop et al. (1977) argues that such events lead to immunosuppression.

- **High parity**: Increasing incidence of CIN/cervical cancer has been correlated with an increasing number of pregnancies and births (Brinton et al. 1987; Brinton et al. 1993; Wang & Lin 1996; Schiffman et al. 1998; Hildesheim et al. 2001; Thomas et al. 2001).

  High parity is associated with lower socio-economic status and lower educational status of women and so may be a cofactor rather than an independent risk factor (Peters et al. 1986; Lerman et al. 1991; Brinton et al. 1993; Visser et al. 2000).

- **Induced termination of pregnancy**: Two or more induced terminations of pregnancy (TOP) were associated with CIN in one study of Taiwanese women (Wang & Lin 1996).

  The reason why the women had the TOP was not accounted for in their study. The question remains unanswered whether other confounding variables such as distressing life events that led to the women having a TOP are more significant than the procedure itself.

- **Immunosuppression**: Women who are HIV positive or on medication following transplant surgery are at increased risk of CIN/cervical cancer (Koutsky 1997; Maiman et al. 1998).

- **Aboriginality**: Compared to non-Aboriginal women, women who identify as Aboriginal are two to five times more likely to be diagnosed with cervical cancer and have a six- to ten-fold increase in mortality from it (Gillies et al. 1995; Bailie et al. 1998).

- **Ethnicity**: Women from developing nations, Central South America, South East Asia, and the former Yugoslavia are at particular risk of CIN/cervical cancer (Ibbotson & Wyke 1995; Potischman & Brinton 1996; Cavalcanti et al. 2000; Public Health Division 2000; Taylor et al. 2001b).
• **Age**: Younger women are at greater risk of having CIN detected on their Pap test, and older women are more likely to be diagnosed with cervical cancer. Women who belong to certain birth cohorts are at increased risk of cervical cancer, especially those cohorts who spent their early adult years during war (Campion *et al.* 1988; Cancer Research Campaign 1994 cited in Ibbotson & Wyke 1995; Lovejoy 1994; Sherman *et al.* 1998; Ylitalo *et al.* 1999; Sellors *et al.* 2000; Visser *et al.* 2000).

• **Familial and hereditary factors**: Family clustering of CIN/cervical cancer occurs but it is not known whether this is due to environmental or genetic causes (Hemminki, Dong & Vaittinen 1999).

• **Obesity**: The woman’s risk of cancer of the cervix is significantly increased if she is obese. This risk is exacerbated because she is less likely to request cervical screening than a non-obese woman and, if screening is requested, health professionals are often reluctant to attend a pelvic examination on an obese woman (Lew & Garfinkel 1979; Adams *et al.* 1993).

• **Negative life events**: Life events especially those that have been life changing or have elements of severe loss are documented risk factors. Intimate partner violence, sexual assault survival and having had a partner who misused alcohol or drugs have also been noted as significant risks (Beresford & Gervaize 1986; Schover, Fife & Gershonon 1989; Quilliam 1990; Gregory & McKie 1991; Kellogg & Parra 1995; McKie 1995; Coker *et al.* 2000; Geyer 2000; Stevens-Simon *et al.* 2000).

Links between CIN/cervical cancer and negative life events may be due to chance as the incidence of violence against women is unacceptably high. Data from Canada, the United States of America, the United Kingdom and Australia report that approximately 20–25% of women are sexually abused as children and the same percentage are sexually assaulted as adults. Ten per cent of all married and cohabitating women are physically assaulted by their partners in any one year (Leventhal 1990; Mazza, Dennerstein & Ryan 1996; Plichta & Abraham 1996; Weir 2000).

• **Role of the male partner**: In considering CIN/cervical cancer, the role of the male partner is always considered secondary or minor compared to the sexual history of the woman and it has been argued that this suggests male investigator bias (Lovejoy 1994; Palmer *et al.* 1993; McKie 1995; Hubbell *et al.* 1996; Duncan & Hart 1999).

  Women at particular risk are those whose male partners have had:

  – **Multiple other sexual partners**: As a risk factor this has been investigated and confirmed in those countries that value female monogamy and male machismo and these are the countries in South East Asia and Central South America with the highest incidence of cervical cancer in the world (Buckley *et al.* 1981; Skegg *et al.* 1982; Zunzunegui *et al.* 1986; Kjaer *et al.* 1991; Lovejoy 1994; Wang & Lin 1996; Haverkos, Rohrer & Pickworth 2000; Thomas *et al.* 2001).

  – **Penile cancer**: This has been reported as an increased risk (Lovejoy 1994) however Hellberg & Nilsson (1989) found no difference in frequency of cervical cancer in women whose partners had penile cancer.

  – **Labour intensive occupations**: These occupations have been reported as a risk factor with women whose partners are labourers or in occupations exposed to dirt and dust. Such women are three times more likely to develop cervical cancer than women whose partners are in professional type occupations. The suggestion is that oncogenic chemicals may be transmitted to the cervix during coitus (Robinson 1982; Lovejoy 1994).

Confounding variables may relate to socio-economic status, nutrition and other yet unknown risk factors.
- **Penile circumcision**: Circumcision may offer partners some protection and was first hypothesised when it was noted in the 18th century that Jewish women had a very low incidence of cervical cancer (Oriel 1988).

  However, the link may be due to monogamous patterns of sexual behaviour in Jewish and Islamic societies rather than the foreskin status of male sexual partners (Martin 1967; Rotkin 1973; Oriel 1988).

- **Vasectomy**: Men with intact vas deferens place their partners at greater risk than men who have had a vasectomy (Swan & Brown 1979). It has been postulated that frequent exposure to sperm acts as a risk factor in the development of CIN/cervical cancer (Brinton *et al.* 1987; Herrero *et al.* 1990; Lovejoy 1994).

  However, it may be that male partners who have undergone a vasectomy are more likely to be in a stable, monogamous relationship. Occupational and socio-economic status may be confounding variables.

There are multiple risk factors reported in the literature but the factors that have captured the most professional attention, media and public fascination are those that relate to the woman’s sexual history.

**Sexual history**

Linking cancer of the cervix with sexual activity dates back to the late 1700s when Rigoni-Stern analysed mortality rates in the Italian city of Verona (Oriel 1988). In the 1950s it was noted that Catholic nuns rarely developed cancer of the cervix and in the 1960s links were made between prostitution and cervical cancer (Oriel 1988). Cervical cancer had been linked with female ‘promiscuity’ in much the same way that Victorian doctors attributed sexually transmissible infections to prostitution (Oriel 1988). In both instances male sexual behaviour was an important but largely ignored risk factor. Adverse newspaper reporting of cervical screening continues to play an active role in labelling women as being sexually irresponsible when their Pap test result is abnormal (Whelan 2000).

In the Herrero *et al.* (1990) study it was noted that, although the greater number of sexual partners increased the risk of cervical cancer, the number of steady sexual partners a woman had had was more significant than the number of nonsteady partners.
This was particularly so for women before 30 years of age, suggesting the need for prolonged or repeated exposures to the transmissible agent, or different safe sex or contraceptive practices. Lovejoy (1994) concluded that constant exposure to one or more steady partners was a requisite to cervical cancer risk, possibly because of cyclic shedding of HPV or varying polyamine concentrations in male semen and sperm.

The presumption of sexual transmission of HPV should never be absolute (Association of Reproductive Health Professionals 2001). The Association of Reproductive Health Professionals in 2001 argued that exposure to HPV is usually but not necessarily always by sexual means. Fomite transmission from sex toys, examination tables and other inanimate objects are difficult to document but may play a role in non-sexual transmission of HPV (Association of Reproductive Health Professionals 2001). If fomite transmission does play a role then the vaginal speculum, although not specifically mentioned, is obviously another possible conveyor of HPV. In children it is reported that HPV transmission occurs during sexual abuse, perinatal transmission, autoinoculation and heteroinoculation from nongenital cutaneous warts during childcare and by indirect means from contaminated fomites such as towels (Stevens-Simon et al. 2000).

Karlsson et al. (1995) reported that the prevalence of HPV is 22% among sexually active women but is also present in virgins with a 4% HPV prevalence rate. Harahap (1986), in an Indonesian study, found no association between cervical cancer and accepted sexual risk factors and he concluded that unnamed cultural risk factors may act independently of other known social and behavioural risk factors. Herrero et al. (1990) found that interval since last Pap smear, number of pregnancies and socio-economic status were correlated with sexual behaviour variables and exerted confounding effects. The occurrence of HPV DNA, although associated with the highest relative risk, was not correlated with sexual behaviour and, when included in the regression model of statistical analysis, produced only minor alterations in the Herrero et al. (1990) study.

The a priori focus of the media and professional literature on sexual risk factors for developing CIN and invasive cervical cancer leads many to believe that female ‘promiscuity’ is the major cause of cervical cancer. By implication, they are factors attributed to abnormal Pap test results and fear of being considered ‘promiscuous’ may deter some women from having cervical screening (Robinson 1982; Saffron 1983 cited
in Doyal 1995, p. 74). The stronger the belief that CIN/cervical cancer is linked to sexual behaviour, the less likely women are to attend cervical screening (Gregory & McKie 1991; Hubbell et al. 1996; Neilson & Jones 1998). Hubbell et al. (1996) concluded that stressing the sexual transmission of cervical cancer was counterproductive to cervical screening recruitment.

Currently, the literature indicates that the most influential sexual risk factors are the woman’s age at coitarche and the number of sexual partners she has had.

**Age at coitarche**

Early coitarche, usually defined as first heterosexual intercourse before the age of eighteen, is a frequently reported risk factor for HPV infection, CIN and progression to cervical cancer in both the media and professional literature (Wassertheil-Smoller et al. 1981; La Vecchia et al. 1986; McDonald et al. 1989; Koutsky et al. 1992; Brinton et al. 1993; Schiffman & Brinton 1995; Franco 1997; Schiffman et al. 1998; Deacon et al. 2000; Murthy & Mathew 2000). Peters et al. (1986) suggested that early coitarche is a risk factor because of the increased vulnerability of the immature cervical transformation zone to oncogenic factors which decreases with age because of progressive maturation.

In 1990, Herrero et al. reported a two-fold increase of cervical cancer among women reporting coitarche at 14–15 years compared with 20+ years. However, those whose coitarche was before 14 years of age were not at increased risk (Herrero et al. 1990). They concluded that there is a period of increased susceptibility to carcinogens during adolescence and suggested that this may be an important determinant in the high incidence of cervical cancer in Latin America. Colombia has the highest incidence of cervical cancer in the world with 48.2 cases per 100,000 women compared with the lowest incidence of 3.8 per 100,000 women in Israel (Haverkos, Rohrer & Pickworth 2000).

It is possible that early coitarche is affected by a number of intervening sociological confounding variables that influence the development of cervical pathology. As an example, early coitarche is correlated with early school leaving (Grunseit & Richters 2000) and in turn socio-economic disadvantage. In an Australian study conducted by Grunseit and Richters (2000) involving TAFE college students, as school education
increased so did age at first intercourse. Women with limited school education are
significantly more likely to have abnormal Pap test results (Peters et al. 1986; Lerman et
al. 1991; Visser et al. 2000).

Koutsky (1997) and Reeves et al. (1985) argue that although an early coitarche is a risk
factor for developing HPV, after adjusting for the number of sexual partners a woman
has had, there is no independent effect.

Number of sexual partners
The number of sexual partners a woman has had reportedly increases her risk of HPV
infection and progression from low to high grades of CIN (La Vecchia et al. 1986;
Schiffman & Brinton 1995; Munoz et al. 1996; Franco 1997; Koutsky 1997; Deacon et
al. 2000; Murthy & Mathew 2000). Women with more than four lifetime partners are
twice as likely to have HPV than women with only one partner (Kenney 1996). Harris
et al. (1980) concluded that women with three to five lifetime sexual partners are four
times as likely as women with two or less partners to have CIN 1, and eight times more
likely to develop CIN 3.

This viewpoint has been propagated in the media. In 2000, the Sydney Morning Herald
reported on women not having follow-up Pap tests when a result was abnormal (Whelan
2000). In the article, Rod MacMahon a spokesperson for the Rural Australian College
of General Practitioners was quoted as saying, ‘It is because carcinoma of the cervix is
related to the number of partners you have’ and he added that younger women tend to
experiment more with sexual partners. Later in the article, Geoff White, a spokesperson
for the General Practitioners’ Cervical Screening taskforce, stated that women failed to
take up referral of their general practitioner for further tests. This article blamed women
for failing to follow-up on abnormal Pap test results, equated cancer (carcinoma) with
an abnormal Pap test and then provided only one explanation for the cause of abnormal
Pap test results – the number of sexual partners a woman has had.

This is an example of promotion of a professional discourse on cervical screening that
influences clinical services and public perception. It allows for professional attitudes
that demean and disempower women to continue unquestioned. Women are blamed for
not ‘coming forward’ for screening to be ‘saved’ by medical intervention if they have an
abnormal Pap test result. Use of terms such as cervical screening ‘campaign’ and
women ‘coming forward’ for screening are used with evangelistic zeal in the health promotion literature (Posner 1991). She argues that cervical screening campaigns are based on the deception that it is basically a matter of life and death to have a Pap test – a medical construction that uses cultural meanings to lay fears for its own purposes. Women who do not have regular Pap tests or who ‘fail’ to follow-up an abnormal Pap test result, already feeling judged for the number of sexual partners they may or may not have had, are further stigmatised and considered by health workers to be irresponsible, feckless and non-compliers (McKie 1995; Whelan 2000).

The stigmatisation of women with cervical cancer dates back at least to the 1950s. Stephenson and Grace (1954) described the woman with cervical cancer as having severe personality and sexual maladjustment. Tarlau and Smalheiser (1951, p. 118) compared women who had breast cancer with women who had cervical cancer and described how the woman with cervical cancer ‘presents a totally different picture’ to the woman with breast cancer. The woman with cervical cancer, they said, having engaged in sexual intercourse at an earlier age, is more likely to be divorced or separated than a woman with breast cancer. Images of women with CIN and cervical cancer have not become more positive in the last half-century. Women continue to feel stigmatised when diagnosed with a condition associated with sexual ‘promiscuity’ (Wardle, Pernet & Stephens 1995). McCormick (1989, p. 208) argued that ‘their character as well as their cervix is smeared’.

Psychological paradigm

The attribution of blame leans heavily toward the woman in the biomedical sources reviewed and is advanced in the psychological literature. Women likely to suffer the most severe ill effects from an abnormal Pap test result are those reported as being more worried before they received the result, who live alone, have had previous mental health problems, demonstrate social maladjustment, have negative self-image, high neuroticism, low extroversion and use passive/avoidant coping strategies (Reelick, de Haes & Schuurman 1984; Bell et al. 1995; Gath et al. 1995). These studies focus on perceived negative personality traits of the women rather than examining the reasons why a woman might demonstrate a given attribute.
Links between personality type, intimate relationships and cervical health

Personality traits, as well as affecting women’s response to an abnormal Pap test result, have been alluded to in both protecting and predisposing the woman to CIN/cervical cancer. Women are reported as being resilient to CIN/cervical cancer if they are confident, active, optimistic, sociable and socially supported (Goodkin, Antoni & Blaney 1986; Levy et al. 1990). The opposite perceived negative personality traits are correlated with a predisposition to CIN and cervical cancer (Tarlau & Smalheiser 1951; Stephenson & Grace 1954; Schmale & Iker 1966, 1971; Antoni & Goodkin 1989; Palmer et al. 1993; Byrnes et al. 1998).

The idea of certain personality characteristics contributing to cancer risk dates back centuries. Galen, the ancient Greek philosopher, noted that melancholic women were more prone to malignant tumours than other women (Rosch 1984). In more recent times, personality traits considered to relate to susceptibility to cervical cancer have included pessimism, passivity, conforming attitudes, social inhibition, somatic and general anxiety, social alienation, feelings of hopelessness, depression and avoidance/denial type coping mechanisms (Schmale & Iker 1971; Goodkin, Antoni & Blaney 1986; Antoni & Goodkin 1989; Palmer et al. 1993; Byrnes et al. 1998). It is noted that Schmale and Iker (1971) used no objective standardised measure of hopelessness and their sample of women reported as having cancer actually had CIN 3. Byrnes et al. (1998) determined that pessimism put women at greater risk of progressing from low grades to high grades of CIN. However, their sample consisted of 36 women of ethnic minority who were coinfected with HPV and human immunodeficiency virus (HIV). The subjective impact of negative life events was controlled for, but the study did not adequately address how this was done.

Uncooperative interpersonal styles are said to place women at risk of cervical cancer (Goodkin, Antoni & Blaney 1986). This interpersonal style is characterised as being hostile, projecting and fearless. These women are seen as hard-headed realists, socially blunt and with a castigating, punitive interpersonal style – a composite style that is opposite to most studies describing women with cancer per se. If stressful life events are common for women with cervical cancer as described in the Schover, Fife and Gershenson (1989) and Geyer (2000) studies, then the personality traits described may be a protective and appropriate response.
In direct contrast to the uncooperative interpersonal style described by Goodkin, Antoni and Blaney (1986), it is argued that women who are alexithymic – a personality trait that is characterised as having difficulty in expressing emotion and being overly respectful and cooperative – are at increased risk of CIN and cervical cancer (Todarello, Casamassima & Marinaccio 1994; Todarello, Casamassima & Daniele 1997).

The cited items that refer to personality traits associated with cervical pathology are judgmental, inconsistent and suggest gender bias in their negative portrayal of women. Women appear damned whatever their personality style. Incongruently, personality traits associated with cervical pathology include women who are both inhibited and hostile; anxious and fearless; realists and deniers; socially blunt and overly respectful; castigating/punitive and avoiders; uncooperative and cooperative.

Research that focuses on personality traits blames women for their own cervical disease. Fisher (1986) argued that the consistent response in a capitalistic society is to blame the victim and ignore the social, environmental and occupational hazards. Furthermore, medicine has much to gain from sustaining the belief that it is the individual who is to blame. It may be a very realistic response for women who are socially unsupported, for example, to feel pessimistic, anxious, inhibited and alienated. Conversely, women who are supported are more likely to feel confident and optimistic. The personality traits alluded to in the literature may not be as significant as the level of social support or the accumulation of negative life events.

Negative life events that cause a loss of personal control are associated with immune status decline over a three-year period (Antoni & Goodkin 1988). In relation to loss of personal control, Schover, Fife and Gershenon (1989) found in their study of women with cervical cancer that 38% of participants were/had been in violent relationships, 46% had partners who abused drugs and/or alcohol and 27% had suffered sexual trauma. In an earlier study, Stephenson and Grace (1954) argued that women with cervical cancer were more likely to have an aversion to sex, be anorgasmic, be unhappily married or separated from their partner and have a higher degree of severe personality maladjustment (not defined) than women with other cancers. When the Schover, Fife and Gershenon (1989) findings are articulated with those of Stephenson and Grace (1954), it seems to reflect a tautological finding that violent intimate relationships, a partner’s misuse of drugs and/or alcohol and sexual trauma are not
conditions conducive to sexual desire, sexual/relationship satisfaction and/or a sense of personal control.

Investigating life stressors as correlating factors with cervical cancer, Graham et al. (1979) found no difference in respect to life stressors for women with cervical cancer in a large, case control, double-blind study that utilised interviews. However, the study did not include healthy women in the control group but rather women with cancer (not cervical) and the psychological test measures and statistical tests, on which the authors’ conclusions were made, are not described.

Marital dissatisfaction is a risk factor for CIN and cancer as it adversely affects the immune system (Antoni & Goodkin 1988). This study found that more than half of the women with cancer were reportedly very dissatisfied with their marriage and also were more likely to be highly respectful of others. If violence is a factor in a marriage, then it could explain why the women are very dissatisfied and use respect as a protective mechanism to try to avert physical abuse. Antoni and Goodkin (1988) did not explore the possibility of interpersonal violence and abuse in their research. CIN and invasive cancer are associated with changes in several systematic and local immune parameters and some immune measures are also affected by psychosocial factors (Bartop et al. 1977). Visser et al. (2000) suggested a synergistic relationship between the immune system and psychosocial factors.

Studies seeking to label women as being mentally ill, with depression, for example, or having any other amorphous personality traits that predispose them to cervical pathology, suggest a cultural bias against women. Brown et al. (1994) argue that most research about women is akin to two people, one researcher and one ‘subject’, in a darkened room. The researcher has a torch that they shine on the ‘subject’ being studied and she is considered to be the only focus of the study. Any researcher bias, any environmental factors in the room, the impact of any other people are ignored – they remain in darkness. So it is with the studies that describe personality traits of the woman with CIN without considering her life context. An example of this phenomenon is described in the autobiography, Bridge Across My Sorrows: The Christina Noble Story (Noble & Coram 1994). Christina Noble was institutionalised and treated with electroconvulsive therapy for severe depression. She was (mis)diagnosed with both schizophrenia and depression. Christina did not have schizophrenia but was depressed –
a reaction to having survived child sexual and physical assault, neglect, homelessness and, as an adult, severe physical and emotional violence, mental cruelty and sexual assault by her husband.

**Social barriers to receiving follow-up investigations**

Women with a screening detected cervical abnormality require follow-up for diagnosis and possible treatment. Social barriers may hinder them from attending these diagnostic investigations. In an Australian retrospective cohort study, Kavanagh and Simpson (1996) identified two common barriers to women attending a colposcopy clinic for further investigation. These were health insurance status and whether or not a woman had received prior treatment to her cervix.

Women with private health insurance were more likely to attend for further investigations even though their health insurance status did not affect the amount they had to pay for the procedure. There is a positive correlation between socio-economic status and private health insurance, with young, single income families being least likely to afford private health insurance (Australian Bureau of Statistics 1993). The economic hardships of young, single income women would be exacerbated by the costs of transport, childminding and possible loss of income necessitated by a visit to a colposcopy clinic, often a long distance from the home of rural women. The woman’s visible and immediate economic needs, such as having enough money to feed, clothe and house her family, are likely to take precedence over the need to further investigate an invisible and asymptomatic potential problem such as CIN (Kavanagh & Simpson 1996).

Iatrogenic barriers also exist which inhibit a woman from seeking medical attention following a diagnosis of CIN. A second group of women identified by Kavanagh and Simpson (1996) as less likely to attend a colposcopy clinic for follow-up investigations are those women who have received treatment for prior CIN. This is cause for concern because women with previous abnormal cervical cytology are reported as being more likely to develop cervical cancer in the future (Mitchell, Medley & Carlin 1990; Souter et al. 1997). Kavanagh (1994) argued that these women may wrongly perceive their risk of going on to develop cervical cancer is reduced or negligible. Women attending focus groups in the study conducted by Gregory and McKie (1991) offered an alternative explanation. These women reported their reluctance to have Pap testing and further
investigations when a Pap test was abnormal as being due to previous upsetting cervical screening experiences. They described encounters with unpleasant and insensitive health professionals. The participants described the dehumanising effects of gynaecological examinations that exacerbated their feelings of fear, vulnerability and embarrassment. Some women in the Gridley et al. (1998) study reported negative experiences during medical procedures due to inappropriate behaviour from the health professional conducting the examination, but few felt able to complain at the time or afterwards. The range of inappropriate behaviour reported in the Gridley et al. (1998) study included sexual comments; behaviour that made the woman feel shame, embarrassment or humiliation about something sexual; inappropriate touching; the clinician’s sexual and romantic interaction with a client; and sexual assault. Long-term consequences of this iatrogenic abuse include impairment of subsequent relationships with health professionals with implications for the woman’s ongoing health maintenance and, in some cases, severe emotional disability.

Lack of understanding of the purpose for colposcopy, fear of cancer, embarrassment, indignity of the procedure, male medical practitioners, forgetting appointments, lack of time, work commitments, scheduling difficulties and inconvenient appointment time, financial difficulties such as the doctor’s fee, inconvenient venue, parental resistance in the case of adolescents or lack of child care are the most common reasons listed by women for not attending for a colposcopy or follow-up Pap test (Perucci et al. 1990; Gregory & McKie 1991; Murray & McMillan 1993; Milburn & MacAskill 1994; Hubbell et al. 1996; Neilson & Jones 1998; Hamilton & Bauchman 1999; Khanna & Phillips 2001). The strategies suggested by Khanna and Phillips (2001) to overcome these barriers are not congruent with their own study findings as their recommendations relate to the interests of the physician and not the woman. Their recommendations include providing personal reminders to ‘patients’ by their primary physician, and case management strategies to encourage follow-up (Khanna & Phillips 2001). These strategies are unrelated to the woman’s identified psychosocial needs. In contrast to Khanna and Phillips’ (2001) recommendations, but more in keeping with their findings, Crane (1996) recommended supportive interventions that include the provision of information, emotional support, child care and transport to help ensure maximum follow-up for women with abnormal Pap test results. Crane (1996) noted that, while health professionals provide excellent informational support, they rarely provide
emotional or tangible support. Emotional support is the most likely form of support to ensure follow-up adherence and conveys the message that the recipient is valued.

**Women’s experience**

Many women find the Pap test procedure itself degrading, difficult, embarrassing, humiliating, frightening and painful (Foxwell & Alder 1993; Barling & Moore 1996). This was regardless of their knowledge about the cervical screening process being extensive. The Foxwell and Alder (1993) study had a large sample of women who were described as highly motivated, well-informed and middle class, almost half of whom were in managerial or professional type occupations. It is not known whether the negative experiences of cervical screening would have been more or less marked if the women in these two studies had been significantly older or younger, less informed and educated, from lower socio-economic or so-called ‘minority’ groups.

Norwegian research on Pap testing revealed ambivalence in women because of its intimate relationship between sex, power and medical knowledge (Larsen, Oldeide & Malterud 1997). This study concluded that, while women believed in the potential of the test to discover hidden disease well beyond its scope, the researchers questioned whether it deserved such confidence. Larsen, Oldeide and Malterud (1997) argued that if women have unrealistic beliefs in the diagnostic validity of an unpleasant examination and have a misplaced trust in medical knowledge, then they are not giving informed consent. The imbalance of power is consequently even more serious than that reported by the women in their study.

Women submit themselves to Pap testing because they believe it protects them from developing cervical cancer and they desire objective, medical proof that they are as healthy as they believe themselves to be (Posner & Vessey 1988). The clinician, in contrast, convinced of the value of and receiving a financial reward for cervical screening, may be more concerned about reaching ‘targets’ set by cervical screening programs, undertaking surveillance to ensure no cervical pathology would ever be missed and controlling dysplastic cells that may, in a minority of women, progress to become malignant.

Not all women choose to be involved in cervical screening. Compared to women who have regular Pap tests, the literature suggests that women who have not had a Pap test
are likely to have more fear of the screening consequences, greater social anxiety, fatalistic attitudes, lower self-esteem, intimate relationship difficulties, worry, embarrassment and other negative attitudes towards screening (Elkind et al. 1988; Murray & McMillan 1993; Kowalski & Brown 1994; Orbell et al. 1995; Wilson & Fazey 1995). Conversely, the most important predictor of regular Pap testing is lack of fear of the consequences of the investigation (Murray & McMillan 1993; Neilson & Jones 1998). This is significant when many health promotion campaigns intended to encourage cervical screening rely on fear to motivate women, including the recent NSW campaign [Cervical Cancer] ‘It can’t happen to me’. Such strategies may have unintended effects. When the Pap test is associated with cervical cancer, many women believe that any abnormal test indicates cancer and they will ultimately die from it, making them reluctant to participate in cervical screening services (Gregory & McKie 1991). Fear is the most frequently cited barrier to women having regular cervical screening. Women fear that the Pap test procedure will be painful or that the result might detect a problem and this would imply immoral or promiscuous behaviour (Perucci et al. 1990; Gregory & McKie 1991; Murray & McMillan 1993; Milburn & MacAskill 1994; Hubbell et al. 1996; Neilson & Jones 1998).

Some women attending focus groups in the Gregory & McKie (1991) and McKie (1995) studies reported a form of emotional abuse that hindered them from having cervical screening. They described their partner’s proprietorial attitudes towards their bodies and reported that their partners believed that both the woman and the health professional derived some form of sexual enjoyment from cervical screening.

A few women in the Howson study (1993 cited in Milburn & MacAskill 1994) argued that they would rather not know if they had a cervical abnormality and others believed that they would have symptoms and know if they had a cervical abnormality and so chose not to have a Pap test (Howson 1993 cited in Milburn & MacAskill 1994). Milburn and MacAskill (1994) argued that these views represented a culturally based resistance to the medicalisation of women’s bodies and, provided that women had been offered accurate information, their right to choose or resist such medicalisation needed to be respected.
The all-pervasive effects of an abnormal Pap test result

The literature revealed that receiving an abnormal Pap test result often leads to feelings of fear, anxiety, self-blame, dirtiness, bodily betrayal and guilt as well as vulnerability and powerlessness and is a trigger for depression, insomnia and sexual dysfunction in some women (Clarke et al. 1985; Campion et al. 1998; Quilliam 1990, 1992; Lerman et al. 1991; Cull, Cowie & Farquharson 1993; Wilson 1994; Gath et al. 1995; Miller, Shoda & Hurley 1996; Posner & Vessey 1988).

Most research on the topic indicated that women experience significant distress when they have an abnormal Pap test result (Posner & Vessey 1988; Wardle, Pernet & Stephens 1995). Studies by Reelick, de Haes and Schuurman (1984) and Lerman, Caputo and Brody (1990) were exceptions. They argued that, although an abnormal Pap test result causes adverse psychological side effects for the majority of women, these effects are not of a lasting or serious nature. It is important to note that face-to-face, personalised contact with the women was not made in either of the two studies. Women reported the strongest adverse effects in studies where the data were collected in face-to-face interviews (Beresford & Gervaize 1986; Posner & Vessey 1988; Quilliam 1989) compared with studies that used data collection methods without face-to-face contact (Reelick, de Haes & Schuurman 1984; Lerman, Caputo & Brody 1990). Wardle, Pernet and Stephens (1995) argued that it is possible that the subjectivity of the interview method increases apparent emotional distress. However, it is likely that women feel more comfortable sharing the full impact of their emotional distress when being interviewed by a sympathetic listener, rather than completing a written questionnaire or telephone interview.

When a woman is informed of her abnormal Pap test result, she is usually referred to a gynaecologist for a colposcopy and possible biopsy. Some time usually elapses until she is able to obtain an appointment and arrange for these procedures to be undertaken (Wilson 1994). More time then elapses while the woman waits for her biopsy results. Waiting heightens the anxiety and apprehension experienced by the woman (McCormick 1989; Wilson 1994).

Shock – The initial reaction

Women describe feelings of disbelief and being stunned when an abnormality is detected on what they expect to be a routine Pap test (Wilson 1994). These feelings of
shock are not surprising. Ward, Harding and Sanson-Fisher (1997) reported in their study of medical practitioners, that no practitioner adequately discussed the possibility of an abnormal Pap test result with women at the time of their screening and less than ten per cent of women received even partial information about the possibility of an abnormal result. Following the shock of being told they had an abnormal Pap test result, women report feeling fear, horror and/or panic (Gath et al. 1995).

**Fear and anxiety – Universal responses**

Fear, the predominant reason why women are reluctant to have Pap tests (Baileff 2000), is also the most cited response when a woman has an abnormal Pap test result. In a study conducted by Gath et al. (1995), ninety per cent of women with an abnormal smear experienced fear and worry. The findings from this study are considered conservative and are limited because the research was conducted at and by the staff of a colposcopy clinic where the women attended. The women interviewed may have been reluctant to report emotional morbidity out of loyalty to the colposcopy clinic and staff.

The levels of fear and anxiety experienced by women with an abnormal Pap test result are quite marked according to the literature. Compared to women who receive a normal Pap test result, women with an abnormal result are up to twice as likely to achieve anxiety scores high enough to indicate a psychiatric disorder (Bell et al. 1995; Wardle, Pernet & Stephens 1995). Some women experience the news of an abnormal Pap test result as the equivalent of a temporary diagnosis of cancer with implications of distressful treatment, pain and death (Summers 1998). The level of anxiety induced by the initial notification of an abnormal Pap test result has been compared by Palmer et al. (1993) with that following the death of a parent. Anxiety and fear are increased when women are experiencing a concomitant stressor at the time of their abnormal Pap test result such as unemployment of self or spouse, relationship breakdown, postgraduate studies, severe illness in family members, unwanted pregnancy, intimate partner violence and/or rape (Beresford & Gervaize 1986).

Women fear cancer and death, the medical procedures, recurrence of the disease, the threat to their fertility and sexuality and being judged by others as dirty and/or promiscuous (Campion et al. 1988; McCormick 1989; Wilson 1994; Bennetts et al. 1995; Teale et al. 2000). The fear they experience is exacerbated by health and medical professional language and clinical practice (Schiffman et al. 1998).
Fear of cancer and death
A number of studies reported that women believe the function of the Pap test is to detect cancer rather than prevent it (Schwartz et al. 1989; Wilkinson, Jones & McBride 1990; Nicoll, Narayan & Paterson 1991; Porter, Bell & Fraser 1993 cited in Milburn & MacAskill 1994; McKie 1995). As a consequence of the association of Pap testing with cervical cancer and cancer with death, many women with even a minor abnormality, as occurs in 3–5% of all Pap tests attended, fear they have cancer and will die from it (Beresford & Gervaize 1986; Campion et al. 1988; McDonald et al. 1989; Quilliam 1989; Wilkinson, Jones & McBride 1990; Gregory & McKie 1991; Lauver & Rubin 1991; Flannelly et al. 1994; Wardle, Pernet & Stephens 1995; Ferreira 1998; Somerset & Peters 1998; Lauver, Baggot & Kruse 1999). Among women with mildly abnormal smears, almost half of those having a colposcopy, as reported in the Jones, Singer and Jenkins (1996) study, believed they were actually being treated for cancer.

Fear of medical procedures
The majority of participants interviewed by Posner and Vessey (1988) describe the gynaecological examination as uncomfortable, distressing, unpleasant, inelegant and/or undignified. Women describe being anxious and being gripped by fear and/or panic when they entered the colposcopy room (Posner & Vessey 1988; Tomaino-Brunner, Comerford Freda & Runcowicz 1996).

Fear of the required follow-up medical procedures affected almost two-thirds of participants in the Beresford and Gervaize (1986) study. Women were concerned about who was going to be present and feared being dependent upon medical personnel for their survival (Quilliam 1990; Lauver, Baggot & Kruse 1999).

Fear of losing fertility and altered sexuality
When a woman has an abnormal Pap test result she is fearful for her sexuality and fertility, which may or may not be linked (Quilliam 1990). The majority of women fear that their sexuality and/or fertility will be impaired by the required treatment and believe they will need a hysterectomy to treat the cervical abnormality (Beresford & Gervaize 1986; Quilliam 1990). The younger women are more likely to fear for both their sexual and reproductive potential.
Women’s fear for their future fertility, described in the Lauver, Baggot and Kruse (1999) study, is significant because while only 3% of screening tests are abnormal (Centers for Disease Control and Prevention 1996), this figure is higher at 11–12% for women under 20 (Mangan et al. 1997). With reduced age and increased incidence of CIN, the fear of possible loss of reproductive function is increasingly of greater concern for women (McDonald et al. 1989; Campion et al. 1988). In the 1995 study by Wardle, Pernet and Stephens, adolescents and women requiring a colposcopy felt apprehensive about their loss of autonomy in the medico-patient relationship and feared a loss of control over their reproductive health. Exacerbating this sense of loss, adolescents in particular questioned their ability to make effective sexual decisions (Hamilton & Bauchman 1999).

Adverse effects on sexual expression are exacerbated when a woman feels she is less attractive or desirable or that her female sexuality or femininity has been undermined by the abnormal Pap test result. Sexual difficulties are also more common when a woman believes her sexual history has caused her abnormal Pap test result, or that sexual activity may worsen or cause a recurrence of the cervical pathology, or when she is experiencing concomitant stressful life events (Campion et al. 1988; Cull, Cowie & Farquharson 1993; Miller, Shoda & Hurley 1996; Taylor, Keller & Egan 1997; Duncan & Hart 1999).

The literature reports many effects on a woman’s sexual expression that adversely affect all phases of her sexual response following cervical abnormality diagnosis and treatment. These effects include a dampening of spontaneous sexual interest and desire, decreased frequency of sexual intercourse, reduced vaginal lubrication, less sexual arousal, reduced frequency of orgasm and increased dyspareunia (Campion et al. 1988; Anderson, Anderson & de Prosse 1989; Cull, Cowie & Farquharson 1993; Wilson 1994). These effects can persist for twelve months or longer after the cervical treatment (Anderson, Anderson & de Prosse 1989).

The basis of the sexual difficulty may be emotional, situational or physical. Anxiety, fear, depression or guilt, fear of sexual intercourse exacerbating the disease, financial concerns relating to further investigations and/or treatment, fatigue and/or pain caused by treatment, or medical advice to abstain from sexual intercourse following treatment
do not enhance libido, arousal or orgasm (Campion et al. 1988; Klemm & Guarnieri 1996; De Marquiegui & Huish 1999).

Klemm and Guarnieri (1996) argue that women find it easier to resume sexual expression after cervical treatment if they have an opportunity to express their anxiety and fears before being referred for colposcopy.

**Fear of being judged as dirty or promiscuous**

Already feeling vulnerable and powerless, many women fear that they will be judged by health professionals and others as promiscuous and/or dirty when they have an abnormal Pap test result (Clarke et al. 1985; McKie 1995; Taylor, Keller & Egan 1997). This fear of judgment may be justified when statements are made in the professional literature such as: ‘the disease could, to a large extent, be prevented altogether through healthful behaviour and sexual practices’ (Sevin 1999, p. 759). Statements such as this imply that a woman develops cervical cancer because she has chosen either unhealthy behavioural or sexual practices. They exacerbate the fear and anxiety experienced by women with an abnormal Pap test result (Quilliam 1990; Bell et al. 1995; Gath et al. 1995; Taylor, Keller & Egan 1997; Summers 1998; Teale et al. 2000).

Some women fear telling their partner that they have an abnormal Pap smear result because of the implications of sexual transmission. Their partners may not be aware of other sexual partners the woman has had. Or knowing their own fidelity, women fear the repercussions that the revelation of their partner’s infidelity may have on their relationship (Taylor, Keller & Egan 1997; Hubbell et al. 1996). Believing that HPV can only ever be sexually transmitted and knowing their own sexual fidelity, some women assume, blame and are angry that their partner has been sexually unfaithful, which leads to feelings of distrust at a time when they need their partner’s support (Quilliam 1990; Taylor, Keller & Egan 1997; Hamilton & Bauchman 1999). The mean anger scores for women with abnormal Pap test results were more than one standard deviation higher than women with negative smears in the Palmer et al. (1993) study. The anger was directed towards either their sexual partner(s), themselves or upon sexual intercourse itself (Clarke et al. 1985; Campion et al. 1988).
Language used in professional and health promotion literature provokes fear

Even when informed that their abnormality does not detect cancer, but rather pre-cancer or abnormal changes, many women are unable to understand these concepts (Wilkinson, Jones & McBride 1990; Milburn & MacAskill 1994; Kavanagh & Broom 1997; Lauver, Baggot & Kruse 1999). Women do not find terms such as abnormal cells, early changes, wart virus and pre-cancer easy to understand and believe that pre-cancer is cancer and cancer means death, and so they are forced to reflect on their own mortality (Tomaino-Brunner, Comerford Freda & Runcowicz 1996; Kavanagh & Broom 1997).

Schiffman et al. (1998) argue that HPV and CIN 1 are too common, changeable, transient and benign to be considered a pre-cancer. Adding to the confusion, the concepts of Pap testing and cervical cancer have been married in both professional and health promotion material. Cervical screening public health programs often refer to cervical cancer screening (Marcus & Crane 1998) and nomenclature in professional literature is equally biased. The NSW Cervical Screening Program, as an example, more than once discusses ‘cervical cancer participation’ when referring to cervical screening participation rates of a given population: ‘targeted health promotion activities enhance cervical cancer participation’ (Taylor et al. 2001a; Taylor et al. 2001b, p. 55). A glance at the reference list of this thesis demonstrates many more instances of professional literature equating abnormal Pap test results with cervical cancer. The terminology used in health promotion material does not focus on how screening prevents cancer but discusses detection of cervical cancer, pre-cancer and early changes. This terminology might be clear to health professionals but rarely to women who have a Pap test. It is therefore not surprising that many women conclude that any abnormality must be cancer: ‘you either get an all clear or you have cancer’ (Kavanagh & Broom 1997, p. 1389).

Power differentials heighten fear

Women have long waits and short visits when attending for gynaecological treatment or screening (Kapsalis 1997) and, because of the power differential between clinician and themselves, may feel unable to take the time of the ‘busy’ doctor to ask questions that may help to alleviate their confusion and fear (Kavanagh & Broom 1997). Many women, in multiple studies, reported that they did not receive the information they required at either the time of the Pap test, when notified of the abnormal result or during any follow-up (Haran et al. 1989; Schwartz et al. 1989; Kincey, Stratham & McFarlane
Due to the need to control time within the medical culture, providing the opportunity for women to express their anxiety and concerns may not be considered, or it may even be actively discouraged (Baker, Yoels & Clair 1996). In contrast to the needs of clinicians, data from gynaecological examinations in Holland demonstrate that where the gynaecologist is willing to listen to women’s concerns, the women are always grateful and accept the opportunity to express their anxiety (Weijts, Widdershoven & Kuk 1991).

**Strategies identified in the literature to reduce fear**

It has been argued that the provision of information and emotional support reduces the psychological costs for women with an abnormal Pap test result (Campion *et al.* 1988; Wardle & Pope 1992). Providing time for women to express their anxiety empowers them and helps increase their decision-making skills (Kfir & Slevin 1991). It reduces the power differential between the woman and health professional, increases satisfaction and compliance with care, enhances understanding of the disease process and improves quality of life (Kfir & Slevin 1991; Miller *et al.* 1994; Somerset & Peters 1998).

In contrast, Foxwell and Alder (1993) concluded that giving detailed information to women before screening does not actually reduce the fear, embarrassment or pain of having a Pap test, but does have a positive outcome in terms of reducing anxiety levels after the test results. Tomaino-Brunner *et al.* (1998) found that providing information about colposcopy increases knowledge but does not decrease anxiety. Their research, however, did not include an opportunity for counselling or discussion with the women. The intervention consisted of only a fact sheet which may have limited any other positive effects of informational and emotional support given to women prior to a colposcopy.

**Sense of self threatened by an abnormal Pap test result**

Terms such as altered body image, self-image, self-esteem, self-perception and self-concept are used synonymously and interchangeably in the literature. For the purposes of this study they have all been encapsulated under the heading ‘sense of self’. The literature identifies a number of ways in which women’s sense of self is threatened.
when they have an abnormal Pap test result. Women report feeling differently about themselves and express a loss of attractiveness, desirability and an undermining of their female sexuality or femininity that adversely affects their sexual expression and relationships (Miller, Shoda & Hurley 1996; Taylor, Keller & Egan 1997; Duncan & Hart 1999). This altered and negative sense of self persists for over a year following the abnormal Pap test result (Campion et al. 1988; Posner & Vessey 1988; McDonald et al. 1989; Quilliam 1990; Lauver & Rubin 1991; Keller & Egan 1994 cited in Taylor, Keller & Egan 1997; Kavanagh & Broom 1997; Ferreira 1998).

**Feeling dirty**

Women feel differently about themselves when they have an abnormal Pap test result and the most common feelings of difference expressed by women are a sense of defilement, being unclean, contaminated or dirty (Posner & Vessey 1988; Quilliam 1990; Gregory & McKie 1991; Lauver & Rubin 1991; Taylor, Keller & Egan 1997; Ferreira 1998).

Feeling unclean is exacerbated by the abnormal Pap test result but often precedes it. Many women express their feelings of embarrassment, humiliation, vulnerability and shame because they perceive their vaginas as unclean (Posner & Vessey 1988). In the context of the women’s health clinic, it was not unusual for women to tell me that they had ‘scrubbed’ their vaginal/vulval area prior to attending for a Pap test, as they feared they might be considered ‘dirty’.

Kubie, in 1937, proposed a ‘dirt hierarchy’ which he argued is almost universally embedded in the unconscious. When this assumption of ‘dirt’ is considered, it is easy to understand why women fear being judged as dirty and find the experience of cervical screening unpleasant and even distressing. The assumptions proposed by Kubie (1937 cited in Lawler 1991) and later supported by Ross, Hirt and Kurtz (1968), Kurtz et al. (1968 cited in Lawler 1991), Hirt et al. (1969 cited in Lawler 1991, pp. 78–79) and Dimond and Hirt (1974) include:

1. Softness, wetness and hairiness, respectively, are always looked upon as dirtier than hardness, dryness and the absence of hair.

2. Old age is dirtier than youth.
3. Pigmentation signifies dirt and dark hair is dirtier than blond hair.

4. A cavity, cleft, hole or pit in the body carries the presumption of dirt, whereas a prominent or outjutting part of the body carries a presumption of cleanliness.

5. Wrinkled skin is dirtier than smooth skin.

6. Fat people are dirtier than thin people.

7. Women are dirtier than men.

From the above tacit dirt hierarchy, it is evident that while all female genitalia, owing to its physiology (soft, wet, wrinkled, mucoid and internal), is considered unclean, some women are considered dirtier than others. In particular, women who are older, obese and with darker skin pigmentation may be perceived by themselves and/or others, including health professionals, as dirtier than other women and experience shame. When women feel shame about their bodies, they devalue themselves (Koff & Rierdan 1995). Rowland (1988) argued that negative self-image exacerbates women's perceptions of themselves as unclean, dirty and having a malfunctioning biological ‘self’.

Messages about the role environmental dirt plays in CIN cause many women to have an altered self-concept and to believe that their abnormal Pap test result implies poor personal hygiene (Quilliam 1990).

Bodily betrayal

Almost two-thirds of women in the Beresford and Gervaize (1986) study described feeling a ‘bodily betrayal’ when they had a CIN Pap test result. Bodily betrayal is defined as the first realisation in young, typically healthy women that their bodies might not be functionally perfect and under their direct control. Women with the strongest sense of bodily betrayal are those highly knowledgeable in complementary health modalities (Beresford & Gervaize 1986). Believing themselves to be healthy and seeking a Pap test to affirm their health, women are unexpectedly labelled as sick and reminded of their vulnerability and mortality when the Pap test results are abnormal (Quilliam 1989). This sense of bodily betrayal is exacerbated for some women who feel that their private space has been invaded during cervical screening and follow-up procedures (Posner & Vessey 1988).
Guilt and self-blame

A woman’s sense of self is further eroded by feelings of self-blame and guilt when she has an abnormal Pap test result (Quilliam 1989; Lauver & Rubin 1991; Ferreira 1998; Hamilton & Bauchman 1999). When learning of their cervical abnormality, some women feel guilt and loss of control over their body and more than one-third of women in the Cull, Cowie and Farquharson (1993) study blamed themselves for having caused this abnormality through making what they or the health professional considered to be unwise choices in relation to their past or present sexual expression.

Assuming the cause of the abnormal Pap test result to be of a sexual nature, health professionals add to the woman’s feelings of guilt by taking a detailed sexual history. Detailed sexual history taking such as that espoused by Ferreira (1998) can play a dominant role in the therapeutic relationship between clinician and the woman with an abnormal Pap test result. During a history-taking session, a broad array of past and present, personal and intimate behaviours of the woman can be analysed and interpreted by the health professional. Such probing puts the health professional into the role of ‘moral entrepreneur’ (Baker, Yoels & Clair 1996, p. 192). Many women in the Posner and Vessey (1988) study felt that medical questioning about their sexual history including age at coitarche and/or number of sexual partners was unwarranted, added to their feelings of powerlessness and vulnerability and had no bearing on the management of their condition. It can be argued that in questioning women about their sexual history, health professionals are using their authority to gain privileged information that will not affect therapeutic outcomes. They are ‘extracting a confession without giving absolution’ (Posner & Vessey 1988, p. 95). Posner and Vessey (1988) concluded that if the information is not clinically necessary, does not alter treatment or is not to be used with prior consent for research purposes, then it should not be collected.

Feelings of guilt, self-loathing, embarrassment, shame and anxiety are exacerbated with increasing perception that HPV is primarily a sexually transmitted infection linked to the number of sexual partners a woman has had (Beresford & Gervaize 1986; McDonald et al. 1989; Posner 1991). The McDonald et al. (1989, p. 348) study involved interviews with women with CIN. Of interest in this study is the language used: ‘their current coital pattern failed to reveal promiscuous behaviour with respect to number of partners or frequency of intercourse’. ‘Promiscuity’, never defined in the literature by health professionals, was once again linked, in this case as a null
hypothesis, to women with abnormal Pap test results. The only attempt to define promiscuity in the literature was by women attending focus groups on cervical screening (McKie 1995). Promiscuity was defined by these women as having a sexual partner outside the long-term relationship, having more than one partner, sex at an early age and ‘going at it too much and in unusual ways’. Elleschild (1994 cited in McKie 1995) argued that, having accepted the dominant medical discourse on CIN, women as well as health professionals reinforce the ‘respectable/promiscuous’ dualism by moral policing of themselves and others. Prior to having further investigations and treatment for a cervical screening abnormality, women tended to say that they believed the cervical abnormality had been caused by stress, gynaecological or obstetric factors, oral contraceptive use, bad luck, fate or ‘just one of those things’. Following the medical process women changed their belief and said they now realised their abnormal Pap test result was due to ‘promiscuity’ or having engaged in sexual intercourse at an early age and factors such as bad luck were not mentioned at all by women in the Posner and Vessey (1988) study.

The impact on day-to-day living
Following an abnormal Pap test result women reported significantly greater impairment of day-to-day activities and insomnia and these effects persisted after the colposcopy (Lerman et al. 1991). It is not known for how long the impairment or insomnia persisted as Lerman et al. (1991) interviewed the women for only three months following the colposcopy. Other reported adverse emotional effects include high levels of irritability, crying episodes, outbursts of anger, moodiness, tension and feelings of social isolation (Beresford & Gervaize 1986; Lerman et al. 1991; Women’s Health Resource Collective 1991; Gath et al. 1995; Somerset & Peters 1998; Summers 1998).

Posner and Vessey (1988) concluded that the experience of having an abnormal Pap test result causes psychological and emotional distress, psychosexual problems, and an altered body image and attitude to health status. Physical symptoms such as pain and discharge are also common.

Physical effects of cervical treatment
The colposcopy examination was described by almost half the participants in the Posner and Vessey (1988) study as uncomfortable while 16% said that the punch biopsies hurt and were the most physically painful and symbolically significant aspect of the
examination. Both cryocautery and laser treatment were reported as equally painful in two studies conducted by Lowles (1983) and Posner and Vessey (1988) respectively. Almost 50% of women reported moderate to severe pain either during or immediately following cryocautery or laser treatment (Lowles 1983; Posner & Vessey 1988). There was no agreed consensus in the professional literature as to the amount of pain experienced by women undergoing laser treatment to their cervix, and wide variations in the provision of anaesthesia and analgesia are reported (Lowles 1983). In the Lowles (1983) study, the vast majority of women undergoing laser treatment did so without any form of anaesthesia or analgesia.

Pain was described as more than physical by many women in Posner and Vessey’s (1988) study. One woman described it as a spiritual hurt. The study claims that the pain is harder for women to bear for a number of reasons including the fact that the lesion is invisible and therefore seen as a greater threat to their sense of identity; the condition has an association with cancer described as ‘a scourge, and a malign, indestructible consumer of the human body and spirit’ (p. 42); CIN is linked with sex, and many women believe hurtful assumptions are being made about their sexual history; and the pain is visceral rather than surface and therefore harder to detach from.

The women’s experience of pain is in contrast to published medical opinion. Mazza (1999) in a patient information form stated that ‘the biopsies generally are not painful’ (p. 265) and Lowles (1983) stated that cryotherapy was almost completely painless and never required anaesthesia, the antithesis of the women’s experience in the Posner and Vessey (1988) study.

Apart from severe cramping and stabbing-like pain, some women also experienced burning, flushing, dizziness, shortlasting but severe headaches and nausea that they found to be distressing during the treatment. Almost one-third of women complained about a watery discharge following cryocautery that was copious and lasted up to 3–4 weeks longer than the women had expected or had been warned (Posner & Vessey 1988). Although most women experienced some bleeding and/or discharge following cervical treatment, many women in the Kavanagh and Broom (1997) study were uninformed and unprepared for this experience and were frightened that it signified a problem. Few women had any conceptual framework for interpreting symptoms after treatment, for example, if a woman was told to report any heavy bleeding, she was
unable to judge whether what she was experiencing was heavy or not (Kavanagh & Broom 1997).

The persistent haunt of past and/or present violence

When a woman has an abnormal Pap test result it is not only her past lifestyle choices that return to haunt her, but may also include any violent attacks that were made against her person. Many women with an abnormal Pap test result have survived sexual assault and/or violence in intimate relationships. Plichta and Abraham (1996) reported a significant association between childhood and adult sexual and physical abuse and gynaecological problems.

Young and Katz (1998) attended a cross-sectional survey examining the experiences of 843 Canadian Aboriginal and non-Aboriginal women. Over a third of respondents reported having been sexually assaulted, the result being higher among Canadian Aboriginal than non-Aboriginal women. Women who had been sexually abused were younger when they first had sexual intercourse, they were more likely to have had multiple partners and a history of sexually transmissible infections and be smokers – all factors that place women at increased risk of HPV, CIN and cervical cancer. Aboriginal women who had been sexually abused were more likely to have had abnormal Pap test results.

Although a direct causal link between sexual assault and CIN cannot be established, women who have been sexually assaulted are more likely to have negative sequelae from cervical screening and cases of extreme anxiety may be related to past gynaecological and/or sexual trauma (Baird 1997). Only 2–16% of sexual assault survivors in the Golding, Wilsnack and Learman (1998) study had disclosed the sexual assault to gynaecological care providers. The researchers argued that many survivors of sexual assault are fearful of pelvic examinations, and Pap tests evoke memories of previous traumatic events. Women with a history of child sexual assault report more anxiety, embarrassment, vulnerability, shame and fear about pelvic examinations and screening than do other women. Robohm and Buttenheim (1996) argued that traumatic symptoms such as disassociation and re-experiencing the abuse are frequently present in women having a pelvic examination.
Coker et al. (2000) concluded that intimate partner violence (IPV) increases a woman’s risk of both CIN and cervical cancer with the incidence and severity of the assault positively correlated with cervical cancer. They hypothesised that IPV related to CIN/cervical cancer either through direct transmission of HPV or by psychosocial stress and negative coping strategies. The psychological profile of a woman prone to cancer has been reported as similar to the emotional traits associated with being a victim of IPV – low self-esteem, poor self-image, a tendency towards anxiety, depression and psychosomatic illnesses (Parker 1995). Such traits, however, are likely to be the result rather than a contributing factor toward IPV.

**The experience of ‘marginalised’ women**

With the exception of Price et al. (1996) and Quilliam (1990) all accessed literature in relation to the psychosexual sequelae of the abnormal Pap test result for women implied or presumed the women sampled were heterosexual and able-bodied. Deeply rooted Western stigma around physical disability, poverty, homosexuality, indigenerity, ethnicity, obesity and ageing has devalued the personhood and worth of these women (Stanley & Wise 1993; Broom 1995; Anderson 1996 cited in Cooper & Temby 1998; Doyal 1998; Firebrace 1998; Thomas 1998). Even in feminist literature, which can also be blinded by cultural norms (Olesen 1994), the experiences of women who are not able-bodied, middle class, well-educated, within a specified age and weight range (usually young and slim) have often been rendered invisible.

**Heterosexist assumptions**

Price et al. (1996) reported that lesbians perceived themselves to be less susceptible to cervical cancer than heterosexual women. Sexual orientation (lesbian, bisexual or heterosexual) offers no protection from CIN and twelve per cent of lesbians questioned in the Price et al. study had had an abnormal Pap test result at some time. Sexual orientation, sexual identity and sexual expression are not synonymous or necessarily static – many lesbians have had sexual intercourse with male penetration and this could account for the number of lesbians in the Price et al. (1996) study who had heterosexual risk factors.

Marrazzo et al. (2001) argued that, because of the occurrence of genital HPV in lesbians, cervical screening recommendations should not differ for women who have sex with women, regardless of their sexual history with men. However, women who
identify as lesbian are less likely to have cervical screening than women identifying as heterosexual. The Anti-Cancer Council of Victoria (2000) reported that one in four lesbians had not had a Pap test in the previous three years, compared with one in five of all women in Victoria in 1997, and 7.6% of lesbians had never had a Pap test.

In the North American study by Marrazzo et al. (2001), lesbians were less likely to have had regular Pap tests because of lack of insurance, previous adverse experiences with cervical screening and the mistaken belief that Pap tests were unnecessary. When a lesbian has an abnormal Pap test, she is often assumed by clinicians to be heterosexual, facing either invisibility as a homosexual woman or the need to assert herself as a lesbian and challenge heterosexist attitudes at a time when she is feeling particularly vulnerable (Quilliam 1990).

**Women with a disability**

There are low cervical screening rates amongst women with a disability (Wilson et al. 1998). Disability has been defined as: ‘… the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers’ (Disabled People’s International 1982, p. 84 cited in Cooper & Temby 1998).

Women with physical, emotional or intellectual disabilities consistently report that they face systematic and individual discrimination (Anderson 1996 cited in Cooper & Temby 1998). Negative health professional attitudes toward women with a disability exist, with over one-third (37%) of physicians reporting reluctance to gynaecologically examine a woman with a severe disability (Adams et al. 1993).

There are structural, financial and psychological barriers to women with a disability gaining access to cervical screening services (Temby 1996). Women with a physical disability report that, while existing material relates to the physiological aspects of the Pap test, they require information on how they can negotiate the process of having a test and about alternative positions in which the test can be taken (Webster & Wilson 1993). Women with intellectual disabilities suggest that much information is presented in a way that they cannot easily understand. These women either have a Pap test without understanding what the test entails, which raises issues in regard to informed consent, or they do not have a test because they are unaware of its importance (Wilson et al. 1998).
When a woman with a disability has an abnormal Pap test result, all of the described adverse effects for able-bodied women can be exacerbated and coexist with the added stigma that disability and sexual expression are considered incompatible by many health professionals and lay community members (Anderson 1996 cited in Cooper & Temby 1998).

The obesity stigma

Women who are 40% or more overweight are at greater risk of cervical cancer and have the most negative attitude toward the pelvic examination. They are most likely to avoid gynaecological screening and least likely to be offered a Pap test by a physician (Lew & Garfinkel 1979; Adams et al. 1993).

Body weight and self-image influence health considering attitudes and behaviour (Haskew & Adams 1989). That is, with increasing weight, women’s negative opinions about their appearance and reluctance to have pelvic examinations increase while the likelihood of having regular gynaecological screenings decreases (Adams et al. 1993). Obese women relate reports of prejudice and discrimination by health professionals toward them, and medical practitioners hold particularly negative attitudes toward obese women (Kaplan 1982 cited in Adams et al. 1993; Liese 1986; Rand & MacGregor 1990). It is reported that medical practitioners prefer not to manage overweight women (Maddox & Liederman 1969). The studies cited are not current; however, the reluctance to examine an obese woman is increasing rather than decreasing, and Adams et al. (1993) reported that the younger the physician the more reluctant they are to examine obese women. One in six (17%) physicians reported a reluctance to perform a gynaecological examination on an obese woman which contrasts sharply with the 0–2% reported reluctance of doctors to examine very thin women, very attractive or very unattractive women or a woman of different ethnic background to the physician’s own (Adams et al. 1993).

Aboriginality

Broom (1998) questioned the relationship between the continual erosion of Aboriginal rights and the persistently poor health, including cervical health, for Australian Aboriginal people. Aboriginal women in Australia continue to have a significantly increased risk of CIN/cervical cancer. Life expectancy of Aboriginal women in Australia is about 18 years less than non-Aboriginal women and only half as many
Aboriginal women reach the age of 65 years compared with non-indigenous females (Guest, Mitchell & Plant 1990; Gillies et al. 1995; Mak 1995; Bailie et al. 1998; Firebrace 1998). Firebrace (1998) argues that cultural differences, the history of dispossession and disadvantage, entrenched institutional and personal racism (particularly in rural areas), the pain of the stolen generations, negative stereotyping and the land rights struggle, all conspire to discourage Aboriginal people from accessing mainstream health services. Services such as cervical screening and follow-up investigations and treatment are perceived as ‘white man’s medicine’ to be used only as a last resort and with some trepidation (Firebrace 1998).

The language barrier
Women from non-English speaking backgrounds are less likely to have opportunities to learn English than men and this leads to unequal access to the health system (Thomas 1998). Furthermore, while most Australian born women experience barriers to regular cervical screening in one way or another, women from a non-English speaking background experience those barriers to a greater extent and are therefore more likely to present once their cervical pathology has become symptomatic at a later stage of its development (Balcomb & Stoden 1991; NSW Health Department 1994).

Socio-economic disadvantage
Most cancers, including cervical cancer, demonstrate a social gradient to the detriment of socio-economically disadvantaged populations and Geyer (2000) noted that even though breast cancer was more common in women from a higher social status, the chances of survival are poorer when breast cancer is diagnosed in a woman who is socio-economically disadvantaged. Geyer (2000) argued that evidence of the effects of social stress, especially life-changing and severe loss events, on the incidence of cancer have not been sought and urged further research on the role of socio-economic factors in the onset of malignancies.

Women who are homeless are among the most socio-economically disadvantaged of all women. These women are often homeless because they have experienced physical and/or sexual assault in their previous homes. Rew et al. (2001) reported that in their study, 75% of homeless girls had been sexually assaulted. Homeless young women are at particular risk for adverse health outcomes: they live in dangerous environments with inadequate housing and nutrition, have high levels of stress and inadequate social and
institutional resources (Rew et al. 2001) – all significant identified risk factors for the development of CIN and cervical cancer.

**Rurality**
Women living in rural and remote Australia report difficulties in accessing adequate health information, health services and female clinicians (Wainer 1998). Inadequate transport and the high financial costs involved in accessing health services are also reported (Farrell & Knight 1998). There is virtually no public transport access within or between towns and villages in many rural and remote areas in Australia. Access to health services, such as specialist colposcopy clinics, is almost entirely dependent on private transport but many of the women, especially those at greatest risk of CIN, do not have access to private cars (Wainer 1998).

**Ageist attitudes**
Increasing age has been reported as a risk factor for cervical cancer, especially for those women who do not have regular Pap tests (NSW Cervical Screening Program 1997). As women become older, they are increasingly less likely to attend a practitioner for cervical screening (McCormick 1989) and, when they do attend, a substantial percentage of physicians (40% in the Adams et al. 1993 study) are reluctant to conduct a gynaecological examination on an older woman.

**The literature, or lack thereof, confirms the need for this study**
This phenomenological study was initiated following the realisation that, compared to biomedical research on CIN, very little research had been published about the experience of women who have had an abnormal Pap test result. Only a few researchers explored the effects of detection of a cervical abnormality on a woman’s emotional, social or sexual well being (Campion et al. 1988; Posner & Vessey 1988; Quilliam 1990, 1992; Wilkinson, Jones & McBride 1990; Lauver & Rubin 1991; Wolfe et al. 1992; Cull, Cowie & Farquharson 1993; Kavanagh 1994; Bell et al. 1995; Bennetts et al. 1995; Paskett & Rimer 1995; Jones, Singer & Jenkins 1996; Kavanagh & Simpson 1996; Klemm & Guarneri 1996; Summers 1998; Sevin 1999; Khanna & Phillips 2001). Summers (1998) argued that the mental health consequences of cervical screening and its sequelae deserve further research if the adverse effects are to be reduced. Many of the above-cited studies explored women’s psychosocial responses when they were
diagnosed with cervical cancer rather than the more common CIN and therefore caution must be exercised when interpreting the conclusions of these studies.

Literature describing the possible emotional, social and sexual effects of an abnormal Pap test result on lesbians is extremely limited and there is no literature describing the experience of an abnormal Pap test result, from the woman’s perspective, for women who have a disability, or are obese, Aboriginal, from a non-English speaking background, socio-economically and/or geographically disadvantaged or aged at either end of the recommended cervical screening spectrum (18–70 years). The experience of women from ‘marginalised’ groups who have had an abnormal Pap test result has not been published. This research project actively sought the narratives of women from groups whose voices have previously gone unheard and unpublished. They were invited to share their stories in order to uncover the ‘essence’ (Polit & Hungler 1995) of the experience when they had an abnormal Pap test result. By approaching each participant interview with only two predetermined prompts: ‘Please tell me about yourself as a woman’ and ‘Please tell me about your experience when you had an abnormal Pap test result’, this study sought to obtain the contextualised and personally most significant aspects of the woman’s experience when she had a screening which detected cervical abnormality.
Chapter 2
The philosophy, theory and methodology
that informed this study

To understand, challenge and change attitudes towards women, their health, and their bodies ... all those concerned must listen and learn how women perceive the world, must understand what forces shape their experiences ... Good health care for women ... can only come from a correct understanding of how women feel about their bodies and a correct understanding of the lives they live.

Whitlam 1975, pp. 16–18

Introduction
Phenomenology is a philosophy, a methodology and a qualitative research method (Psathas 1973; McPherson 1987; Kretlow 1990; Taylor 1993). As an investigation of phenomena, the appearance of things, phenomenology studies the human experience as it is lived and from the individual’s perspective (Merleau-Ponty 1964; Keen 1975; Knaack 1984; Cohen 1987; Baker, Wuest & Stern 1992). The aim of phenomenology is to transform lived experience into a textual expression of its essence (or being) in such a way that the effect of the text is a reflexive re-living and a reflective appropriation of something meaningful (Van Manen 1997).

Phenomenology has been typologised as firstly, descriptive/transcendental, secondly, hermeneutic/interpretive/existential and, most recently, critical/radical hermeneutic phenomenology (Spiegelberg 1970; Bleicher 1980; Caputo 1987; Thompson 1990). The terms selected for use in this study are descriptive, hermeneutic and critical hermeneutic phenomenology respectively. The prime intent of critical hermeneutic phenomenology, adopted in this woman-centred study, is to discover, uncover, explore, describe, interpret and critique.

The competing concepts of Cartesianism and embodiment, because of their key influence on the development of both phenomenology and nursing practice/research are threaded throughout this chapter. The chapter traces the phenomenological evolution as it is traditionally marked by the philosophers that led each stage of the movement, the
developing phenomenological stances attributed to them and the impact that critical and feminist ideologies have had on nursing phenomenological research, and hence this study. Signposts along the path highlight the reasons why a given phenomenological perspective was either rejected, accepted in part or fully incorporated into this study.

The continuing evolution of phenomenology has led to struggles between philosophers, many claiming to subvert or supersede the others (Peterman 1998; Harrington 1999). In contrast, this project, informed by Gadamerian phenomenology and presenting phenomenology in a chronological and developing order, is not claiming superiority for Gadamerian or the later phenomenologies. At no stage does it propose that one type of phenomenology makes a previous type redundant (Ricoeur 1981). Depending on the purpose of the project, an earlier phenomenological philosophy/methodology that seeks to describe may be a more appropriate foundation than one that aims to interpret and/or critique. Each evolutionary phase is believed to have influenced Gadamerian thought and played a role in the development of critical hermeneutic phenomenology.

**The phenomenological evolution**

*Phenomenologists view the person as integral with their environment. The world is shaped by the self and also shapes the self.*

Burns & Grove 1997, p. 71

Phenomenology stemmed from the phenomenological movement that grew out of the Frankfurt School in the later 19th and early 20th centuries. Phenomenology has been described in three discrete historical phases: the preparatory, German and French (Spiegelberg 1975). It is the latter two phases that are described in this chapter. Beginning in Germany, Husserl (1859–1938), who is considered the ‘father’ of phenomenology, had been influenced by the psychologist, Brentano (Stumpf 1994). Husserl was the teacher and professorial predecessor of Heidegger (1889–1976) who in turn influenced Gadamer (1900–2002) and Habermas (1929–) and the French philosophers including Merleau-Ponty (1908–1961) (Rose 1995). A synopsis of these three historical phases is presented in Table 1.

Phenomenologists hold diverse views on epistemological and ontological questions, meaning that there can never be a school with a rigid and uniform perspective. There is, instead, a phenomenological movement, the processes of which will always be open to future developments (Spiegelberg 1976; Ricoeur 1981; Weinsheimer 1991).
Table 1: Synopsis of the phenomenological evolution

<table>
<thead>
<tr>
<th>Philosophical paradigm</th>
<th>Influenced by the phenomenologists</th>
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<tbody>
<tr>
<td>Descriptive/transcendental phenomenology</td>
<td>Husserl</td>
</tr>
<tr>
<td>Hermeneutic/interpretive phenomenology (sometimes referred to as existential phenomenology)</td>
<td>Heidegger, Gadamer and Merleau-Ponty</td>
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<tr>
<td>Critical hermeneutic phenomenology</td>
<td>Gadamer and Habermas</td>
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**Husserlian phenomenology**

*The ethos embedded in existential phenomenology is respect for the social and cultural nature of being human.*

Benner 1984, p. xv

Husserl was influenced by and committed to the Descartian (1596–1650) concept of the body and mind as two separate mechanistic entities (Lawler 1991; Plager 1994; Koch 1995; Crotty 1996). Cartesian dualism divided human beings into ‘body’ to be studied by science and ‘mind’ or ‘soul’ to be studied by philosophy and religion (Helman 1994). In modern Western medicine, ‘mind’ was handed over to psychiatrists and psychologists to study rather than priests, while ‘body’, Helman (1994) argued, was seen increasingly as an animated machine, to be studied by medical science and its diagnostic technology. Cartesian dualism, the subject/object dichotomy and the notion of ‘bracketing’ became the fork in the road where Husserl split from later phenomenologists.

‘Bracketing’ is the mathematical term introduced into phenomenology by Husserl. It refers to the necessity of the researcher to suspend belief in the existence of phenomena (Parse, Coyne & Smith 1985; Denzin 1989 cited in Plager 1994; Crotty 1996). The purpose of bracketing is to provide the means whereby a researcher can look at things as they actually appear in the data, without any preconceptions, biases or judgments. By bracketing out or holding the world ‘in brackets’, it was believed the philosopher could return to pure consciousness of the phenomenon (Beech 1999). Bracketing continues to be one of the most controversial issues in phenomenology with some academics arguing that it is a non-negotiable aspect of phenomenology (Kvale 1983; Crotty 1996). Others, such as the nurse-academic Walters (1995a), disagree and argue that bracketing is Cartesian in its turning away from the world and is not necessary or even desirable.
Husserlian phenomenology is considered a pure phenomenological method and esteemed by many Australian academics including Crotty (1996). There are merits in Husserl’s quest to develop a ‘scientific’ approach. In considering whether to adopt a Husserlian approach for this study, one advantage was that this would be the most likely of the phenomenological methods to be accepted by the conservative health service environment and dominant nursing/medical system to which I belong. As a fledgling scholar, the idea of having set rules to follow and steps to take in a research process that might be accepted by others was especially attractive. However, it was not selected for this study for a number of reasons, including that the positivist nature of Husserlian phenomenology did not fit easily with the women-centred values at the core of this work. For over a decade, women had shared with me, in the clinical setting, the most intimate and deepest concerns about themselves and their health. These women had taught me many valuable lessons about what it meant to be a woman living in intimate relationships and experiencing the health system. If a fundamentalist and pure Husserlian phenomenological method were selected, I would need to bracket out these women’s stories, including any thoughts of possible violence, abuse and exploitation. From many years of clinical practice, listening to the horrifying stories of women, I did not think this would be possible, nor desirable. To attempt to bracket out women’s collective stories seemed an act of disloyalty to those incredible women who had survived such horror.

Husserlian or descriptive phenomenology focuses on describing epistemological questions of knowing (Spiegelberg 1965; Thompson 1990). Husserl took on the lifelong task of continuing to modify and clarify the philosophy and method of phenomenology. He went on to influence both German and French philosophers who developed or reworked his original phenomenological concepts (Baker, Wuest & Stern 1992). While there have been many divisions and philosophical debates between phenomenologists, all since Husserl have esteemed phenomenology as a people-valuing philosophy and methodology and all have claimed that human experience is not the external environment of the natural sciences but rather the ‘life-world’ (Keen 1975).

In the next phase of phenomenology informed by Husserl’s student Heidegger, the focus moves from description to interpretation. Phenomenologically, a person is valued and seen as self-interpreting. Contrasting the Husserlian and Heideggerian perspectives, Husserl argued that these interpretations were a product of individual consciousness but
for Heidegger these interpretations could never be final or closed because they were not generated in individual consciousness but rather were given in a person’s linguistic and cultural traditions and made sense only when placed in context (Allen 1985; Leonard 1994).

Heideggerian phenomenology

Heidegger’s temporal analytics of human existence (Dasein) has, I think, shown convincingly that understanding is not just one of the various possible behaviours of the subject, but the mode of being of There-being itself. This is the sense in which the term ‘hermeneutics’ is used here.

Gadamer 1975b, p. xviii

Martin Heidegger was considered an accomplished philosopher and academic when he became Husserl’s assistant in 1922. Heidegger’s work brought together ideas from both Husserl and Soren Kierkegaard, a 19th century existential philosopher, to create the philosophical science of existential phenomenology with its hermeneutic focus, an offshoot from descriptive phenomenology (Parse, Coyne & Smith 1985; Annells 1996). Heidegger’s goal was to explore the ‘deepest nature of an individual’s thinking when he is thinking as an existing human being’ (Stumpf 1994, p. 503). Existential phenomenology, or what is more commonly referred to as interpretive or hermeneutic phenomenology, aims to discover, uncover, interpret and contextualise meaning (Spiegelberg 1970; Geertz 1979; Mischler 1979; Weinsheimer 1991; Plager 1994).

Hermeneutics, an ancient discipline, can be traced back to the Ancient Greeks. Early Greek root words for hermeneutics suggest the idea of bringing to understanding, particularly through language (Leonard 1994). That is, something foreign, strange or separated in time, space or experience is revealed so as to seem familiar and comprehensible (Palmer 1969). In more recent times, hermeneutics has focused on Biblical exegesis, legal discourse, literary criticism and philosophical exploration (Bernstein 1988; Leonard 1994). In the early 19th century, Schleiermacher redefined hermeneutics as the study of understanding and, in the latter part of that century, Wilhelm Dilthey (1833–1911) argued that hermeneutics is important in all humanities and social science research (Palmer 1969). Schleiermacher and Dilthey influenced Bultmann, Heidegger, Gadamer and the writings of Habermas who were instrumental in ensuring hermeneutics retained its position as an option for researchers aiming to increase their understanding of a given phenomenon (Bernstein 1988).
Hermeneutic phenomenology has become concerned with human behaviour and practicalities as they occur and unfold in the everyday setting, and has turned epistemological questions to ontological-existential questions of what it means to be a person existing in the world, experiencing and making sense of it (Reeder 1985; McPherson 1987; Benner & Wrubel 1989; Thompson 1990; Dreyfus 1991; Leonard 1994; Plager 1994; Taylor 1994).

In contrast to Husserlian phenomenology, the expressed goal of phenomenology as first described by Heidegger and then advanced by Gadamer is to break down Cartesian dualism, to reject the notion of subject/object and consider the human being as a bodily subject (Fjelland & Gjengedal 1994; Leonard 1994). Husserl was criticised by Heidegger for not being able to grasp the basic ontological interpretations of consciousness (Kaelin 1988). Heidegger added that a detached, objectifying approach reduced phenomena to what could be statistically correlated and that this approach could not account for everyday human experiences that are historical and temporal and based on participation in language and cultural practices (Benner 1985). Heidegger used the principles of Aristotelian philosophy to counter Husserl’s allegiance to Cartesianism and to argue against the authority of positivism (Heidegger 1958; Stumpf 1994; Annells 1996).

*Being and Time* (Heidegger 1962) offered an analysis of human existence in order to establish ‘an interpretation of the meaning of Being as such’ (Mueller-Vollmer 1986, p. 214). In aiming to methodically uncover the concealed structures of human existence in the world, Heidegger discussed ‘the clearing’ by which he meant the shared world of the researcher and informant which made it possible to have both shared and individual interpretations of the everyday world (Plager 1994). Heidegger originally described this ‘clearing’ as ahistorical and acultural, not specific to any particular culture or historical time. However, in later works, he explicited the ‘clearing’ as it pertained to Western civilisation and had evolved throughout its history – a cultural and historical understanding of being (Plager 1994). This study was guided by Heidegger’s later philosophical leanings that were expanded by Gadamer (1975b), in that it placed the informants’ narratives of their experience in both a cultural and historical setting.

In contrast to Husserl, Heideggerian phenomenology described how the researcher must be attuned to both the text as narrative and to their own narrative, which is referred to as
their forestructure of understanding (Plager 1994). This study is more attuned to Heideggerian than Husserlian phenomenology, in that my preunderstanding is documented but not discounted on the provision that it never corrupts the data collection, interpretation, analysis or reporting process. Plager (1994) argued that this requires openness, sensitivity and scrutiny on the part of the researcher. Heidegger used the word, ‘Gelassenheit’, to infer this sense of openness and passivity in relating to the phenomenon being explored. He urged the researcher to ‘simply open ourselves and await the advent of Being’ (Crotty 1996, p. 161). Nelms (1996) described the Gelassenheit concept as an openness to a possible change in the understanding of being. Openness, rather than bracketing, became the philosophical prerequisite to approaching and conducting the research project.

Taylor (1994) concluded that the basic difference, in practical terms, between Husserl and Heidegger was their different interpretation of the concepts of ‘world’ and ‘Bracketing’. Husserl sought understanding of the ‘level below the natural world’, or the genesis of consciousness (Taylor 1994). Heidegger, according to Taylor (1994), was concerned with Being-in-the-world, so, instead of bracketing presuppositions, he explored them as legitimate parts of Being, a concept advanced by Gadamer.

In considering whether to adopt a primarily Heideggerian approach to hermeneutic phenomenology, I was partly influenced by the controversies and debates in the nursing literature. Holmes (1996) argued against the widespread valuing and utilisation of Heideggerian interpretive approaches stating that Heideggerian phenomenology is not only unsuitable as a means of enhancing nursing knowledge but is actively counterproductive to nursing aspirations. Holmes was concerned that many nurses are either unaware of, or unmoved by, Heidegger’s enthusiastic involvement in Nazism and anti-humanist ideology that he never denounced (Collins & Selina 1998). Holmes (1996) argued that nurses must be alert to and consciously reject all fascist, anti-Semitic and ultranationalistic elements of his work. He urged nurse researchers to use Heideggerian phenomenology only with extreme caution, and quoted Sheehan’s (1988 cited in Holmes 1996, p. 582) warning:

… read nothing of Heidegger’s anymore without raising political questions … (O)n must re-read his works – particularly but not exclusively from 1933 on – with strict attention to the political movement with which Heidegger himself chose to link his ideas.
With the urging of Holmes and Sheehan’s warning in mind, I moved on to read more about the phenomenological standpoint advanced by Hans-Georg Gadamer.

**Gadamerian phenomenology**

_Gadamer ... argues_ there is an inextricable connection of the theoretical and the practical in all understanding and interpretation – that hermeneutical understanding shapes our practical lives (and is not purely a disinterested, theoretical activity).

Bernstein 1988, p. 141

The work of Gadamer, the German philosopher and student of Heidegger, has been recognised as central to the evolution of hermeneutic phenomenology and the genesis of critical hermeneutic phenomenology (Thompson 1990; Pascoe 1996). It became the philosophy of choice for this study. Gadamer developed the ideas published by Heidegger (1962) and drew on the work of Dilthey who had an intense interest in methodological studies relating to the nature and history of the humanities. Gadamer (1975a) furthered the Dilthey position and argued that hermeneutics had developed beyond the theological discipline and into a system which made it the basis of all human sciences. In contrast to Dilthey, however, Gadamer chose not to work on methodology, but rather he concentrated on exposing and critically appraising the Husserlian and Heideggerian hermeneutic principles that underpinned the human sciences. Gadamerian hermeneutic phenomenology was founded on two main concepts – the rejection of the Cartesian notion of subject-object and the role of preunderstanding in interpreting phenomena (Gadamer 1975a). He argued that the task of hermeneutical reflection was to provide self-conscious awareness of ourselves and our world and therefore to be worthwhile it must make a contribution to scholarly and scientific knowledge (Mueller-Vollmer 1986). It was Gadamer’s insistence on applying theoretical knowledge to practice that most advanced the Heideggerian notion of hermeneutic phenomenology and influenced my decision to make Gadamerian phenomenology central to this study.

Gadamer criticised Husserlian hermeneutics because, although it was intended to demonstrate the legitimacy of the human sciences as autonomous disciplines, it nevertheless propagated the Cartesian subjective and objective dichotomy (Weinsheimer 1991). Gadamer (1975a) argued that phenomenological hermeneutics must go beyond relativism and objectivism if it is to offer optimum value to learning and understanding. The basis of the Gadamerian Cartesian critique is ontological
because, he argued, Cartesianism is based on a misunderstanding of being, and in particular upon a misunderstanding of a person’s being-in-the-world (Bernstein 1988). Bernstein (1988) expressed Gadamer’s thinking as that which directed us back to an ontological understanding of what it means to be finite historical beings who are always ‘on the way’ and who must assume personal responsibility for decisions and choices made in daily ‘lived experience’.

**Lived experience**

> Because [lived experience] is itself within the whole of life, in it too the whole of life is present.

Gadamer 1975a cited by Annells 1996

> Thus the concept of experience is the epistemological basis for all knowledge of the objective … experiences exist only insofar as something is experienced and meant in them.

Gadamer 1975b, p. 59

The philosophical concept of ‘lived experience’ was introduced by Husserl, expanded upon by Heidegger and further advanced by Gadamer (Annells 1996). Gadamer (1975b) described ‘lived experience’ as encompassing three interrelated aspects in a ‘hermeneutic circle’. The first was the idea of unity, where ‘lived experience’ took on a significant whole and a new way of being. The second was part of and could not be replaced in relation to the whole of life – it was an inner relationship to life, and the third aspect had infinite properties in determining meaning and enhancing understanding.

**The hermeneutic circle**

Pre-Heideggerian descriptions of the hermeneutic circle focused exclusively on the relation of part to whole in the phenomena under investigation (Bernstein 1988). Gadamer argued that Heidegger transformed the meaning, scope and significance of the hermeneutical circle so that the focus was now on the ‘thing itself’:

> For the very first time the positive ontological meaning of the circle that understanding implies is explicitly affirmed … In order to be authentic the inquiring gaze must be focussed on the ‘thing itself’, and in such a manner that it may be grasped, as it were, ‘in person’ (Gadamer 1979, pp. 149).

Heidegger’s (1962) concept of the hermeneutic circle was the observation that we understood something only in relation to the whole of which it is a part and vice versa.
This ‘circle of understanding’ referred to how a person made meaning from daily activities and interpreted something as valid because they had a background of shared human understanding with another (Heidegger 1962; Plager 1994). Heidegger proposed no privileged position for objective knowing, rather, that all knowledge emanated from persons who were already in the world, that is to say, one was always within the hermeneutical circle of interpretation (Leonard 1994). Furthering Heidegger’s proposition, Gadamer (1975b) believed that every human experience was taken out of the continuity of life and at the same time related to the whole of one’s life. It is not simply that it remains a living experience only until it is fully integrated into the context of one’s life consciousness, but the very way in which it is preserved through its being worked into the whole of life-consciousness, goes far beyond any significance it might be thought to have: ‘it is itself within the whole of life, in it too the whole of life is present’ (Gadamer 1975b, p. 62). Gadamer (1979) argued all human life, including research into human life, took place within this ontological circle of understanding and the principle of the individual (or part) informing the system (or whole) in reciprocal fashion was a central tenet of the hermeneutic circle. Gadamer saw the hermeneutic circle (see Figure 1) as the place where ‘the practical and the theoretical are inextricably joined …’ (Bernstein 1988, p. 134). This joining of theory and praxis is what primarily differentiates Gadamerian from Heideggerian portrayals of the hermeneutic circle and becomes the staging point for a unique social critique within phenomenology.

Gadamerian and Husserlian phenomenology are irreconcilable on the issue of bracketing. Husserl described bracketing as essential but Gadamer called it absurd:

A person who imagines that he is free of prejudices, basing his knowledge on the objectivity of his procedures and denying that he is himself influenced by historical circumstances, experiences the power of the prejudices that unconsciously dominate him (Gadamer 1975b, p. 324).
Researcher’s preunderstanding open to critical reflection

Informant’s experiences expressed in narrative

Whole informs part

Part informs whole

Recommendations for enhancing practice

Researcher’s preunderstanding open to critical reflection

Meaning is created in the Fusion of Horizons

Figure 1: The hermeneutic circle
Gadamer argued that we deceive ourselves if we believe we can somehow extract ourselves contextually or think that, by some pure act of empathy, we can bracket our own situation. To eradicate prejudice, he argued, was prejudicial in itself (Gadamer 1975b). Meaning and understanding are not psychological processes, discrete events or states of mind; they are essentially and intrinsically linguistic (Gadamer 1976). One of the most controversial aspects of Gadamer’s concept of hermeneutic phenomenology is his defence of prejudice and his argument with the Enlightenment’s ‘prejudice against prejudice’ (Gadamer 1975a, p. 240). In *Philosophical Hermeneutics*, Gadamer argued that all understanding inevitably involved some prejudice and it is prejudice that gave hermeneutics its direction:

> It can be shown that the concept of prejudice did not originally have the meaning we have attached to it. Prejudices are not necessarily unjustified and erroneous, so that they inevitably distort the truth. In fact the historicity of our existence entails that prejudices, in the literal sense of the word, constitute the initial directness of our whole ability to experience. Prejudices are biases of our openness to the world. They are simply conditions whereby we experience something – whereby what we encounter says something to us (Gadamer 1976, p. 9).

Gadamer maintained that there is no essential difference between understanding and interpretation (Bernstein 1988). For this reason the process of understanding could never be finalised, it is always open and anticipatory. Misunderstandings and misinterpretations can be revealed, but this involves interpretation rather than bracketing. Understanding and interpretation occur simultaneously with our prejudgments or prejudices, which are ever changing in the course of learning and history (Bernstein 1988). Phenomenological inquiry in this study follows the model where preunderstandings are acknowledged but not discounted:

> … the first of all hermeneutic requirements remains one’s own foreunderstanding, which proceeds from being concerned with the same subject. It is this that determines what unified meaning can be raised … (Gadamer 1975b, p. 262).

The study was approached with an already established background of preunderstanding. As Thompson (1990) argued, it is the researcher’s situation in history and context that is the precondition of truth, not an obstacle to it. Providing my preunderstanding did not lead to investing the data analysis with interpretations that could not be obtained from the informants’ narrations of their experience it had a ‘rightful place’ in this study.
One of the key problems of research is then the realisation that ‘pure objectivity’ can never be achieved (Lichtenstein 1987). Gadamer sought to solve this dilemma by encouraging the researcher to disclose the application of their theory in the process of its development. Keller (1985) built on Gadamer’s recommendation and proposed an approach she called, ‘dynamic objectivity’, which fits this study well. Keller (1985) argued that more effective objectivity is achieved through pursuing the subjective experience. The concept encourages the researcher to be more objective by not only disclosing but also critically reflecting on their prejudgments. Dynamic objectivity relies upon the connectivity or oneness of emotional (subjective) experience with cognitive (objective) experience. It insists upon the validity of the subjective and emphasises personal experience as a source of knowledge (Keller 1985; Lichtenstein 1987).

A task in this study is not to remove all prejudice and preconceptions but, rather, to be open to them, open about them and test them critically in the course of inquiry (Bernstein 1988). By testing them critically, blind prejudice and enabling prejudices that produce knowledge can be differentiated. Prejudices are risked and tested, not through Husserlian bracketing nor the Cartesian concept of pure self-reflection, for as Gadamer insisted, there is no knowledge and no understanding without prejudices. Rather, prejudices are risked and tested through being open and receptive to another’s opinion, experience or narrative. To quote Gadamer (1979, p.152):

In keeping to this [receptive and open] attitude we grant the text the opportunity to appear as an authentically different being and to manifest its own truth, over and against our own preconceived notions.

This study selected the principles espoused by Gadamer primarily because of the potential for critical application and his insistence on the linking of understanding and interpretation to practice (Gadamer 1975a). The fusion of hermeneutics and praxis, Bernstein (1988) argued, is central to Gadamer’s hermeneutic phenomenology.

**Fusion of horizons**

*Hermeneutics is the shared understandings that we already have with one another. Sharing is done through language, as language is so thoroughly the medium of all hermeneutic experience.*

Koch 1999, pp. 20–34

Gadamer adopted Heidegger’s concept of ‘the clearing’ and added that understanding is only possible because the object to be understood has relatedness to the person involved.
in the act of understanding. In practice this means that, when people converse with one another, they work through their perceptions to find a place of mutual understanding (Taylor 1994), a fusion of their horizons.

Gadamer described a horizon as ‘the range of vision that includes everything that can be seen from a particular vantage point’ (Gadamer 1975a, p. 269). Horizons are changing and fluid and require looking well beyond what is close in order to view the phenomenon in proportion and clearly as part of a larger whole (Bernstein 1988; Annells 1996). To understand another’s horizon, we need to achieve a ‘fusion of horizons’ whereby our own horizon is enlarged and enriched through visualising and accepting another’s horizon as fusing with our own, enabling our prejudices to be risked and critically tested (Bernstein 1988). Gadamer (1975a) appealed to a truth that enables the researcher to go beyond their own historical preunderstanding through to a fusion of horizons.

The Gadamerian phenomenological approach was selected because it acknowledges both the inevitability and the worth of subjectivity and values holism, accepting that every original intuition is a legitimate source of knowledge (Kockelmans 1967; Parse, Coyne & Smith 1985; Benner 1994). It does not seek to reveal causal relationships, but rather to increase understanding and reveal the nature of phenomena as humanly experienced (Allen 1985; Parse, Coyne & Smith 1985). First person account stories of experience provide access to a kind of knowledge not ordinarily regarded as appropriate for epistemological consideration (Omery 1983; MacPherson 1983; Code 1988). Van Manen (1984) described the point of phenomenological research to be the borrowing of other people’s experiences in order to understand the deeper meaning of it in the context of the whole human experience. Understanding rather than knowing is the key concept (Code 1988). Gadamerian phenomenology encourages personal and professional introspection (Chinn 1985) – an essential component of this project if it is to ensure that clinical practice is enhanced in order to minimise the negative sequelae of cervical screening.

The dilemma of which phenomenological philosophy best suited this study was considered to be resolved by adopting a Gadamerian (hermeneutic) approach. However, once the first three preliminary interviews with participants were completed, it became obvious that women were choosing to share multiple instances of extensive oppression
and violation by both intimate others and the health system. The study could, therefore, not remain purely hermeneutic but by necessity had to be critical.

Hermeneutic phenomenology, traditionally considered an interpretive methodology, can also be a critical philosophy of action (Bleicher 1980; Caputo 1987; Thompson 1990; Van Manen 1997). Gadamer, although influenced by Heidegger, avoided his teacher’s insistence of ontologising and presented a more socially and historically contextualised hermeneutic phenomenology. Gadamer was the first phenomenologist to introduce the possibility that phenomenology could take a critical standpoint (Thompson 1990; Pascoe 1996). Like a relay baton, hermeneutic phenomenology was taken from Heidegger by Gadamer and would eventually be passed to Habermas for a very short time. In the process, because of Gadamer’s argument that there could never be a neutral, objective interpretation (Gadamer 1975b), phenomenology was able to undergo a metamorphosis into the next and latest step in the evolutionary ladder – critical hermeneutic phenomenology.

**Critical hermeneutic phenomenology**

Critical hermeneutic phenomenology seeks not only to describe and uncover social inequality and resource maldistribution but to rearrange the disequilibrium to create a fairer, more equal world (Lather 1986). In so doing, Thompson (1990) argued, it is undergirded by the worldview that not all social actors are heard equally, or at all. Critical hermeneutic phenomenology proposes that many socially accepted meanings are hegemonic and represent the interests of a powerful few. It strives to uncover, resist, challenge and change oppression that may go unnoticed even by the participants themselves (Thompson 1990). In the context of this study, the social actors who have not been adequately heard are women, especially ‘marginalised’ women who have experienced an abnormal Pap test result. Accepted meanings are those perpetuated by well-meaning health professionals but which have the unintentional effect of maintaining the dominance of medicine and serving the requirements of the health system at the expense of the women who use it.

Gadamer was criticised by Habermas for not being critical enough and for his acceptance of the role of authority and tradition and ignoring the political and/or economic factors that oppressed people (Annells 1999). However, both Habermas and Gadamer agreed that in order to understand another person – their behaviour, beliefs
and history – researchers need to enter into the dialogue with their informants about the nature of their ‘lived experience’ (Harrington 1999).

**Habermasian phenomenology**

Although Habermas is not usually thought of as a phenomenologist but a critical theorist, his critical theory grew from his phenomenological roots in the Frankfurt School and the teachings of Gadamer (McCarthy 1978; Peterman 1998; Ingram 1999). Ingram (1999) argued that Habermas abandoned his allegiance to phenomenology in 1954 to advocate for social justice. However, he continued to borrow heavily from hermeneutic phenomenology as he generated his ‘Theory of Communication’ and the ideology of ‘Universal Pragmatics’ (Peterman 1998; Rohmann 2000). In these, Habermas sought to create conditions for an ideal speech situation where all could engage in free political dialogue unaffected by unequal power relations or constricting ideologies (Rohmann 2000). In his attempt to reconcile science and morality, Habermas argued that it was imperative for all concerned parties to be included in the discussions, that everyone should have equal opportunities to speak and that each need to do so freely and sincerely. In a small way, this thesis seeks to emulate the Habermas ideology of ‘Universal Pragmatics’ and attempts to restore some of the equity between health caregiver and recipient by giving voice to women in the cervical screening encounter. The narratives shared by the women in this study allude to multiple oppressive influences and, in keeping with Habermasian principles, these are exposed and critiqued in the discussion chapters of this thesis.

As this study seeks to reveal oppressive and suppressive influences which adversely affected women’s health, an approach following the principles initiated by Habermas (1971a, 1987) was seriously considered. However, the primacy of this method could not be used because central to the critical approach of Habermas was the need for informants in the project to personally experience an emancipatory outcome. This study could not promise such an outcome for the informants themselves. Nonetheless, a critical approach is essential if the participants’ stories are to be justified and used to enhance clinical practice for women with an abnormal Pap test result. Fortunately, Gadamerian hermeneutics can be used in congruence with a critical approach that aims to uncover oppressive and suppressive influences that affect women (Annells 1999).
Concomitantly with the latter German phenomenological movement, but with different foci, French phenomenologists were establishing a discrete branch in the phenomenological tree.

**The French phenomenologists**

*The perceiving mind is an incarnated mind. I have tried, first of all, to re-establish the roots of the mind in its body and in its world.*

Merleau-Ponty 1964, p. 3

The French philosophers, Gabriel Marcel, Jean Paul Sartre and especially Maurice Merleau-Ponty expanded the existential phenomenological movement in a separate branch to that of Heidegger, Gadamer and Habermas (Parse, Coyne & Smith 1985). Merleau-Ponty, unlike the German hermeneutic phenomenologists, continued the Husserlian practice of bracketing but, like Heidegger, Gadamer and Habermas, discarded the Husserlian allegiance to Cartesianism.

Merleau-Ponty is described as a neopositivist and the phenomenologist who pays most attention to the body (Fjelland & Gjengedal 1994; Annells 1999). For Merleau-Ponty, phenomenology is a sociology and a philosophy that never forgets the origin of all our knowledge – human experience (Merleau-Ponty 1964; Crotty 1996).

Maintaining Gadamerian principles, this study seeks to articulate with the Merleau-Ponty concept of ‘being of the world’. It concurs with his and the Van Manen perspective:

> From a phenomenological point of view, to do research is always to question the way we experience the world, to want to know the world in which we live as human beings. And since to know the world is profoundly to be in the world in a certain way, the act of researching – questioning – theorising is the intentional act of attaching ourselves to the world, to become more fully part of it, or better, to become the world. Phenomenology calls this inseparable connection to the world the principle of ‘intentionality’. In doing research we question the world’s very secrets and intimacies which are constitutive of the world, and which bring the world as world into being for us and is us (Van Manen 1990, p. 5).

Where Husserl promoted the Cartesian concept of separate mind and body, Merleau-Ponty advanced the concept of embodiment as interdependent with personhood and as the integration of the object body-as-thing with the lived body-as-experience (Harre 1986; Lawler 1991). The artificial split between mind and body is overcome by arguing
that personal identity is the sum of human experience and embodiment (Shalom 1989). Shalom (1989, p. 77) concluded that ‘body and mind are what we actually experience as ourselves. They are ourselves as the substance of experiencing’. This view of person is fundamentally different from the Cartesian notion of the body as object of possession (Leonard 1994). Merleau-Ponty (1962) stressed the need to locate the body in context and he argued for the centrality of the body in the development of identity and one’s sense of personhood. Merleau-Ponty directed his phenomenological analysis to the bodily dimensions of human existence, seeing each person as a ‘body subject’, who is at all times situated in concrete lived experience. In his view, everything human is embodied, including thought and language (Crotty 1996).

The works of Merleau-Ponty, especially in regard to the notions of embodiment and perception, share many of the values adhered to in this study. However, it could not be the prime approach for a number of reasons, including Merleau-Ponty’s argument that bracketing is non-negotiable (Merleau-Ponty 1956 cited in Oiler 1982). Another concern was that, if the Merleau-Ponty approach was taken, the oppressive influences that adversely affect women could be rendered invisible or at least placed in the background rather than the foreground of the study. Both Merleau-Ponty and nursing phenomenological research have been criticised in the past as being too subjective, with the psychological taking dominance over the sociological (Crotty 1996; Van Manen 1997). Nursing, medical and social practices that adversely affect women’s lives are perpetuated in an ongoing, ever deepening spiral that, in the interests of women, must be broken.

**Theoretical principles at the heart of this study**

Uncovering oppressive sociological influences that affect women when they have an abnormal Pap test result is part of the core of this study and consequently there are a number of critical and feminist theories considered fundamental. These theoretical principles include that:

- Western medical discourse is privileged and medical power is maintained through its claim to own superior knowledge (Foucault 1976)

- medicalisation of female bodies supports and maintains medical domination (Foucault 1976; Rowland 1988, 1992; Ussher 1989)
women’s lives are able to be defined and dismissed, in part, because their bodies have been medicalised (Rowland 1988, 1992; Ussher 1989)

women using a language normalised by a dominant male medical infrastructure have few words to describe or name what they are experiencing or feeling so their dependency on medicalisation as a means to self-definition becomes self-fulfilling (Orr 1986)

the current status quo of medicalisation of women’s bodies maintaining medical domination and being used as a tool to define and dismiss women is not irreversible. Once identified and named any power can be resisted and overcome (Foucault 1976; Street 1989).

Hermeneutic phenomenological methods have, at their heart, the desire to increase understanding through interpretation. Feminist and critical methods aim at emancipating – bringing about valuable change. This study seeks to articulate hermeneutic phenomenological and feminist/critical paradigms in an endeavour to generate a greater understanding of women’s experiences, harnessing this knowledge to improve the encounter women have with nursing and medical personnel when their Pap test returns an abnormal result.

Emancipation: The feminist approach

*An emancipatory intent is no guarantee of an emancipatory outcome.*

Acker, Barry & Esseveld 1983, p. 431

There is no one universally accepted definition of feminism. Feminist thought and ideology that underpin this study, like phenomenology, are evolving. The working definition of feminism that informed this study is documented as:

The recognition that, virtually across time and place, men and women are unequal in the power they have, either in society or over their own lives, and the corollary belief that men and women should be equal (Arneil 1999, pp. 3–4).

Feminist research considers the woman’s view as particular and privileged (Olesen 1994) and articulates well with the informant-centred methodology of critical hermeneutic phenomenology. Feminism, therefore, provides the matrix in which this study’s design, data collection, relationships between myself and participants, data interpreting and reporting occur.
Although studying women is not new, ‘to see the world from women’s place in it’ (Callaway 1981, p. 460) is relatively unprecedented in history (Hall & Stevens 1991). The primary goal of feminist research in the human sciences is to correct both the invisibility and distortion of female experience in ways that seek to change women’s unequal social position (Harding 1987; Lather 1991). This study is designed, implemented and continues to be disseminated, with the aim of articulating for and with women, explanations they own about phenomena affecting their lives. This understanding is then used to make recommendations to health professionals for practice enhancement, helping to change women’s unequal social position within the medical/nursing hierarchy and the health system.

Haraway (1988) argued that no feminist investigation could be total or complete. While this study illuminates some aspects of women’s experience that have previously been suppressed or ignored within the dominant biomedical view, it can never speak for ‘woman’ because no such woman exists (Flax 1987; Broom 1998). Each woman has her ‘Being’ within a specific set of gendered relations, environment and life experiences, making her a unique person. Broom (1998) argued that within the concept of ‘woman’ lie many possibilities to which any particular woman may have access. She concurred with the postmodern notion that the ‘self’ should be seen as a process, rather than an object. However, the arguments put forward in this study are congruent with the contention of Doyal (1998) that, because no two women are identical, it does not mean that different women do not have much in common. Nor does it mean they are not in agreement on certain universal principles and goals. Women do have differences, and these should not be minimised, but there are also great similarities among women and these should not be ignored (Morgan 1984). This project acknowledges the immense challenges and oppressions faced by women. It also recognises that some women face multiple discrimination relating to their body size and shape, socio-economic status, ability/disability as well as racism, sexism and heterosexism.

Rowland (1988) argued that language is a powerful tool by which the consciousness of society is reinforced and controlled. She described how stories are constructed and told through language and how they contribute to the explanation and understanding of humanity. Rowland argued that, historically, men created and maintained the dominant culture. Men told the published stories while female experiences were not adequately represented (Rowland 1988; Holt 1998). This study assumes that a woman’s story is of
utmost value. The role of storytelling is central to hermeneutic phenomenology because when people structure their own narrative accounts, they tap into their more immediate experiences, and the problem of generating false generalities or ideologies is diminished (Benner 1994). Chinn and Wheeler (1991) believe that one of the reasons that the oral tradition of storytelling has survived and is still practised so extensively among women is because it is a simultaneous act of ‘Knowing’ and ‘Doing’ that fits comfortably with women’s wisdom.

Van Maanen (1988) described the concept of ‘critical tales’ that asks questions of power, history, economy and exploitation. ‘Critical tales’ of women are told in this study. Critical theory, like feminist theory: ‘springs from an assumption that we live amid a world of pain, that much can be done to alleviate that pain, and that theory has a crucial role to play in that process’ (Poster 1989, p. 3). An underlying theme in this study is the possibility that enhancing understanding of women’s experience will provide a critical vehicle for positive change, to better understand ‘what is’ so as to more effectively influence ‘what might be’ (Crotty 1996, p. 7). However, ‘an emancipatory intent is no guarantee of an emancipatory outcome’ (Acker, Barry & Esseveld 1983, p. 431). Here lies one of the most challenging aspects of this project: to optimise the possibility of an emancipatory outcome for women.

Since the 1970s, innumerable feminist writings have argued that traditional positivist science is value-laden, acontextual, patriarchal and androcentric (Lichtenstein 1987; Seller 1988; Broom 1989; Rose 1990 as examples). Science, based on objectivity and the fundamental separation between the researcher and the researched, is the mode of knowing most prized in our culture. Broom (1989) concluded that such inquiry excludes the ‘feminine’ and so is not able to be effectively used by women seeking to understand their own lives and experiences. Not only are traditional ‘rational-scientific’ methodologies elitist, they also serve to oppress women both in their process and findings. Many women feel foolish because they can neither express themselves in elitist terms nor understand the methodological applications (Seller 1988).

Feminist philosophy and theory, in contrast to the positivist paradigm, always begins with women, places women and their experiences at the centre, names the oppression of women, involves a holistic view of the world and probes all facets of women’s lives (Rowland & Klein 1996; Roberts & Taylor 1988). Feminism, in the context of this
study, articulates well with Women’s Health Frameworks such as those adopted by the
Centres of Excellence in the Canadian Women’s Health Program. The Canadian
Framework argues that women’s health involves their emotional, social, cultural,
spiritual and physical well being and is determined not only by biology but also the
social, political and economic context of women’s lives. The Canadian Framework also
recognises the validity of women’s life experiences and women’s own beliefs about
their experiences of health (Women’s Health Bureau 1995).

Feminist theory influencing this research asserts that women have been particularly
disempowered through theological and medical discourses, which systematically
devalue the female body (Cheek et al. 1996). Devalued by the theological and medical
structures, which are revered by many women as being the epitome of wisdom and
knowledge, leads to a complex sense of embodied inferiority. Women internalise the
theological and medical paradigms that lead to feelings of poor self-image, shame,
embarrassment and lack of confidence. Mistrusting their own body, and by implication
their personhood, makes it extremely difficult for women to throw off imposed
judgments and take on a stronger and more accurate image that enables them to take
greater power over their lives (Laws 1990).

Women undermine the value of their own understanding because ‘scientific knowledge’
is perceived as all-powerful and all-knowing. This is exemplified in ‘the global struggle
for control of pregnant and birthing women’ (Wagner 1994, p. 5). Stephenson and
Wagner (1993) described the role of physicians as agents of social control. They argued
that this is why discussions on home birth continue to be so heated. In the hospital the
doctor is in control. In the home, the woman and those she chooses to be with her are in
control. In order for a patriarchal society to control women, it must control their bodies,
their reproduction and their birthing and health professionals are agents of this control
(Rowland 1992). Hospital births remain firmly entrenched as the perceived safest place
to give birth, even though there is no compelling scientific evidence to confirm that
hospital birth is safer than planned home birth (Wagner 1994; Zander & Chamberlain
1999). Indeed, as Seller (1988) argues, one of the reasons for the feminist distrust of
science is that issues presented as scientific, often turn out to be political!

Women’s experiences cannot be separated from the contexts in which they occur and a
feminist perspective recognises women’s experiences as inextricably connected to the
larger political, social and economic environment (Hall & Stevens 1991). This research study makes every attempt to place women’s lives and experiences in their broader historical, relational and sociopolitical context, and in so doing takes a critical stance.

Feminist theorists, such as Rose (1990), allude to the replacement of the concepts of power ‘over’ with power ‘to’ and power ‘with’. Women demonstrate tremendous power when they foster the growth of others (Rose 1990). Critical hermeneutic phenomenology research is not ‘external, top-down or expert’, it fosters a ‘power with’ ideology and is done by rather than for the people (Van Manen 1997, p. 156).

The study remains open and vigilant to any information which indicates women’s oppression (Hall & Stevens 1991) and, where validated by the participants, seeks to create positive change. Power differentials are sometimes overt and sometimes covert in the Australian health system. Medical and nursing professionals do not advise women to obey them blindly, but expect them to comply with their ‘orders’ or at least their recommendations, because expert knowledge is valued over a person’s own knowing and because of the high esteem given to educational qualifications and professional experience.

The feminist concepts of embodiment and empowerment (Roberts & Taylor 1998) are integral components of the methodology chosen to guide this study. The feminist notion of embodiment perceives knowledge as the product of our body’s perception of the world (Roberts & Taylor 1998). This study articulates with the principles proposed by Roberts and Taylor (1998) that in feminist thought, embodiment takes on a four-fold purpose. Firstly, it is related to living in a particular female body. The thirteen participants experienced the phenomena of having an abnormal Pap test result because they live in a female body. Secondly, it refers to living a life that values the individual and collective good of women, the motivational force behind the study. The third purpose of embodiment means the person is open to others, and is prepared to listen and collaborate for the collective good of women, the process that underpinned the interviewing, transcription, interpretation, analysis and reporting in this research. The final concept of embodiment means being attentive to those conditions in the world that dominate and oppress women, the reason why this hermeneutic phenomenological study, by necessity, had to take a critical stance. This study adopted the Roberts and Taylor (1988) concept of embodiment because it values women and their issues,
concerns, perceptions and experiences and strives to create change. The ‘lived experience’ of the thirteen participants in this study is explored within the feminist, conceptual framework of embodiment.

Feminism upholds a critical approach to research and, while accepting phenomenology as a legitimate methodology, has been highly critical of Habermas. Some feminists argue that, unlike Gadamer, Habermas paid insufficient attention to the role of interpretation in feminist struggles (Meehan 2000; Warnke 2000). His critical theory is considered androcentric and, unlike Merleau-Ponty, Habermas ignored the role played against the woman’s body in her oppression (Alway 1999; Warnke 2000). In his defence, Johnson (2001) believes that feminism and Habermasian critical theory are not irreconcilable as they both endeavour to uncover hidden oppressions.

Critical theory

The critical thoughts that informed the process of this project include that all research is a political activity shaped by socio-economic relationships that determine its development and dissemination and that knowledge and power are reciprocally produced (Stevens 1989; Calhoun 1995; Davis 1995 cited in Boutain 1999).

This project acknowledges Olesen’s (1994) argument that merely taking experience into account does not reflect on how that experience came to be. Allen (1985) argued that if experience is taken only at face value then oppressive systems and practice are likely to be replicated rather than challenged. To expose foundations which form the basis for the propagation of power and which, in this instance, adversely affect women’s lives demands a process that peels away the layers built on that foundation, so that it can be uncovered, named and not allowed to become the formwork for further oppression. One of the oppressive systems to be challenged in this study is the acceptance of medical dominance, the reason behind the literature imbalance where so much has been published about the biomedical aspects of cervical screening and so little about women’s experience.

Critical theory used to challenge dominant medical discourse

Medical science and medical dominance are situated within an historical context that must be considered. Modern medicine is founded in the Ancient Greek model (Grimshaw 1986). The Ancient Greek doctor had far-reaching influence over both
men’s and women’s lives. In Aristotle’s *Symposium*, the doctor Eryximachus claimed the prerogative to advise on the pleasures of both sexual expression and eating (Foucault 1985). Eryximachus declared it was doctors who ought to say how to enjoy rich food without becoming sick; it also rested with the doctor to advise how one could orgasm without any resulting ill effects! According to Foucault (1985), the Ancient Greeks never believed that sexual pleasure was evil but the texts describe an anxiety concerning the activity itself. Doctors worried over the relationship between sexual activity and health, and they developed an entire theory concerning the dangers of sexual practice. Medical practitioners theorised that man’s mastery, strength and life were at stake during sexual activity. Relationships between men and women during coitus are seen in terms of confrontation and contest, domination and regulation with the man always needing to have the final victory (Foucault 1985).

Modern medicine has done little to challenge its right to medicalise everyday activity like eating and sexual expression, nor the Ancient Greek intellectual and Judeo-Christian-Islamic doctrinal belief in the superiority of man and the ‘uncleanliness of women’ (Delaney, Lupton & Toth 1988, p. 41). Modern medicine was born in the late eighteenth century but has never revoked the need to pathologise female physiology and distrust women’s empirical ways of knowing about their body (Foucault 1976; Webb 1986; Dietsch 1995).

Health care given by and for women is ancient history as well as contemporary practice. In contrast to medicine, women’s knowledge about health was originally passed down orally through generations. It was ‘empirical’ as it was based on observation and testing. Webb (1986) argued that so-called ‘old wives tales’ were based on experiential wisdom. To survive oral transmission, these ‘tales’ must have had some foundation or they would have devolved once they were recognised as incorrect and/or harmful. Women’s health care for themselves and their families was complex. Surviving housekeeping manuals from the nineteenth century reveal an extensive knowledge of herbal and other remedies to treat and prevent illness (Mitchell & Oakley 1976).

Once the church consented to the dead body being dissected, anatomy was easily observed and physiology surmised. The Ancient Greek Galenian concept that women are abnormal and inferior because they are ‘inside out’ to men whose genitalia are external was considered confirmed by autopsy (Webb 1986). From the feminist
perspective, there have been repeated and systematic attempts by the church, state and medical profession to control female health caregivers and recipients (Hyde 1994 cited in Holt 1998; Rowland 1992). This is achieved through both legal regulation and the a priori promotion of medical science as superior to all other forms of knowing (Nicolson 1992; Vadeboncoeur 2000).

Dr Mary Putnam Jacobi, a pioneer in women’s medical education (Lovell 1984), declared in 1895 that skyrocketing ill health among women was due to the increased attention paid to them by physicians who saw women’s new function as ‘lucrative patients’ (Corea 1977). Corea cited Jacobi’s belief that male physicians asserted that all female functions (menstruation, pregnancy, childbirth and menopause) were inherently pathological and therefore needed medical treatment. The language of gynaecologists when discussing female anatomy continues to be strongly oriented towards disease and disorder (Laws 1990). Gynaecology, rooted in empirical-analytic science, attempts to define female physiology as pathological and, by implication, subject to medical control (Laws 1990; Dietsch 1995). The social construction of menstruation, menopause and pregnancy as illnesses focuses control not on women experiencing these life events but rather on medical and health professionals with technical knowledge (Allen 1985).

In the early 20th century, medical textbooks argued that only a minority of women were free from disability during menstruation (Golub 1992). As late as the 1975 edition of Sir Norman Jeffcoate’s textbook, *Principles of Gynaecology*, menstruation was described as ‘the weeping of a disappointed uterus’ (Laws 1990, p. 93). Koutroulis (1990) attended a content analysis of obstetric and gynaecological textbooks recommended for medical students at four Australian universities and found a sexist ideology, that deprecated women, was pervasive. Her research revealed that ‘almost every physiological function of a woman’s body has been treated as inherently defective’ (p. 82).

It was once the role of religion to ensure that women, their bodies and their sexuality were subjected to male norms and referencing and pathologised as being unclean and inferior (Daly 1978). However, Foucault (1976) and Illich (1976a) both argued that health had replaced salvation in modern thinking and, by implication, the doctor has become at least the high priest if not the saviour in this new religion. Lovell (1980 cited in Lovell 1984) and Corea (1977) described the medical profession as a powerful
structure equal in its effectiveness to any previous religious dogma and designed to control women and keep them in a subordinate role.

The medicalisation of female bodies, physiology and life phases such as menstruation, pregnancy, birth and menopause is advantageous to the medical profession struggling to subvert women, in order to establish their dominance (Foucault 1976). Taylor (1991) cited Darbyshire (1985) when she argued that the wise woman-healer posed a threat to the male medical profession’s urge to exclusively control healing and their jealous guarding of health and illness knowledge. Historically, the medical men (barbers) had little social power as surgeons, as demonstrated by the lack of rigour required to become surgeons (Foucault 1976). Barber surgeons persisted as the underdogs in the medical establishment until nursing/midwifery were under their control.

With power over women healers complete, medicine was able to exert greater social control and became a prominent influence in the whole of Western society (Gerhardt 1987). Medical ideology is presented as objective, scientific proof, effectively making women feel they have no basis on which to doubt its information (Laws 1990). For women, ‘the body is their first reality, the physicality in which the self resides’ (Rowland 1988, p. 20). As long as female physiology continues to be medicalised and pathologised, women’s lives will be defined and dismissed through their bodies (Rowland 1988, 1992; Ussher 1989; Broom 1995). These negative constructions have harmful effects on women’s self-image, identity, self-evaluation and behaviour (Koff & Rierdan 1996).

Medical science grows stronger as a privileged discourse in the contemporary West (Broom 1989). The Foucauldian notion of discourse refers to:

> Ways of constituting knowledge, together with social practices, forms of subjectivity and power relations … Discourses are more than ways of thinking and producing meaning. They constitute the nature of the body, unconscious and conscious mind and emotional life of the subjects they wish to govern (Weedon 1987, p. 108).

Western medical discourse is fundamentally linked to power. Medical discourse is considered ideological, functional and pastoral in that it purports to beneficence and serving the needs of others and, though not sited with any individual or conscious malintent, the product of medical discourse is nevertheless subjugating and disempowering of those it allegedly serves (Foucault 1976; Weedon 1987; McHoul &
Western medical practitioners are a professional body with their own values, theories of disease, worldview, rules of behaviour and hierarchical specialised roles (Helman 1994). Helman (1994) argued that medical students, already chosen from the academic elite of secondary education, are enculturated into acquiring a perspective on ill health that lasts throughout their professional lives. Medical practitioners acquire high social status, high earning power and the socially legitimated role of definer of health.

Western medical culture is expert centred and maintains women’s dependence and compliance by means of labelling and treating, which distances the woman from the expert (Menage 1997). Where a phenomenon cannot be objectively observed or measured, for example, a woman’s belief about what caused her abnormal Pap test result, it is perceived as less real than the degree of CIN diagnosed by punch biopsy.

Kleinman (1980 cited in Helman 1994) noted that the clinical consultation is a transaction between lay and professional, between two parties separated by differences in social and symbolic power. This power differential is based on social class, ethnicity, age or gender and has a crucial influence on any consultation (Helman 1994), especially the gynaecological consultation. Medical culture maintains mystique, in part, by using jargon and withholding information (Todd 1989).

Kavanagh and Broom (1997) allege that women’s interaction with health care services contributes to the psychosocial difficulties they experience when they have a cervical screening detected abnormality. Problems in doctor-client communication, time pressures and differences in worldviews compound those problems. Women generally possess less economic and personal power which is reflected in the Australian health care system where, although women are the majority of health care users and health care providers, decision-making power remains largely in the hands of men (Victorian Ministerial Women’s Health Working Party 1987). The medical practitioner’s authority is maintained by the esoteric nature of their knowledge and protected by medicines’ claim to altruism and scientific superiority, which serves to systematically maintain a power imbalance between doctors and women that constrains change (Wright & Morgan 1990; Kavanagh & Broom 1997; Silverman 1987).
The framework used for this study seeks to challenge the conceptual medical model which is directed towards discovering and quantifying physicochemical information about the ‘patient’, rather than the less measurable social and emotional factors (Helman 1994). As Rose (1990) argued, current medical practice/research and the use of acontextual theoretical frameworks and methodologies continue to reduce understanding of women and women’s understanding. Lovell (1984) concurred and concluded that the medical environment/research process silences women and, without a historical past to give meaning to the contextual present, the needs of women remain invisible. Orr (1986) took this invisibility and inaudibility of women a step further when she argued that scientific investigations did not listen to women nor consider their experiences legitimate. She believed that women using a language normalised by men often had no words to ‘name’ what was being experienced or felt.

Doyal (1998) argues that sexism is inherent in health care, and is so deeply embedded in professional and class cultures it will not be ameliorated by criticising doctors or simply replacing male workers with female workers. Nurses can also be misogynists and although this may be due, in part, to their oppression as a group (Freire 1972), it needs to be revealed so that strategies can be developed to reduce it. Mernissi (1975, p. 24) told one woman’s story at a Moroccan Family Planning Clinic, it is an extreme example but worth reflecting on:

The nurse asks you brisk, precise questions that you are supposed to answer like a book. If you take time to think she shouts at you … When we are waiting to get into a gynaecological service they will shout at us, ‘Take your pants off in the hall and sit there waiting’. There are drafts of cold air, people walking by, you feel inhuman.

Such misogynous practices are not confined to third world countries, or to times past. The story given by the Moroccan woman was mirrored in another shared by a client in the course of my clinical practice. It is used with permission and at the request of the woman who shared this experience. The year was 1999 and the place, a colposcopy clinic in rural New South Wales. The client was instructed by the nurse to take off her trousers and underpants and was given a very small towel to cover herself as she walked from the change area, across the large room to the examination table. The woman was mortified to realise that the towel would cover either her pubic area or her buttocks, not both, but she was too afraid to ask the nurse, ‘who seemed so busy and important’ for a larger cover. This woman needed to walk across the room in front of the nurse, a medical student, a gynaecologist and another unknown person with her buttocks on
view. She felt humiliated, degraded, powerless and exposed. If the men or the nurse, the only other female in the room, were aware of this woman’s acute discomfort it was not acknowledged; if they were unaware then the woman was rendered invisible by their actions. Either way, by not responding sensitively to this woman’s unnecessary exposure she was made to feel depersonalised and excluded as an individual from the other humans in the room; all of whom were covered, unexposed and in control of the situation that so humiliated this woman. Van den Berg (1955, p. 55) described this phenomenon of depersonalisation:

When excluded we see ourselves and our bodies as undesirable, unwanted and cannot inhabit our bodies easily and freely as we would when we feel accepted and confirmed by others. There grows a split between mind and body, we become embarrassed, ashamed, self-conscious.

Nursing is predominantly complicit with the ideals propagated by medicine, both in the way the profession operates and in the nursing care given to female clients. Webb (1986) reported in her study of patients receiving gynaecological care that nursing support is often inadequate. The nurses tend not to identify with the women, and misogynous ideas that define women as emotional and manipulative replace empathic and supportive interactions. Nurses provide inadequate information to women about their operation, treatment and likely progress. The Webb (1986) study implied that lack of confidence in their own nursing knowledge, especially when it conflicted with a medical opinion, fear of overstepping professional boundaries and being perceived negatively by a medical practitioner take precedence over the need to provide women with informational support. When favouring the requirements of the medical system over the needs of women, nurses maintain their own place close to the bottom rung of the hierarchical health professional ladder. However, when nurses question misogynous attitudes and provide quality care, support and information to women, they enhance women’s control over their lives and their health and challenge the dominant medicalisation of women’s health.

Janeway (1980) argued that the domination of one group of humans over another, in this case a predominantly male medical system over a predominantly female nursing system, is maintained through the ‘powerless’ believing in the justice of the ‘powerful’s’ position. In Powers of the Weak, Janeway (1980) listed the power of disbelief as a form of resistance. She argued that if the predominantly female nursing profession refused to endorse the medical profession as the dominant model then the
sanction of their authority would be questioned and the health system would be destabilised.

The hegemonic hierarchical ordering of ownership of legitimate and superior knowledge not only supports the domination of medicine but also serves to deskill other health professionals including midwives and nurses (Street 1989). Power, domination and oppression, however, are not static phenomena, but processes dependent on human agency for their perpetuation (Foucault 1980; Street 1989). The social oppression the participants allude to in this study need not be fixed (Foucault 1980; Street 1989). The historical and social conditions that contribute to their production and maintenance, once recognised and named can be overcome (Lorde 1984; Stevens 1989; Davis 1995 cited in Boutain 1999).

Throughout history, the professional development of nursing and the status of women have been interdependent and parallel (Glass & Brand 1975). Intent listening to the spoken word and attention paid to the written word of women in this study, have highlighted the innate power imbalance between health professionals and women as health care recipients. In an endeavour to address this imbalance, feminism and critical hermeneutic phenomenology have been melded in a nursing study that seeks to bring about positive change for women.

**Phenomenology and nursing**

The concept of phenomenology was introduced to nursing by academics who include Paterson and Zderad (1976), Oiler (1982), Omery (1983) and Parse, Coyne and Smith (1985) and, more recently in Australia and New Zealand, the nurse academics Madjar (1991), Taylor (1991) and Koch (1994). Phenomenology was introduced with the aim of providing a new humanistic approach to the discipline of nursing (Ray 1985). While not attempting to replace other methods of nursing inquiry, the phenomenological approach is seen by these nurses as an alternative methodology that is most compatible with the nursing goal of understanding human experience (Oiler 1982).

Leonard (1994) described how the role of hermeneutic phenomenology is to uncover meanings that arise out of the informants’ lived experiences and to create new possibilities for understanding. Critical hermeneutic phenomenology, that seeks to uncover oppression where it is experienced and bring about change, continues to play a
small but significant role in advancing nursing research, understanding and practice (Thompson 1990).

The profession of nursing emphasises a respect for the person’s experience, focuses on the practical concerns of people and embraces a holistic approach to nursing care and research (Taylor 1994). The individual person is valued and nurses advocate for the individual as author of their own world and a definer of their own reality (Munhall 1981; Oiler 1982; Taylor 1994). The holistic approach to nursing research involves data collection methods that value and preserve the informants’ ‘lived experiences’, aiming to understand those experiences from the informants’ perspective (Omery 1983; Taylor 1994).

Owen (1995) conducted a phenomenological study to explore registered nurses ‘lived experience’ of holism as they conceptualised and practised it. He concluded that, to practise holistically, the nurse requires thoughtful, knowledgeable and directed action, which he defined as ‘praxis’. Praxis needs to be supported by a connectedness with the ‘patient’ and nurtured by experience.

The methodology used in this project values the concept of holism described by Owen (1995) and Lazarus and Launier (1978), that is, holism which esteems the individual and places them at the centre of the research. There are, however, potential dangers as well as benefits of a study that focuses on the individual. Owen (1995) argued that it is possible to concentrate so much on the individual that the larger social, political and cultural contexts that affect health are ignored. Social factors that contribute to ill health can be rendered invisible leading to the practice of blaming the ‘victim’ for their health problems (Owen 1995). From the Heideggerian perspective, although a woman’s ‘self’ also constitutes her world, she is constrained by her language, culture and history, by her constitutive purposes and values. Leonard (1994) argued that the world sets up parameters for who a person can become and not become. Known as ‘situated freedom’, the concept indicates that any trend toward ‘victim blaming’ is misdirected (Benner & Wrubel 1989). This study makes every effort to place the participant in their social, political and cultural context, that is, the context participants chose to share during their preliminary interview.
The concept of subjective experience is central to nursing’s humanistic and interactive practice (Orlando 1972; Paterson & Zderad 1976; Travelbee 1971). By implication, nursing practice and this study adopt Seller’s (1988) argument in her postmodern definition of relativism that every woman’s experience is valid, not false, illusory or mistaken.

Nursing focuses on interpersonal relationships and values empathy as it seeks to understand concepts of crisis, motivation, stress and perception (Oiler 1982). An alternative to the positivist paradigm is therefore required if nursing research is to be congruent with nursing practice and critical hermeneutic phenomenology provides such an alternative.

Leonard (1994) argued that nursing has a long history of being adversely influenced by Cartesianism. For too long, nurses have been preoccupied with the notion of humans being an assemblage of traits such as anxiety, control and self-esteem. Leonard (1994) argued that ‘self’ is wrongly viewed as subject, an uninvolved self passively contemplating the world of things via representations that are held in the mind. This self ‘possesses’ a body and, by extension, traits and attributes such as anxiety or self-esteem.

Some caution needs to be exercised when discussing the detrimental influence of Descartes on nursing practice. Bernstein (1988) argued that, when speaking of the Cartesian legacy, it is important to distinguish between the historical writings of Descartes and Cartesianism. There is much disparity between what Descartes’ texts actually say and the interpretation of his works by later scholars. Lawler (1991), a nurse academic, agreed with Bernstein (1988) and argued that the concept of body and mind dualism had been falsely attributed to Descartes. She quoted from the Sixth Meditation of Descartes (1986, p. 159 cited in Lawler 1991, p. 55) where he makes the personal acknowledgment of mind and body interdependency:

Nature … teaches me by … feelings of pain, hunger, thirst, etc. that I am not only lodged in my body like a pilot in his ship, but, besides, that I am joined to it very closely and indeed so compounded and intermingled with my body, that I form, as it were, a single whole with it.

Descartes, Lawler (1991) argued, was attempting to restore some balance to philosophical debate that had traditionally been concerned with the mind, and social scientists had largely ignored the body.
The rejection of Cartesian dualism as it is traditionally understood and the interweaving of body and personhood in embodiment are concepts particularly conducive to nursing philosophy and practice. Lawler (1991) defined personhood as an essentially human condition and a state in which the self is constructed and interacts with others. Personhood is integrated and continuous with human physical form. Lawler (1991) argued that personhood is an experienced, given and acknowledged phenomenon that is to be understood in the context of biosocial interaction among humans and it requires both a physical and a social life.

During everyday ‘lived experience’, embodiment is taken for granted, overlooked by persons and only appears to consciousness when there is a breakdown (Leonard 1994). That is, the Heideggerian concept of ‘ready-to-hand’ understanding:

World, comes not afterward but beforehand … The world as already unveiled in advance is such that we do not in fact specifically occupy ourselves with it, or apprehend it, but instead it is so self-evident, so much a matter of course, that we are completely oblivious to it (Heidegger 1975, p. 165).

However, when illness occurs, this ready-to-hand understanding is no longer subconscious. It is when a person is in a state of ‘breakdown’ that they develop insight into the taken-for-granted understanding of health – the unity of self and healthy body (Leonard 1994). This position allows the nurse a new position from which to understand their experience. Baron (1985) stated that, rather than viewing the problem as one of breakdown in an objective machine, one should approach illness as a rupture in the person’s ability to negotiate the world. It is a person’s embodiment that is the problem, not their objective body machine.

Benner (1985) argued that phenomenology offers a way of studying the phenomena that overcome the dichotomy of extreme subjectivity and extreme objectivity and Koch (1998) listed a number of reported potential benefits of phenomenological nursing research, including the potential to:

- evaluate community development (Rappaport 1993; Traynor 1993; Dixon 1995)
• enhance effective therapy (Sedney, Baker & Gross 1994; Heiney 1995; McDaniel, Hepworth & Doherty 1995)

• inform social policy (Van der Staay 1994)

• facilitate change in organisations (Gabriel 1995)

• allow marginalised groups to have a voice (Mellina & Mellina 1992; Bartlett & Font 1994; Dean 1995; Biddle 1996; Turton 1997)

• address diversity through understanding (Harvey 1994; Debeljak 1994; Kelly 1996; Greene, Jensen & Jones 1996)

• facilitate self-help groups (Steffen 1995; Appel 1996).

Koch (1998) paints a very positive picture of an evolving nursing phenomenology that is not universally accepted. Crotty (1996) implied that phenomenological nursing research was not in the process of being clarified and refined but rather adulterated. He asserted that nurse researchers misrepresent phenomenological methodology to the extent that it is no longer recognisable as mainstream phenomenology. He esteemed Husserlian phenomenology above the emerging developments led by Heidegger and Gadamer. Husserl’s work was portrayed as the only pure phenomenological form and Crotty (1996) questioned the validity of nursing research based on any other form of phenomenology.

Phenomenological nurse researchers and Crotty (1996) parted understanding when he valued the phenomena being studied above the participant’s perception of the phenomena. Crotty (1996) argued that nurse phenomenologists were clearly researching humans and ‘topics’ or ‘issues’; whereas mainstream phenomenologists were engaged with a phenomenon rather than a person and any involvement with people was for the sake of illuminating the phenomenon, not the other way around. This study makes no apologies for being aligned with nursing phenomenology. Nursing phenomenology is a person-centred approach to acquiring new knowledge and deeper understanding and this is valued as a positive rather than a negative attribute as Crotty (1996) would deem.

Argument between emerging strands of phenomenologists is not new and predates the current criticisms directed at phenomenological nurse researchers. Crotty (1996), in criticising the evolution of nurse phenomenology, missed the significance of Husserl’s
thought: ‘Every dependent thinker would really have to change his name every decade, since he then has become another’ (Letter to Georg Misch cited in Spiegelberg 1982, p. 84). Pivcevic (1975) defended the notion that there are different views as to what course a phenomenological researcher should pursue and what the principal objectives of such research should be. Phenomenology, he argued, does not designate a well-defined body of doctrine but could be used in a variety of philosophical contexts. Nursing phenomenology would seem destined for further evolution, development, innovation, change and debate!

From philosophy, theory and methodology to method

What unites … the ‘phenomenological school’ initiated by Brentano and Husserl – is their acceptance of the general principle that philosophical priority should be given to an analysis of experiences from the point of view of those who have the experiences or are able to have them.

Pivcevic 1975, p. xii

This chapter has provided a very brief overview of phenomenological philosophy and methodology as well as the feminist and critical ideologies that informed the study. It has been argued that there is no one phenomenological methodology but rather a multifaceted, ever-evolving series of approaches which have at their core a valuing and willingness to learn from the experiences and the perspective of the person living that experience. It is the valuing of humanity and, in this context, the valuing of women’s lives and experiences that drive this study.

Listening to, dialoguing and valuing women’s stories is the lynchpin that articulates the methodology to the method in this research project. Gadamer (1975a, p. 347), describes dialogue as:

A process of two people understanding each other. Thus it is characteristic of every true conversation that each opens himself to the other person, truly accepts his point of view as worthy of consideration and gets inside the other to such an extent that he understands not a particular individual, but what he says. The thing that has to be grasped is the objective rightness or otherwise of his opinion, so that they can agree with each other on the subject.

In describing dialogue, Gadamer stressed the need for mutuality, respect, genuineness in listening, willingness to understand what another is saying, and the importance of openness, risking and testing our own opinions through the dialogue (Bernstein 1988, p. 162). The primary voices in this study’s dialogue will always be the thirteen
participants, but they will, on occasions, be joined by a number of critical and/or feminist theorists as diverse as Julia Kristeva, Robyn Rowland, Michel Foucault, Ivan Illich, Ann Oakley and Jurgen Habermas. The six principal theorists used as conversationalists with the participants’ narratives are diverse but each are agreed, to a greater or lesser extent, in their desire to understand human experience as a means to promote social change (DePoy, Hartman & Haslett 1999).

The voices of the named theorists are dialogued with the voices of the women in a manner that provides reciprocal recognition and mutual validity to both theorist and participant. It is for this reason, and to do justice to the depth and breadth of experience shared by the participants, that works from a number of theorists are utilised. The methods used to generate meaningful dialogue that could be used to answer the research question, ‘what is the “lived experience” of women with a cervical screening detected abnormality?’ will be discussed in the chapter to follow.
Chapter 3
Method

The notion of legitimacy is informed by Gadamer’s philosophical hermeneutics which does not show us what to do, but asks us to question what is ‘going on’ while researching.

Koch 1998, p. 1

... it is a question not simply of defining a specific method, but rather, of recognising an entirely different notion of knowledge and truth.

Gadamer 1979, p. 13

In this study, the participants converse with the selected theorists to question the hidden power imbalances built into the societal structures and dominant medical discourse that encompass the woman when she has an abnormal Pap test result. Gartrell (1987) argued that, traditionally, research interests have focused on the development of the medical profession, institutions and scientific breakthroughs rather than on the experiences of ordinary people. She concluded that when women are mentioned at all, the view is often disparaging. This study aims to reverse this tradition.

During the literature review that preceded the data collection phase of this project, it was noted that Schover, Fife and Gershenon (1989) reported how women who develop early stage cervical cancer are more likely to have lived ‘troubled lives’. In their sample, almost half the women were victims of intimate partner violence, almost half had partners who abused drugs or alcohol and over a quarter of women reported sexual trauma (rape, incest, molestation as a child, molestation of own children or multiple events). Stress, particularly chronic, relapsing and major stress, is shown to correlate with the onset of cancer, and by implication CIN (Kotsirilos 1998). Anecdotally, my clinical practice as a women’s health nurse consultant confirmed the Schover, Fife and Gershenon (1989) and Kotsirilos (1998) findings. This confirmation became a major impetus for commencing this project; it also became an ethical, academic and philosophical dilemma. In keeping with Gadamerian hermeneutic tradition, and in the interests of research transparency, the trail taken to resolve these ethical, academic and philosophical challenges and the steps taken to move the project forward are documented in this chapter.
The ethical dilemma

Physical, emotional, social and sexual violence against women and their children are known to be common in our society (Leventhal 1990; Mazza, Dennerstein & Ryan 1996; Plichta & Abraham 1996; Weir 2000; Taubman-Ben-Ari et al. 2001), so the Schover, Fife and Gershenon (1989) findings could possibly be due to chance. If the ‘troubled life’ became the issue of the research question and focus of the study, a method of research investigation would have needed to be selected to refute or confirm the hypothesis of a causal relationship between living a ‘troubled life’ and an abnormal Pap test result. The NSW Pap Test Register was considered a source of ‘subjects’ and a triangulated quantitative and qualitative methodology such as that described by Jick (1979) could have been used to explore this hypothesis. Women with a screening detected abnormality could have been approached to complete a survey listing any relevant aspects of their life history, including those documented by Schover, Fife and Gershenon (1989). A sample of consenting women could then have completed an open-ended type questionnaire to gain more in-depth qualitative data. ‘Controls’ could have been the next woman of same age on the register who had always had normal Pap test results. This idea was, of course, quickly dismissed. Even if ethical approval were granted, I dared not question women about such traumatic events without offering to listen and support them during the process.

The next method considered to examine the phenomenon was an action research project using women’s health nurses as coresearchers and utilising a social critical theoretical framework, such as the paradigm promoted by Fay (1987). An action research project underpinned by critical social theory had the potential to bring about maximum improvement in clinical practice (Carr & Kemmis 1983; Hart & Bond 1995). However, the focus would have been on the clinical environment and the roles played by the clinicians rather than on the women and their experience of having an abnormal Pap test result. For this reason it was not adopted as the method of choice.

A grounded theory approach (Strauss & Corbin 1990) was next considered. This approach uses a systematic set of procedures to arrive at theory about basic social processes at a higher level of abstraction (Wilson & Hutchinson 1991). Founded in symbolic interactionism and the social sciences (LoBiondo-Wood & Haber 1998), it seemed an ideal method to explore women’s experience of having an abnormal Pap test result because it could focus on how women view their circumstances, how they interact
and how these processes change (Wilson & Hutchinson 1991). During in-depth interviews women could be asked to share their experience of having both the abnormal Pap test result and any life trauma. Women could be supported during their storytelling. However, in the contexts of this particular study, I questioned if the women were being ‘used’ to develop a theory in relation to ‘troubled life’ events and cervical abnormalities. It was not in keeping with feminist philosophy to ask women to disclose specific traumatic events in a ‘captured’ environment. Women may not choose to share such information but, in their desire to please or cooperate, may feel that they had no option. It was a concern that women may have been disempowered by the process and the research project may have turned voyeuristic rather than investigative. Theory would be generated but at a potential cost to the women participating in the study. Grounded theory was not to be the chosen method for this project as too many ethical concerns remained unanswered and it may not have led to the greatest possible depth of understanding of the woman’s experience.

Women had stories and they deserved to be heard and their stories retold. Women had a right to be understood. Finally, phenomenology was decided as the method of choice to address these issues. The data produced from memory would not be collected with the intention of generalising to a larger population but rather to add to an understanding of women’s experience of having an abnormal Pap test result. Women could be invited to share their stories of having an abnormal Pap test result and any other aspect of their lives they considered relevant. The participants may or may not elect to reveal information about a ‘troubled life’ story – it would be their choice. If the women, as part of their stories, shared a history of life trauma, it would, of course, become part of the data. If the women did not disclose such information it could mean one of three things. They may have no history of trauma, or they may choose not to share that aspect of their lives, or it could mean that they consider such a history inconsequential to either their stories or the research. Whatever the scenario, in the context of what was now to be a phenomenological study, it is not an issue and would remain unknown.

**The academic dilemma**

A phenomenological inquiry could never provide the answer to the question of whether a troubled life history was correlated with a woman developing CIN. It is accepted that answers to questions specifically seeking a cause and effect between life experience and CIN will remain unknown until perhaps another research project at a future time.
The philosophical dilemma

Philosophically, phenomenology became the method of choice. However, phenomenology is like the rim of a wheel, containing many spokes, all of which lead to the hub of enhanced understanding. It was not known at the beginning of the research process which spokes would prove strongest and be the most likely to lead to the greatest level of understanding and enhanced services for women. This question underpinned my reading as I set out on the journey to select a specific phenomenological approach for the study. This part of the journey ended when it was decided that the aims of this study would be best met by adopting a phenomenological approach based on critical hermeneutic phenomenology informed by Gadamer. My desire to use a method that could be followed in a step-like fashion to ensure that the validity of this research project was as widely accepted as possible, needed to be discarded. While Giorgio (1970, 1985) and Colaizzi (1978) documented similar step-like processes that could be adopted, when it came to putting either the Colaizzi or Giorgio methods into practice, they were both grounded in Husserlian phenomenological principles and unsuitable for use in this study.

The phenomenological process

*Phenomenological research is the description of the experiential meanings we live as we live them.*

Van Manen 1997, p. 11

As this study is based on Gadamerian principles it is a misnomer to describe the investigative processes as ‘method’. Gadamer (1975b) and Van Manen (1990) concur that there is no method per se. Gadamer specifically argued that his work did not describe a system of rules and could not be used to direct methodical procedure in human science investigations (Weinsheimer 1991). Consequently, method in the context of this study is a description of the investigative process adopted rather than a method or set of rules that was followed to give validation to the findings.

Ethical considerations

*The ethical stance of the interpretive researcher is one of respect for the voice and experience described in the text.*

Benner 1994, p. 101

considered essential components of this research project which builds on a phenomenological, women-centred framework and has the goal of making visible, the hidden (Habermas 1971a; Benner & Wrubel 1989). Phenomenological engagement is always personal engagement and the fundamental focus of the study is the valuing and validation of women’s subjective experience. The need to eliminate or at least minimise any power differential between researcher and participant is omnipresent. Reciprocal relationships with participants are valued and develop in an endeavour to see the world through the informants’ eyes rather than construct how their world is observed from an objective perspective (Scott 1988; Marshall 1988; Warren 1988 cited in Hall & Stevens 1991). In keeping with the principles described by Oakley (1993), participants in the study were encouraged to share, debrief and ask questions before, during and after the formal interview. The participants were offered ongoing counselling from either myself or the women’s health nurse who introduced them to the study, but this formal counselling was never required. Every effort was made to minimise or eliminate power differentials between myself and all participants, but it was not possible to create a research process that completely erased all contradictions in power (Acker, Barry & Esseveld 1991). However, conscious avoidance of coercion, manipulation, control and domination was of paramount importance at every step of the research pathway.

Potential harmful effects to the short- and long-term physical, psychological, sexual and social well being of informants from participating in this study were considered very unlikely but possible. There was also the counter-possibility that having the opportunity to share their stories might be therapeutic for some informants. Their stories are legitimated and valued as they are used to inform clinical practice. Younger (1995) described three potential benefits for participants as they share their stories for research purposes. First, it encourages the woman’s emotionally and/or physically painful experience to be reconstructed by her in order to gain some distance from it, to put it in the past and gain mastery over it. Secondly, it gives the interviewer an opportunity to affirm the participant as they create new meanings from their reconstructed stories. Finally, it can lead to liberation of the participant as they free themselves from at least some of the negative impact of their experience, allowing their suffering and themselves to be transformed by it, rather than melded to it. In retrospect, all the women in this project commented on the benefits to them from having had the opportunity to share their experience at interview and knowing that their participation in the research might be of value to other women who have an abnormal Pap test result. Other
phenomenological researchers have noted a similar response from participants (Hutchinson, Wilson & Wilson 1994; Imeson & McMurray 1996). Eichblat (1996 cited in Koch 1998) argued that the validation process and therapeutic value for informants participating in phenomenological research could be significant and needed to be more extensively explored.

The informants had a clinical or a collegial relationship with either myself or the women’s health nurse who introduced them to the study. Owing to the possible power differential of this relationship, it was particularly important that the exact nature of the study be described to participants so an ‘informed choice’ could be made. Participants were assured that the choice to accept or reject participation in the study would in no way affect the nurse/client clinical relationship. In the instance of a second party introducing the participant to the study, the introductory women’s health nurse was not informed of the participant’s decline or acceptance to participate, unless the participant herself chose to inform that nurse of that decision. All potential and actual informants did choose to tell the referring nurse of their decision to accept or decline the invitation to participate in the study. Each participant spontaneously requested the opportunity for the referring nurse to be part of the research support team and to have the opportunity to learn from the experiences shared during the interviewing process.

**Identifying the phenomenon**

*Insight is more than the knowledge of this or that situation. It always involves an escape from something that had deceived us and held us captive … Insight too is something to which we come.*

Gadamer 1975b, pp. 319–320

The first step in phenomenological research is to identify the phenomenon, that is, a circumstance that can be investigated (Parse, Coyne & Smith 1985). The phenomenon for this investigation was selected because, in my clinical practice, I had become aware of the potential for harm, as well as healing, when a woman experienced an abnormal Pap test result. Almost every aspect of a woman’s life is affected when she receives the news that her Pap test detects an abnormality. What may have been just a simple, routine but somewhat inconvenient procedure suddenly takes on a significance that is threatening to the woman’s health and her sense of well being. This project was approached with the preunderstanding that the necessity of requiring further medical investigations often created financial hardship and social disruption for the woman.
Relationships, especially with her sexual partner(s), could be affected by the perception that this problem was related to her past or present sexual expression or trauma. A woman’s sense of self was altered as she imagined the changing cells on a part of her body, invisible, unfelt and yet so intricately linked with her sexuality. Fear, anxiety, guilt, depression or feelings of vulnerability and powerlessness could hinder her sexual responses. This preunderstanding is disclosed as being the catalyst for the research project. It is not bracketed, but rather acknowledged and kept open to the possibility of change and adaptation.

The peripheral mention in the literature (Schover, Fife & Gershenon 1989) that women who developed early stage cervical cancer were more likely to have lived ‘troubled lives’ was not surprising as my women’s health nursing practice was challenged daily by the realisation of the effects of violence against women and children. What was surprising and disturbing was that these women’s stories remained untold, unheard and unpublished. The need to research women’s ‘lived experience’ when they had an abnormal Pap test result became evident.

**Selection of participants**

Representativeness in qualitative research is concerned with the data and not the sampling units (Sandelowski 1986). Phenomenological studies describe a given phenomenon and informants are chosen because they have lived the experience being investigated (Baker, Wuest & Stern 1992). Selection of participants is therefore purposive and, in keeping with the phenomenological aim of illuminating the richness of the individual experience, the number of participants is kept deliberately small (Baker, Wuest & Stern 1992).

In selecting women to participate in this study, the emphasis was on the woman’s strong desire to share her story and her ability to reflect, focus, intuit and describe, as the phenomenological method required (Crotty 1996). Informants were selected so as to provide the broadest range of information possible (Rose 1990). In phenomenological studies the participants are often known as participants/informants or ‘coresearchers’. Throughout this research study, the term coresearcher is consciously avoided. This is not because the participant is seen as anything less than equal. They are the women providing the data, knowledge and experience that inform the study. Together we constructed the meanings that became the data for interpretation. The term coresearcher
is not used because it may be seen as patronising – the participants did not choose to ‘research’ the experience but rather to generously share their experience for the purposes of the study. The term coresearcher was described by one informant as a ‘trendy term that means less than nothing because it’s not true’ (Jayne).

By saying that the participant is a coresearcher implies a value discrepancy between participants and researcher where the researching is seen to be more valuable than the informing – this is not the case with this study. Careful consideration was given to terminology and it was decided that the terms participant and informant could be used interchangeably. This is in recognition of the study’s women-centred nature, which considers the participants as informers; it is the participants’ knowledge and experience, their ‘knowing’, their stories that are of paramount value. Similarly, although it is traditional to write a thesis in the third person, this tradition is not observed. A conscious choice was made to write in the first person in recognition of the nature of the study and of the relationship between the informants and myself.

Selection of participants was purposive, in that the selection process ensured that women who belonged to groups least likely to have had a distinct voice in published literature were invited to participate. These women identified as Aboriginal or were from a non-English speaking background, they had a disability or were aged at either end of the cervical screening spectrum (18 years and 70 years old), they identified as lesbian, were socio-economically disadvantaged, obese, sex-industry workers or immunocompromised. These are also women prioritised for access to women’s health nurse services because they are identified in the literature as being least likely to present to a health professional for cervical screening and who are also identified as being at increased risk of developing CIN/cervical cancer (Griffith-Kenney 1986; Howard 1987; Guest, Mitchell & Plant 1990; Balcombe & Stoden 1991; NSW Health Department 1994; Mak 1995; Anderson 1996 cited in Cooper & Temby 1998; Temby 1996; Firebrace 1998; Wilson 1998; Kahn et al. 1999; Kahn & Emans 1999; Vidler 1999). Hall and Stevens (1991) supported this selection process in their argument for inclusion of women from a variety of ethnic/racial backgrounds and sexual orientations, a range of socio-economic circumstances and a latitude of ages and physical abilities in women-centred studies.
Three women self-selected their participation in the study. These professional women chose the pseudonyms of Marie, Jayne and Margaret. Clients and/or colleagues of women’s health nurses, they had heard of the project by word of mouth and contacted me, requesting that they participate. Marie, Jayne and Margaret did not belong to a prioritised group, but expressed a desire to share their stories and so were invited to participate. A total of sixteen women who had contact with women’s health nurse services in the Greater Murray Area Health Service (GMAHS) were invited to participate in this study.

In addition to the three self-selected participants and Julie, whose selection is described below, the first twelve women attending a GMAHS women’s health nurse clinic in 1999 who were from prioritised groups and who had had abnormal Pap test results were invited to participate by the nurse who they consulted. All twelve women expressed an interest in participating and, with their permission, the nurse contacted me and a package that contained information about the study, a consent form for them to sign if they wished to participate and a return envelope, was mailed to them. Three women, all aged in their twenties, then declined the invitation. These women included an Australian born woman who was a sex industry worker and who had recently become a mother. Although she expressed interest in participating in the study she believed that her commitment to her newborn baby precluded time being available to be interviewed. A second young woman who was Japanese did not feel confident in her English language skills and was hesitant to use an interpreter, and the third woman from Vietnam elected not to return a signed consent form.

The thirteen women who participated in the study all chose their own pseudonym. Prior to their preliminary interview, I was aware of the women’s history of abnormal Pap test results but very little else about most of the participants. At the commencement of the preliminary interview, I knew that Janette was aged in her early sixties and confined to a wheelchair; Jayne was a professional woman aged in her twenties and Annabelle was 18 years old. During the interview Annabelle shared how she had been homeless for a period of time before moving to a caravan park. She was an extremely strong young woman but was embarrassed by her perceived problems with being overweight. Prior to interview I knew that Ann identified as Aboriginal. During the interview it became obvious that Ann was a well-educated, very attractive young Aboriginal woman and was very proud of her Aboriginality. Ann also expressed her distress about being
overweight. At the commencement of the preliminary interview I knew that Margaret was a health professional aged in her late thirties and Marie, in her early forties, was a midwife. During the interview Marie shared that she had a non-English speaking background. Prior to interview I knew that Rita was a lesbian and a professional woman aged in her late thirties and Melanie, also aged in her late thirties, was a refugee from Bosnia. During the interview Melanie shared how she was a widow with a young son. Prior to interview, I knew that Joyce was in her late sixties. At interview she described the circumstances of her widowhood. Before the first interview I knew that Faye had had multiple life-threatening illnesses, had a hearing disability and was aged in her early sixties. Prior to interview I knew that Terry was in her forties and her ex-husband had been charged with indecent assault of minors. I knew prior to interview that Megan, aged in her thirties, had had multiple abnormal Pap tests and that Janette, Annabelle, Joyce, Faye and Megan were economically disadvantaged and in receipt of social security payments. Julie, who was in her thirties, was what Minichiello et al. (1996) described as a ‘negative case’ in that she was invited to participate near the end of the data collection phase because she was neither from a prioritised group nor self-selected.

If the women’s narratives were to be as detailed and meaningful as possible, it was important that the women felt safe and comfortable in their chosen interview environment and with me, the interviewer. Ramsden (1993) described cultural safety as working in ways that did not ‘demean, diminish or disempower people from different cultures’. Cultural safety was extremely important in this study and every effort was made to ensure the research process and use of language optimised the women’s sense of cultural safety.

**Gathering the data**

*Practise a thinking hearing: a thinking which listens, a listening that is thoughtful.*

Levin 1989, p. 17

Being a phenomenological study, the phenomenon to be studied was approached naively, that is, all data were accepted as given (Omery 1983). Data gathered included the subjective meanings that the experience had for the informants and the aim was to understand and interpret that experience from the informant’s perspective.
Data were gathered during in-depth interviewing, using only interview prompts that were broad, open-ended and designed to avoid influencing the informants’ responses in any way (Baker, Wuest & Stern 1992). It was recognised that women would only be comfortable in self-disclosing when interest in understanding their experience was communicated, together with a suspension of any moral judgment I may have had (Keen 1975).

Listening was at the very core of this study. Gadamer (1976) and Crotty (1996) argued that, by its nature, listening lent itself to characterising the phenomenological endeavours of remaining open and receptive – components of the intuiting process described below. Levin (1989, p. 17) stated that Heidegger was urging us to consider ‘the way of thinking that will be open to an experience with Being, as speculative “reason” never has been, needs to be a way of thinking deeply intertwined with an ontologically developed listening’. That is, listening needed to mesh with thinking. Mueller-Vollmer (1986) forged listening with phenomenological understanding. He described listening as Dasein’s existential way of Being-open as Being-with for others. Listening to, dwelling on and reporting the depth of the informants’ shared stories have great potential to enhance nursing practice through illuminating both the woman’s experience of having an abnormal Pap test result and her relationships with health professionals.

Rose (1990) described the assumptions and approach of Colaizzi’s (1978) interview techniques. This study adopted two of those principles:

- The informant was more than a source of data – she was exquisitely a person.
- I could make contact with the verbalised experiences of the participant only when listening with my total being and entirety of personality.

**Interviewing process**

Each participant chose the time and venue for her interview. Interview locations were most often in the woman’s home but also included her workplace, a women’s health centre, community health centre, a women’s health clinic and my home. Prior to each interview, I took the advice of Munhall (1994) and spent time in a simple process of quiet reflection, silencing my own thoughts and concerns through the use of gentle background music and treating each new interview as a brand new process. Each
preliminary interview lasted from 1–6 hours (average time two and three-quarter hours), of which between 1 and 3 hours were audiotaped and transcribed (average one and three-quarter hours). Between two and four formal interviews were attended with each participant. However, it was only the preliminary interviews that were audiotaped, transcribed and used as a primary source of data. Information gathered in subsequent interviews was used for clarification purposes and, where referred to in the thesis, is documented as being from a subsequent interview.

Some links between interviewing in nursing phenomenological research and listening styles in humanistic psychology are evident, especially those proposed by Carl Rogers (Crotty 1996). However, the Rogerian presupposition that a process of personal change and individual effort could lead by themselves to individual liberation and fulfilment and the abolition of sexism, racism and ageism was rejected. Dobbie (1991, p. 826), a nurse researcher, described a recommended interviewing style that was congruent with Rogerian principles:

> Empathy was conveyed by attending to each woman through maintaining eye-contact, an open face-on posture and responding to verbal narratives with frequent ‘uh-hums’. Reflective silences and repetition of statements often prompted exploration by the woman.

Similar attempts at conveying empathy were adopted in response to perceived and actual participant comfort levels in this study. Dobbie’s (1991) style provided useful guidelines but was not prescriptive. For example, in this study it was not appropriate to maintain eye contact with Ann, who identified as Aboriginal. Adaptation therefore occurred through my mirroring of the participant’s preferred natural style of communication.

As stated, interview prompts were non-specific, open-ended and designed to avoid influencing the informants’ answers in any way (Baker, Wuest & Stern 1992). Only two prompts were decided upon prior to each preliminary interview: ‘Please tell me about yourself as a woman’ and ‘Please tell me about your experience when you had an abnormal Pap test result’. The stories the women chose to tell in response to those prompts were then listened to intently, as far as possible without interruption, except for conversational acknowledgments indicating that they were being listened to and heard. Additional information was only sought if they or I could no longer follow the conversational flow. Where needed, probes were used to encourage the woman to fill in
unclear details of her story. A recursive model was utilised where the interview followed normal conversational flow and the informant guided the pace and direction of the interview. A modified ‘funnelling’ technique (Minichiello et al. 1996) was used to encourage the participant to flow from the broader aspects of her story to the more precise details, clarifying her reflection of having an abnormal Pap test result and enhancing my understanding of her experience.

The in-depth preliminary interviews were audiotaped and transcribed verbatim. Transcription provided another opportunity to become further ‘immersed’ in the data (Minichiello et al. 1996). All identifying details were changed to protect informant confidentiality. Transcripts were offered to the women to read and discuss before and after interpretive analysis. This process of verifying the transcript with the informants served to increase catalytic validity. Only one informant, Jayne, elected not to participate in this aspect of the research. Verification of the transcript and the interpretation processes was in keeping with the recommendations of Colaizzi (1978) who advocated that the phenomenological researcher return to the informants to validate the findings and reflect on their perceptions of the experiences.

Following each interview, I followed a process suggested by Oiler (1982) that again utilised quiet reflection in order to bring the experience into clearer focus by allowing and even encouraging wonderment, confusion, conflict and/or uncertainty as I endeavoured to understand what each participant had shared with me. Time was given to critical self-reflection and evaluation of my interview style. Benner (1994) provided the guidance for the interview evaluation that was used for self-assessment following each interview and its transcription. Steps involved in the process included being alert to the possibility of any avoidance or leading of participant narratives, inappropriate silences, or the inability to follow-up or hear about certain concerns and meanings.

**Analysing the data**

*The goal of analytic phenomenology ... is to explore the intimate structure of objects, and clarify the essential categories that constitute them.*

Kockelmans 1967, p. 98

The issue in any qualitative study is whether the findings of the research are worth paying attention to (Lincoln & Guba 1985). In phenomenological studies this depends
on the extent that the findings are reflecting the essence of a phenomenon as experienced by the informants (Baker, Wuest & Stern 1992).

The data analysis process used in this study drew upon some of the articulated processes described by Spiegelberg (1975), Benner (1985, 1994) and Polit and Hungler (1995). Polit and Hungler (1995) and Spiegelberg (1975) adhered to the primacy of bracketing, which was not followed, but their principles of intuiting, analysis and describing were compatible with this study. Figure 2 documents the interplay between these processes. The aim was to generate a critical interpretive report that was as true as possible to the stories told by the women interviewed.

Parse, Coyne and Smith (1985) discussed the concept of ‘contemplative dwelling’ which they described as the undistracted reading and re-reading of the transcriptions with the intent to uncover the meaning of the lived experience for the informant. In this study, it also meant the listening and relistening to the audiotaped interviews, before, during and after the transcription process. Contemplative dwelling allowed me to be open to both the tacit and the explicit messages in the data in order to intuit meanings. As the study progressed, the participants were revisited, the literature was re-searched, and the opinions of others were actively sought and welcomed in an endeavour to bring about further intuiting, clarification and understanding.

**Intuiting**

*Intuiting and faithful description are not to be taken for granted and they require a considerable degree of aptitude, training and conscientious self-criticism.*

Spiegelberg 1982, p. 689

The three operations described by Polit and Hungler (1995) of intuiting, analysing/interpreting and describing were essential processes for this study. Intuiting, interpreting/analysing and describing are closely related and, although discrete, occurred simultaneously.

The intuiting process was informed by a synthesis of the processes described by Merleau-Ponty (1962), Spiegelberg (1975), Polit and Hungler (1995), Crotty (1996) and Van Manen (1997). Polit and Hungler (1995) related intuiting to the researcher remaining open to the meanings attributed to the phenomenon by those who have
Figure 2: The phenomenological process
experienced it. In the context of intuiting, Merleau-Ponty (1962, p. 58) argued that ‘nothing is more difficult to know than precisely what we see’. Crotty (1996, p. 163) urged the researcher to consider the following questions as part of the intuiting phase of phenomenological inquiry: ‘What is giving itself to us in this moment? What is presenting itself to our gaze? What is the phenomenon saying to us? What does this phenomena strike us as being?’ The questions asked by Crotty (1996) were applied through addressing the transcribed data during the interpretation and analysis phases of this study.

Van Manen (1997) argued that phenomenological research was the study of essences which were gleaned from the intuiting of the particular phenomenon. The Van Manen (1997) idea of essence was highly complex and was not a single, fixed property. Van Manen (1997, p. xv) defined essence as ‘meaning constituted by a complex array of aspects, properties and qualities – some of which are incidental and some of which are more critical to the being of things’. Essence is derived from the verb ‘to be’, and is therefore existential. Essence asks for what something ‘is’ and without which it would no longer be what it is. It was argued by Van Manen (1997) that essences could be illusory and could even be dangerous if used categorically and in absolute terms to derive moral convictions. In order to understand and reveal the essence of the experience of having an abnormal Pap test result, the intuiting process involved an examination of the minute details given by the informants, a process known as eidetic description (Crotty 1996).

Hermeneutical interpretation was the final step in Spiegelberg’s (1975) phenomenological process of intuiting. Following ‘contemplative dwelling’ in the informants’ descriptions, the intuiting process involved going beyond what was explicitly given to interpret the ‘sense’ of certain phenomena. Parse, Coyne and Smith (1985) described this as an appropriate and intuitive leap, which was a shift in the level of discourse from the concrete to the abstract. The meaning of lived experience, Van Manen (1997) argued, was usually hidden or veiled. The whole process of Spiegelberg’s (1975) description of phenomenological inquiry did not occur in a vacuum, but in frequent collaboration with the participants and in subsequent formal interviews to ensure primary and secondary validity of the information.
Analysing

Analysing was the second operation in the process of investigating the phenomenon in this study. Parse, Coyne and Smith (1985) defined analysing in phenomenological studies as the strict intentional tracing of the elements and structure of the phenomenon revealed through intuiting. The process of analysis utilised in this study was informed by Van Manen (1978–79 cited in Lynch-Sauer 1985), Benner (1984), Parse, Coyne and Smith (1985), Ray (1985), Polit and Hungler (1995) and Crotty (1996). During the analysis process the distinguishing characteristics of the phenomenon were explored and their connectedness and relationship to other phenomena determined. Through analysing, an attempt was made to reveal the constitutional elements of the phenomenon in order to shape its meaning as a lived experience for the participants.

Ray (1985) argued that there was a constant dialectic to be maintained in phenomenology between both analytical and concrete inquiry. She reflected on the discussions of Spurling (1977) that analytic inquiry was a reflexive process concerned with the grounds (underlying principles, laws and assumptions) that made something intelligible. The concept of ground structure was not ‘some kind of product or achievement’ but rather ‘an interpretive instance in an ongoing dialogue of interpretive method’ (Van Manen 1978–79, p. 54 cited in Lynch-Sauer 1985).

Analysis according to Polit and Hungler (1995) referred to making sense of the essential meanings of the phenomenon. Heidegger described ‘phenomenological moments’ (Crotty 1996) when the researcher had the sense that what they were perceiving comes from the experience itself and from no other source. Merleau-Ponty described this as ‘natal bonding’ of the perceiver with the perceived – where what was being described was the phenomenon (Crotty 1996). In this study, natal bonding or phenomenological moments were sought through a hermeneutic paradigm. So-called ‘phenomenological moments’ or ‘natal bonding’ became the foundation for each of the four discussion/interpretive chapters.

Three interrelated processes were followed in the analysis of the transcribed interviews. Benner (1985) and Leonard (1994) referred to these as thematic analysis, analysis of exemplars and the search for paradigm cases. The three processes are not linear but occur concomitantly and provide the basis for entering the practical worlds of the participants and their socially embedded knowledge. Thematic analysis and identifying
paradigm cases and exemplars worked as both discovery and presentation strategies in this study. They allowed for the presentation of context and meanings (Benner 1985). In hermeneutic phenomenology, the goal is not to decontextualise the meaning or extract theoretical concepts at a higher level of abstraction but to uncover the main aspects that illuminate the phenomenon, to discover meanings and to achieve better understanding (Benner 1985; Taylor 1994).

Thematic analysis, for the purposes of this project, involved immersing myself in the data, until my horizons were fused with the participants’. This concept allowed the horizon of the transcribed interview and participant perspective to fuse with the horizon of my own awareness in order to harness the most significant themes that would form the basis of the discussion chapters. Discriminate themes were identified and built on each other in the tradition ascribed to Omery (1983). Theme identification and synthesis led to the eventual description of the contextualised experience, shared by the informants, of having a cervical screening detected abnormality. The analysis was thematic in nature because meaningful patterns, stances or concerns were considered rather than more elemental units such as words or phrases. It was done on an individual transcript basis and then across all transcripts to clarify similarities and differences between the participants’ stories. In keeping with the guidelines described by Benner (1994), inconsistencies and even incoherent aspects of the text were identified and no attempt was made to make the informant’s experience more rational, coherent or consistent than it really was. During the thematic analysis phase of the research process, the conclusions of Merleau-Ponty (1962), Leonard (1993 cited in Benner 1994, p. 115) and MacIntytre (1993 cited in Benner 1994, p. 115) were noted to be true in this study. They argued that people lived with great incongruities in their lives and there were often gaps between stated ideologies and actual practices with lives projected into an ambiguous future, and the past and present experienced in qualitatively different ways. The participants in this study demonstrated how their future had been threatened by their past psychosexual-social history and medical diagnosis of CIN/adenocarcinoma, and how they were experiencing a sense of transformation in their present. These processes are discussed in the four interpretive/discussion chapters.

As the researcher, I was able to understand the situation of the informant, not because I could look ‘deeply into her soul’ but because I was enabled by the informant to imagine her life world (Fjelland & Gjengedal 1994). Fusion of horizons did not mean that I was
able to recover the experience as it actually was nor could I enter the mind of the informant. Rather, I was enabled by the participants to share their concept of ‘being in the world’ which led to a fusing of their and my ‘horizons’ and the emergence of meaning.

Analysis of exemplars involved the analysis of specific episodes or incidents described by the participants. Benner (1985, p. 10) defined an exemplar as ‘a strong instance of a particularly meaningful transaction, intention or capacity’. Having identified a pattern of meaning, common situation or embodied experience, exemplars were extracted from the text to demonstrate similarity or contrast in accordance with Benner’s (1994) principles. The exemplars identified from the data in this project formed vignettes taken from the women’s narratives. These are quoted verbatim. Where information was provided by the informant that was not relevant to the exemplar, the gaps in conversation were identified by the notation ‘…//…’ in the vignette.

Paradigm cases referred to the transcript and were strong instances of concerns or ways of being in the world which could be augmented by exemplars and thematic analyses. Identifying individual paradigm cases allowed for themes and exemplars to be highlighted. These were then integrated and synthesised to give insight into the total meaning and understanding of an abnormal Pap test result for the women interviewed. The paradigm cases are incorporated into the conclusion of each discrete interpretive/discussion chapter.

**Describing**

*The aim of the phenomenological approach is to describe experience as it is lived.*

Oiler 1982, p. 178

Describing is an integral part of intuiting and analysing. Following the step of intuiting and often concomitantly with analysing was the process of describing what had been revealed about the contextualised experience of having an abnormal Pap test result. The process of describing focused attention on the major characteristics of the phenomenon, revealing the essences and pointing beyond them. It was a selective rather than an exhaustive process and culminated in what Parse, Coyne and Smith (1985) described as an elaboration of the meaning of the elements and structure of the lived experience.
Between interviews, I invited critique and review from my supervisors and/or women’s health nurse colleagues to help uncover missed opportunities or any avoided issues. Interpretive dialogue began with the first interview so that data collection, inquiry and analysis occurred simultaneously, formatively and summatively.

Describing was an extremely difficult task and necessitated the use of language. Language could never adequately describe the participant’s experience. Words could not capture the fullness and uniqueness of the informant’s lived experience. However, it was only through the collectivity of language that experience could be accessed and described. Language was the medium through which objects and experience are represented.

**Reporting the findings**

*The final proof of ... phenomenology ... lies in the knowledge it uncovers.*

Benner 1985

Having intuited, interpreted/analysed and described themes, exemplars and paradigm cases from the data, the final step in the phenomenological process was to report the findings. Dissemination of findings and recommendations to nurses and health professionals through seminars, workshops, conferences, refereed journal articles and this thesis continues to be a major component of the study.

**Validity and reliability in phenomenological research**

*Feelings have a validity on their own. They reflect one's relationship to a situation.*

Benner & Wrubel 1989, p. 277

*The job of validation is not to support an interpretation, but to find out what might be wrong with it. A proposition deserves some degree of trust only when it has survived serious attempts to falsify it.*

Cronbach 1980 cited in Lather 1986

Validity in phenomenology refers to gaining knowledge and understanding of the true nature, essence, meanings, attributes and characteristics of a particular phenomenon. Drew (1986) argued that phenomenological data are valid to the extent that the interview taps the informant’s experience within the context of their singular view of the world. Flexibility, insight and ability to build on tacit knowledge are valued and evaluated to enhance rigour (Patton 1990). Packer and Addison (1989) argued that
interpretive accounts are ‘evaluated’ rather than tested and ‘validated’. Phenomenology deals with a valid knowledge of things derived by rigorous, critical, systematic and intellectual investigation and validity confirms the truth and understanding of the phenomenon (Ray 1985). Emphasis in this study was on establishing the existence and nature of the phenomenon with its meanings, attributes and contextual features through ensuring construct, catalytic and face validity as well as concurrent and external validity as part of the research process.

Construct validity focuses on identifying and knowing the nature, essence and underlying attributes of the phenomenon under study (Plager 1994). Construct validity in this study was enhanced by consultation with participants, my supervisors and members of the women’s health nurse research support team. Participants and colleagues were encouraged to question, challenge, affirm or refute my interpretation of the reported narratives.

Catalytic and face validity (Lather 1986) are the processes through which informants confirm, challenge and contribute to my interpretation of the information they had shared in their interviews. Lather (1986) argued that recycling interpretations, emerging analysis and conclusions back through at least a subsample of informants established face validity, which is seen as integral to the process of data credibility. Catalytic validity occurred as my role as a possessor of expert knowledge was redefined to that of a catalyst who worked with informants to gain understanding of the phenomenon from their expert ‘knowing’. This feminist research study affirmed informants through the processes of face and catalytic validity. All but one participant, Jayne, elected to participate in this aspect of the research process.

Concurrent validity in this study refers to the ability to demonstrate congruency and a logical development in the interpretation of meanings. Knowing and understanding the phenomena as fully as possible is the framework on which phenomenological concurrent validity is based (Leininger 1985). Collaborative discussions relating to the data and descriptions of phenomena were conducted with individual participants or research support team members to enhance deeper insights and understandings in a process recommended by Van Manen (1997). A secondary gain from this strategy was that the concept of a research culture within a rural women’s clinical nurse specialist team was enhanced. In this project, the research support team externally validated the
knowledge learnt from the informants. The reading and collaborative discussion of sample transcripts were part of the research pathway and endorsed the critical feminist framework of the study helping to ensure an emancipatory outcome as the clinicians learnt from the informants. This expert consensual validation also helped to guard against the importation of meanings that were not supported by the text or the data. The assumption was that the interpretations offered were based on shared cultural meanings and therefore recognisable by other readers who shared the same culture. In keeping with the principles espoused by Benner (1985) and Freire (1972), the process of concurrent validation had the potential to have an ‘arousing effect’ to reorient nurses’ perceptions of issues in ways that influenced subsequent attitudes and behaviours.

The secondary gain was realised during this study in the enhanced uptake of research into rural women’s health nurse practice. Theory and research were articulated with clinical practice. Haines and Jones (1994) argued that there is a perceived cultural divide between researcher and clinician and that published research is seen as esoteric and irrelevant to practitioners (Kitson et al. 1996). This project succeeded in bridging that divide in this instance. As a clinician and then as an academic, collaboration with nursing peers to verify the study findings and applicability to clinical practice was a key component of the research process.

Phenomenological validity is comparable to the feminist notion of adequacy. Hall and Stevens (1991) argued that feminist research is best evaluated by standards of rigour that reflect the adequacy of the whole process of inquiry, relative to the purposes of the study. Adequacy of inquiry implies that research processes and outcomes are cogent, justifiable, relevant and meaningful. This critical hermeneutic phenomenological research process aimed to systematically examine women’s experience and from that examination develop consensually validated knowledge. To do this, there needed to be a continual process of critical reflection to ensure optimum outcomes for the participants and women’s health nursing practice.

In the empiricist tradition, reliability means repeatability (Hall & Stevens 1991). However, reliability in phenomenology focuses on identifying and documenting recurrent, accurate and consistent (homogenous) or inconsistent (heterogenous) features, as patterns, themes, values, worldviews, experiences and other phenomena confirmed in similar contexts. Reliability as internal and external consistency and recurrency is
important, to the extent that the phenomenon under study consistently reveals meaningful and accurate truths about particular phenomena (Leininger 1985). The recounting of past experience, as occurred in this study, is regarded as reliable data in that the description of the phenomenon expressed the thoughts, feelings and emotions of the woman sharing her experience (Drew 1986). This study emphasises the uniqueness and the contextualised nature of women’s experiences and interpretations, rather than standardisation and repeatability. Therefore, the essence of reliability in this study is on dependability of the research processes. Dependability is a measure of rigour which does not decontextualise the data and does not expect or require that observations be repeatable or constant across observers and time (Hall & Stevens 1991).

Maintaining rigour

... the goal is to systematically examine human experience and from this examination derive consensually validated knowledge.

Lynch-Sauer 1985, p. 97

Judgment on the value of phenomenological research should be in relation to the degree of rigour employed and reflexivity achieved. Reflexivity or self-critique helps to ensure that the aims of the study are met. The possibility of an emancipatory outcome is enhanced by diligent reflexivity in this study. Reflexivity helps to answer the questions posed by Lather (1991, p. 84) that were applied to each transcribed interview. The questions included, ‘What was muted, repressed, unheard in the interviews?’ and ‘Was the interview shaped, subverted or complicated in any way by my preunderstandings?’ These questions were addressed through both self and peer evaluation.

Rigour is defined as strictness in judgment and conduct which must be used to ensure that the successive steps in a project have been set out clearly and undertaken with scrupulous attention to detail (Sandelowski 1986; Roberts & Taylor 1998). Scientific rigour is valued because it is associated with the worth of research outcomes. Qualitative research methods in general and phenomenological methods in particular have been criticised for a perceived lack of rigour (Barritt et al. 1983 cited in Lynch-Sauer 1985; Burns & Grove 1997). However, the criticisms such as those espoused by Barritt et al. (1983 cited in Lynch-Sauer 1985) are unfounded if attempts to judge the rigour of qualitative studies are based on the same foundation as those used to judge quantitative research. Rigour needs to be defined differently for qualitative research because the desired outcome is different. Rigour in qualitative research is associated
with openness, scrupulous adherence to a philosophical perspective, thoroughness in collecting data and consideration of all the data to provide clarity on the studied phenomenon (Burns & Grove 1997).

To ensure rigour, qualitative research procedures, including where applicable deconstruction and reconstruction, should be explicit and consistent with the underlying assumptions of the specific approach selected (Baker, Wuest & Stern 1992). Burns and Grove (1997) argued that, in this context, deconstructing means that the researcher must be willing to let go of preformed views and reconstructing refers to the formation of new ideas while continuing to recognise that the present reconstructing is only one of many possible ways of organising the data. In this study, the deconstructing process of ‘letting go’ of preformed views occurs through the acknowledgment of preunderstanding and a willingness to risk those prejudices (Gadamer 1975b). Preunderstanding was, by consciously bringing it forward at each step of the analysis process, not allowed to corrupt the data. Preformed ideas were ‘let go’ when indicated by the data. Reconstructing, in this study, was related to openness to the creation of new understandings as the participants shared their stories. It is appreciated that this new understanding is not finite or universal, but rather a product of the selected welding of their shared information and my interpretations, the ‘fusion of horizons’.

In phenomenological studies such as this one, four discrete criteria are required to ensure rigour – they are described by Roberts and Taylor (1998) as credibility, fittingness, auditability and confirmability.

**Credibility**

*Methodological rigor is based upon the rationality of articulation and a strong perspective on what it is to be a human being skilfully embodied and dwelling in a world that is constituted by taken-for-granted background meanings, concerns, practices, habits, relationships and understandings of self and other.*

Benner 1994, p. xix

Koch (1998) argued that credibility is the extent to which participants and readers of the research recognise the lived experiences described in the research as being similar to their own. A study is credible when it presents faithful descriptions (Koch 1998). Ray (1985) further argued that credibility is achieved when there is recognition of the phenomenon as true by those who have lived the experience. Credibility was tested in
this study when, following preliminary interpretation, the participants’ own analysed transcripts were returned to them for comment and sample transcripts were discussed with research team members. Credibility was enhanced by increased self-awareness, demonstrated through the Koch (1994) concept of journalising the content and process of all interactions between the informants and myself. The journal became the record of these relationships and provided material for personal, professional and academic reflection.

**Fittingness**

*Research is what establishes the link between theory and practice.*

Kermode 1995

Van Manen (1978–79, p. 59 cited in Lynch-Sauer 1985) invited the reader to ‘collaborate in the construction of analytic descriptions’. He argued that the concept of ground structure, or fittingness, was not ‘some kind of product or achievement’, but rather ‘an interpretive instance in an ongoing dialogue of interpretive method’ (p. 54). Fittingness is the extent to which a project’s findings fit into other contexts outside the study setting. Koch (1994) used the term ‘transferability’ to denote fittingness. And Appleton (1995) used the term ‘applicability’. Fittingness, transferability and applicability could all be used interchangeably in this study. Together they relate to the extent to which the readers of the study find it has meaning and relevance to them.

The strategy of returning transcripts to the informants and utilising the research team to study sample transcripts was used to enhance the applicability and truth-value of the study. Miles and Huberman (1984, 1994) described two potential dangers in phenomenological research which may adversely affect the applicability or fittingness of a study. These are ‘elite bias’ that refers to overweighting data from articulate, well-informed, usually high status informants and ‘holistic fallacy’ that occurs as the researcher becomes more convinced that their conclusions are correct. Conscious efforts to overcome ‘elite bias’ occurred at the stage of selecting informants for the study and this has been described. Utilisation of the research support team was strategically used to minimise the risk of ‘holistic fallacy’.
Auditability

A study is auditable when another researcher can clearly follow the decision trail used by the investigator in the study.

Sandelowski 1986

Evaluation of the consistency of this study occurred through the concept described by Appleton (1995) as auditability. Auditability also refers to the documentation of a ‘decision trail’ that could be used to determine the extent to which the project had achieved consistency in its processes (Koch 1994). Auditing the study involves determining whether interpretations and recommendations are supported by the data and attests to the dependability of the project (Hall & Stevens 1991; Koch 1998). Auditability would allow for another researcher, with similar perspectives, to use a like approach and possibly arrive at compatible, but not identical, conclusions. Systematically documenting the rationale, outcome and evaluation of all actions related to data collection, sampling, analysis and dissemination of results was therefore an important point of rigour in this study.

Confirmability

A good phenomenological description is collected by lived experience and recollects lived experience – is validated by lived experience and it validates lived experience.

Van Manen 1997, p. 27

Confirmability was achieved when credibility, fittingness and auditability were demonstrated. It relied on the confirmation of the participants and research support team members whose subjectivity was valued as instructive in assessing the extent to which the project achieved neutrality from my stated biases. This step in confirmability borrowed the Heideggerian phenomenology principle, ‘consensus becomes the basis for validating findings’ (Benner & Wrubel 1989, p. 185). In this study, consensus was sought between participants, the research support team and the outcomes of the research process.

Maintaining rigour in a woman-centred study

Relevance without rigor is no better than rigor without relevance.

Guba 1981 cited in Lather 1986

This woman-centred study sought to achieve the same rigour that is judged to give value to all qualitative feminist research. This study was considered credible when the interpretations of the informants’ experiences were recognised, understood and
endorsed as their own. It was a concern that some informants might have been hesitant to negatively evaluate the given interpretations, because they valued our relationship and may not have wished to ‘offend’. Every effort was made to encourage informants to realise that it was their honest appraisal that was sought and valued.

This study acknowledges the unique value of the participants who are situated in particular historical, sociocultural, political, economic and embodied life circumstances (Hall & Stevens 1991). Capturing the complexity of women’s lives involved several tasks which have been described by Fine (1985) as locating the analysis in the context of participants’ everyday lives; exploring the influences of larger social, political and economic structures and providing historical background. The process of contextualising the participants’ stories relied on the women sharing what they believed to be significant in response to the prompt, ‘Please tell me about yourself as a woman’.

The women’s own language and concepts are used to denote the project’s objectives, processes and outcomes. Participants had the right to delete any information from the study if they chose. One participant, Joyce, did delete approximately a third of her preliminary interview data as on reading her transcribed interview she felt uncomfortable with some of what she had shared during the interview process. No other participant elected to remove any data. There was a conscious monitoring of power dynamics throughout the data collection, interpretation and analysis processes to evaluate honesty, mutuality and the relationship between the informants and myself.

**Conclusion**

This chapter on method did not demonstrate a system of rules to be followed in a methodical process. Rather it demonstrated the openness, rigour and reflexivity required of a woman-centred study based on Gadamerian principles. These principles informed the thematic analysis, identification of exemplars and description of paradigm cases that directed the descriptions in the discussion chapters. For the purposes of this thesis, the ‘results and findings’, discussion and interpretations are integrated into four discrete interpretive/discussion chapters to follow, each based on an overriding theme identified during the data analysis phase of the project.
Chapter 4
Women defining themselves: Shared stories about private trauma

It is the women’s responses to the two predetermined prompts that are described in the next four interpretive chapters. The participants’ narratives have been dialogued with the words of the theorists and published literature to create shared meanings, but the primary voices are always those of the informants in this study. The first of the four discussion chapters relates to the women’s responses to the first prompt, ‘Please tell me about yourself as a woman’. With one exception, Margaret, the women defined themselves in relation to the stressors prior to and around the time of the abnormal Pap test result.

Perceived association between stress and cervical intraepithelial neoplasia

It seems to me that when you are emotionally in turmoil, that’s when they seem to be abnormal (Megan)

Many women in this study equated times of stress with changes to the cells on their cervix and their abnormal Pap test result. Terry believed there was a strong correlation between the two abnormal Pap test results she had had, her immune system and the multiple stressors in her life. She also added that her gynaecologist had ironically advised her not to have stress:

Particularly having had all this happen to me physically lately. And being told by the gynaecologist that ‘you must not have any stress’. (Terry)

[Difficult family situation] makes a lot of stress ... it just brings you down so much. It makes you unhealthy ... I think my immune system is just shot, hence the fruit ... that’s when I decided my immune system was just so shot. (Terry)

Terry identified that eating fruit would help repair her damaged immune system. There was a suggestion in the literature that eating fresh fruit and vegetables bolstered the immune system and decreased the risk of a woman developing CIN. In the 1970s and
1980s foods rich in Vitamins A (beta-carotene), B6, C and folate were reported as being protective specifically against CIN and cervical cancer (La Vecchia et al. 1984; Ramaswamy & Natarajan 1984; Wassertheil-Smoller et al. 1981; Lindenbaum, Whitehead & Reyner 1975). However, later results from folic acid and [beta]-carotene chemoprevention trials failed to demonstrate the same protective effects (Giuliano & Gapstur 1998).

**Back to the stresses …**

*But anyway, back to the stresses …//… I just wanted to get rid of it [abnormal cells growing on cervix]. I had too much else in my world! (Terry)*

I’ve got all the stresses that we’ve talked about earlier. (Terry)

The literature contains reports demonstrating that women with certain personality type characteristics, when faced with stressful life events, are more prone to cervical cancer and, by implication, CIN (Antoni & Goodkin 1988; Eysenck & Grossarth-Maticek 1991; Grossarth-Maticek & Eysenck 1991). Victim blaming is endemic in these studies and they need to be read and interpreted with caution. Nevertheless, the suggestion is that chronic psychological distress coincides with immunosuppression, potentiating the cervical cancer disease process (Eysenck & Grossarth-Maticek 1991).

Terry repeatedly stated that stress in a person’s life was common and her narrative provided no evidence of a sense of helplessness or hopelessness identified in the literature (Eysenck & Grossarth-Maticek 1991; Grossarth-Maticek & Eysenck 1991) as predisposing women to CIN/cervical cancer. The opposite was true. She did not want anyone to think that her stresses were unique and, in recounting times of trauma and pain, Terry tended to downplay and ‘normalise’ the distress she was experiencing:

*Life’s got all its same stresses that most people have.* (Terry)

*I mean that’s a big part of my life and it causes me a lot of stress. But when I sit down and think about it – everybody has stress! Their stories are different but everybody does have it.* (Terry)

*And it causes a great deal of stress. And I can say all that, and that’s all very sad but everybody has got the same sort of problems ...//... I mean it might not be their problem, but they’ve got their own.* (Terry)

Like Terry, Megan also equated her abnormal Pap test results with ‘emotional turmoils’. She said:
My husband had a stroke last year. And that, that was another bad Pap smear that time too. When I was going through that ...//... When I had my first [abnormal Pap test result], that’s when I found out Mum had cancer. And again the second time ...//... It seems to me that when you are emotionally in turmoil, that’s when they seem to be abnormal ...//... [Husband] was in hospital; I think when I had my last Pap smear and I was going back and forward to [city, a 200 kilometre plus round trip] every day. He was in there for two months ...//... The week before he came home, I sort of fell in a heap. It just got too much for me. I was really, sort of stressed out ...//... I hadn’t been sick like that for years. I just fell in a heap ...//... it was a lot of travelling. (Megan)

Melanie shared a glimpse of the horrors she had experienced as a refugee:

I am originally from Yugoslavia ...//... I have lived, studied and worked there till I came here, till I came to Australia ...//... I was married and I lost my husband during the war. And I am having my son who is 9 years old; we came here together in 1997 in Australia. As refugees from Bosnia ...//... [Husband] died during the war – he was killed ...//... I escaped with [son] in another part of Yugoslavia ...//... What is normal? Especially after war, after four years spending in war, being there. Looking at all that is happening, killing, uh, ethnic cleansing and all that and, there are periods, carrying with me, it’s not normal. You know nothing is normal ...//... I’m still sensitive talking about those things ...//... there is a story to take two years about what has happened and what we survived and what we did during the war ...//... when you haven’t someone to tell, someone to talk about, you just keep it inside ...//... there are thirteen or fourteen families from Yugoslavia ...//... when we are together we are talking but still it is painful ...//... what the war did to us. (Melanie)

Melanie believed that women’s war experiences in the former Yugoslavia affected not only her own cervical health but also the cervical health of other women in her country. Melanie compared the time before the war to the time of the preliminary interview in 1999:

In Bosnia actually we haven’t much like people, especially women suffering from cancers cervical ...//... Each month I have a telephone conversation with my sister and my mother. And now, I think every 7th woman in Bosnia is suffering from cervical cancer. And they can’t find like, the reason but most they suspect that there is, they suspect there is increased stress during the war and has big, big influence and that is how it is happening to the woman’s uterus. (Melanie)

An increase in cervical cancer that Melanie reported from anecdotal accounts from Bosnia is reflected in empirical data from Australia. Information from the NSW Chief Health Officers Report (Public Health Division 2000) indicated that women born in former Yugoslavia are significantly more likely to be diagnosed with cervical cancer than Australian born women. Less than a decade previously there had been no reported
significant difference in the incidence of cervical cancer between women born in Australia and those born in Yugoslavia (Balcomb & Stoden 1991; NSW Health Department 1994).

Melanie believed that the increased incidence of cervical cancer was probably due to the stressful life events of women living in former Yugoslavia during the war. Compared to World War I, with an estimated 5% civilian casualty rate, an estimated 90% of war casualties in the former Yugoslavia were women and children (Swiss & Giller 1993). Women not only risked being killed or wounded by shelling, sniping, landmines and other acts of war but they were also vulnerable to death of loved ones, loss of home and community, dislocation, untreated illness, torture, murder and sexual assault (Swiss & Giller 1993). It is not possible to know the exact numbers of people who are sexually assaulted at any time, including during war. Estimates given in 1994 ranged from 10,000 to 60,000 women and girls being sexually assaulted during the first three years of fighting in former Yugoslavia (Swiss & Giller 1993; Gunby 1994). It is inferred that sexual assault, as a tool of ‘ethnic cleansing’, was carried out so systematically that it was a product of nationalistic and militaristic policy, a deliberate strategy to undermine community bonds and weaken resistance to aggression (Swiss & Giller 1993; Toole & Waldman 1993; Gunby 1994).

Melanie and her young son were two of the estimated 1.5–5 million refugees from the civil war in the former Yugoslavia (Gunby 1994). She described their traumatic trip to Australia:

*I didn’t know anybody. We actually, we left Belgrade ...//... Thursday morning and then we flew to Athen to Greece, but I applied for immigration ...//... And they got papers and things, and they called us and said, ‘OK, you will fly to Australia next day’. And I asked because my English wasn’t ...//... ‘We will have someone to look after us during the trip?’ ...//... And they said, ‘Yes someone will be there’. Unfortunately, no one was there. We were by ourselves ...//... And there were people and with children, wives and husbands and anyway, we were flying from Belgrade to Athen, from Greece to Bahrain, from Bahrain to Singapore and from Singapore, Sydney. In Sydney I knew I had sleep overnight and then in the morning I had to continue trip to [city]. I came to Sydney, and the first person coming to see me was the customer, airport ...//... And he said, ‘Here is your ticket for tonight’s stay in Sydney hotel’. But everything was, you know it was first time in Australia, it was first time in Sydney and I didn’t know where to go ...//... exhausted, so tired ...//... Anyway, we went there and the hotel and we were so tired and we just couldn’t think. I had to order room service...*
anyway, we were so tired, all I could say was, ‘Wake up, six please’. And that was all the conversation, but they understood. And in the morning we catch the plane and then we came here. Very lonely so alone. (Melanie)

The resilience and strength women like Melanie, Megan and Terry demonstrated stood in stark contrast to the passive personality traits outlined in the literature as those belonging to women prone to cervical cancer and CIN (Antoni & Goodkin 1988; Eysenck & Grossarth-Maticek 1991; Grossarth-Maticek & Eysenck 1991).

Janette asked the question but already had an understanding of the answer:

*Can stress cause changes to the cells on the cervix? Can it? [Elaine: it can seem that stress can affect our immune system, which means that our bodies are not able to cope as well with cell changes as it normally can]. Looking at it that way, then that’s how it is. It was a stressful time. So much of my life has been stressful. Especially with [husband] because of the difficulties with him when he drank. And the lack of money and the lack of thinking of the future. I’ve always thought it was a very stressful life with [husband]. I moved out of my marriage, um, my marriage of 25 years actually. And I’ve been with [partner] since then. (Janette)*

The specific stressors described by the women took many forms. Those described by Schover, Fife and Gershenon (1989) were common and included ‘domestic’ violence, alcohol and drug misuse by partner and sexual trauma. Other stressors not identified in the literature but related by the women in this study included stories of intimate grief and loss. It is the women’s stories of these specific stressors that are described in the remainder of this interpretive chapter.

**Physical violence**

*He put his hands around my throat and tried to choke me and things like that (Julie)*

It was common for women in this study to describe feelings of terror and life-threatening fear of their partners, fathers and stepfathers. At the time of their preliminary interviews, each of the women had left these violent relationships. Again, this stands in contrast to the passive, helpless, cancer prone personality typecast in the literature (Antoni & Goodkin 1988; Eysenck & Grossarth-Maticek 1991; Grossarth-Maticek & Eysenck 1991).
Janette, who was confined to a wheelchair, described fearing for her life when her husband was in a violent rage. She continued to experience frightening flashbacks to those occasions when she smelt stale cigarettes and beer:

I was scared of [husband] ...//... when he was drinking he was quite a violent person ...//... [He] was very violent both to the children and myself ...//... he had been physically quite, yes physically frightening at different times. I had been grabbed and pushed out of my [wheel]chair. Actually pulled out of my [wheel]chair at one stage ...//... We had been to my brother’s marriage in Sydney ...//... I’d taken a shower and he’d been drinking most of the day at the wedding, and I was in the shower. He actually came into the shower, pulled the curtain – the shower curtain back and whatever our discussion, argument was about. He grabbed me and I landed on the floor, the chair broke and he dragged me from the bathroom to the bedroom area and I can’t remember the words we were using at the time, it was quite a lot of years ago now ...//... Terrifying! He threatened to throw me over the side of the um, motel we were staying in. I think we were about 4 or 5 stories up. And actually, he did pick up my wheelchair over his head, as if he was going to throw it over the balcony. And he was telling me he was going to do the same with me ...//... The fear is there when I smell stale beer and stale cigarette smoke. Is pretty frightening stuff! ...//... even though I pretend it doesn’t! (Janette)

Megan’s ex-husband was physically violent towards her and verbally abused her mother:

He was a wife abuser! ...//... He drank a lot and he abused [my mother] verbally quite a few times, through drink. Um, though she could be too, with drink ...//... but I don’t know if she ever knew about him hitting me or not. She never, ever said anything. My father probably would have killed him, if he knew ...//... Actually he was quite good when he was sober. If he was drunk and said, ‘Get me a beer or do this or that’ and you didn’t do it quick enough then he, he belted me. (Megan)

Some women specifically said that their husbands never ‘hit’ them. Nevertheless, their husbands’ behaviour was extremely violent and threatening. A woman does not have to be hit to experience violence as these stories of fear demonstrate. Terry and Julie described their terror and shame:

And I was terrified! I was frightened for my life! I thought he would get a gun and shoot me! He was mad! He was in a really bad, bad place ...//... He was a violent man! He had never hit me ...//... Never ever hit me but he was a violent man. He was violent, he would break things. He put holes in things, you know he was a violent man. (Terry)

Second marriage ended ...//... with a lot of, well there was a bit of violence ...//... he put his hands around my throat and tried to choke me and things like that. I had bruises, and I had to cover up to go to work and things like that. I mean he never sort of, as such really, hit me, but
Many women including Ann, Megan and Rita in this study described feelings of shame when they suffered physical and/or sexual violence by a person whom they love(d) and trust(ed). Wurmser (1981, p. 97) defined shame as ‘the pain of feeling unloved and unlovable’. It is ironic that, in Julie, Ann, Megan and Rita’s experience, it was the shameful acts of another that caused them, the victim/survivor, to experience shame. Younger (1995) explained that shame is the emotion felt by a person when they are exposed to a particularly sensitive, intimate and vulnerable aspect of themselves. Experiences of shame are isolating and highly personal and resulted in feelings of abjection for many women in the study, that is, their sense of self as human beings of worth was threatened.

Julie’s ex-husband was verbally and emotionally abusive as well as physically violent. Her feelings of shame were heightened when she considered that others might have believed his slander:

Then he started running me down in the ground as a woman too! .../... He had to have lovely suits and nicely starched white shirts and polished shoes and all that sort of thing. And I mean I used to do all of that for him .../... Polished his boots for him so to speak. And I mean we’d have people over, and you’d go to a lot of trouble and you’d cook beautiful meals and things like that and when things sort of came to a front, he was telling people that I did nothing for him and you know, that I was a really rotten housewife, and never kept anything clean and you know, sort of ran me into the ground. (Julie)

Ann’s stories typified much of what was written in the literature about the nature and effects of intimate partner violence (Schwarz 1993; Alpert 1995; Mikhailovich 1996; Eisenstat & Bancroft 1999; Sutherland 2001). Her first husband had been a very violent man. She said:

My first husband, I was 18 when I married .../... thought I’d fallen in love, married and proceeded to become, what do you call it? Physical violence or domestic violence. One year and eleven days after we married I walked out! .../... In the meantime I’d spent a night in hospital with a suspected perforated eardrum. The violence was becoming much more prevalent .../... it was about 3 months into the relationship before he actually ever hit me. (Ann)
Ann initially made excuses for her first husband’s violent behaviour:

_and it started out in things where I thought, well you know, maybe he did just do that a bit hard. Little excuses but as it went along it was becoming, instead of, I think between the first one and the second one it was actually about two months, so you’re actually looking about five months into the relationship, the marriage, then the next one it was. Each time I got hit it was getting closer and closer together. When I went to the Women’s Shelter after we’d split up, they said that the cycle that we had taken in twelve months took some couples twenty years to reach._

(Ann)

Ann described a cycle of violence mirroring that published in the literature (Pilkington 2000; Sutherland 2001). Sutherland (2001) described three phases typically experienced in the intimate partner violence cycle:

1. Tension building – the perpetrator made increasingly more unreasonable demands on the woman. The woman was constantly put down and ridiculed. She found it harder and harder to please the perpetrator.

2. Violent episode – the perpetrator eventually exploded with anger and physically, emotionally or sexually assaulted his partner.

3. Honeymoon phase – the tension lifted and the perpetrator was full of remorse. He was often extremely repentant until he tried to regain the power and control over his partner.

Ann illustrated this cycle of violence when she said:

_and you know, a lot of people say, a lot of women ask for it and I now understand ...//... I understand where they get that from. Because as a victim as the wife, you know which buttons to push to accelerate the process. The beating is inevitable, but to an outside person, they would look in and they would say, ‘well, she’s asking for it’. She’s not asking for it, she’s just asking, ‘can we do it now instead of two weeks time’. Get it over and done with because it’s always so much nicer afterwards ...//... The beating is inevitable, the timing is up to you! ...//... And when, after that split up and everything else, I mean there was a lot of shame! ...//... I was such a poor judge of character that I had picked someone to marry for the rest of my life that was capable of doing that to me. My sister’s marriage seemed to be much more successful, um; there was a lot of things associated with that which was sort of like baggage I took with me the next time._

(Ann)

Some of that ‘baggage’ related to the fact that Ann had an expectation that she would be hit again. She described a confrontation she once had with her second non-violent partner:
One day we were actually standing toe to toe arguing, and he just stopped and he said, ‘you’re waiting for me to hit you!’ And, like I mean he was half way through a sentence of, we were really yelling at each other and he just stopped and said, ‘you’re waiting for me to hit you’ and I said, ‘what?’ And he said, ‘I can see it in your eyes’. He said, ‘even though you know I won’t hit you’, he said, ‘I can see you’re waiting for that!’ ...//... that was the end of that argument. We both went away thinking about it. (Ann)

Marie described being exposed to violence in her family home. Both her father and her stepfather had been violent men:

And my stepfather, physically and emotionally abused [my mother] like you wouldn’t believe ...//... My real father left when I was 3 ...//... at that point there was no such thing as supporting mother’s benefits. And she was an immigrant who came over to Australia because she was pregnant with me ...//... my mother had a relationship with my father and he took off to Australia ...//... My grandfather found out my mum was pregnant and my grandmother gave my mother the boat fare to come to Australia to find my father ...//... my real father was an alcoholic ...//... And he was also used domestic violence ...//... In my child, in my mind’s eye I see myself playing house under the table and my Mum kept that fantasy going ...//... She then told me it was domestic violence and in that domestic violence he used to beat her up and then chase me and try to beat me up ...//... my stepfather was an alcoholic as well and he started to beat [my mother] up as well. (Marie)

Rita recalled a period of time when her father was physically violent with his children.

It was around the time that her older brother was sexually abusing her:

There was something about, it was a period of time that was rather awful in my family. And my father was, we used to ‘heil Hitler’ him behind his back. He was a, I would not have said a cruel man, I don’t necessarily think that now. I understand more where he was coming from now. But his actions were cruel. ...//... He would line us up and belt us. If something had happened and he didn’t know who had done it, he would line us up and belt us all ...//... and continue to do that until one of us owned up to it! ...//... And Mum would stand at the other end of the line and beg him to stop. But he would continue, she would try to nurse us as we came off the other end of the line ...//... that was the environment, so it was almost like the attention from [brother] met a need. (Rita)

The after effects of violence, fear and shame were long lasting for the informants in this study. Many years later Julie still experienced fear when she happened to see her ex-husband:

I just have this cold shiver that comes over me. And I would rather not see him, I would rather walk a thousand miles around him, rather than come face-to-face with him ...//... I don’t know whether it is the fear! Or whether I just don’t want to acknowledge that I knew him. Um, but yeah, I just get this cold shiver. Because a couple of times we’ve been shopping
in [regional city] and he’s been over there with his new wife .../... I just get a cold shiver and I say to [husband], ‘let’s go!’ And you know I’d walk a thousand miles away from him if I could. (Julie)

For many of the women in this study there was a link between the violence they experienced and their partners’ alcohol misuse.

**Alcohol and drug misuse**

*When he was drinking he was quite a violent person (Janette)*

Many of the women related stories of their partners’ alcohol abuse and the adverse affect alcohol had on them and their marriage. Some women like Megan, Julie and Janette directly related alcohol to the violent abuse they endured.

Janette was a woman in her early sixties. Having developed polio as a child, she had paraplegia and had used a wheelchair all of her adult life. Janette no longer lived with her husband who was violent to her when he was under the influence of alcohol. She described her relationship with this man as violent and frightening:

*I’d been unhappy in my marriage for a lot of years. My husband was a heavy drinker and gambler and it seems like we always had difficulty in that area .../... when he was drinking he was quite a violent person. And one drink was just too many. Because he never stopped with one. Many nights I pretended to be asleep when he came home from the club. I guess that was a self-preservation thing as much as anything. Because he would wake you up and fight with you .../... So when he was drinking he was a totally different person. Because he is a very gentle person when he was not drinking. And I guess that’s the trap. You think they will change, you think they will stop. But .../... I’ve known him since I was sixteen, he’s always been a drinker .../... But it never changed. He didn’t like coming home before the hotels closed .../... some nights I would be sitting up and some nights I would be, as I say pretending to be asleep .../... It wasn’t all 25 years of bad times. We had some great picnics, some great times down the river, some fun things but we just couldn’t go out anywhere where there was alcohol. Because he would inevitably have the drink and then inevitably have the argument. (Janette)*

Some women related stories of alcohol and drug use in their family of origin, their children or their own experimentation. As a young adolescent girl, Rita had survived sexual abuse by her older brother and physical abuse by her father. She had internalised feelings of shame, guilt and curiosity. She described experimenting with drugs and sex while living in a confused life phase:
Just basically lived with that shame, guilt, curiosity. Whatever it was. So, as a teenager I really acted out, was really rebellious, did lots of things. And when I was doing the experimenting sort of stuff with drugs and sex, I thought I was being hedonistic and there was still a lot of religious upbringing in my mind. So it was a very confusing time and um, without parental or other adult guidance, cause we were an insular family, we didn’t actually mix much with other people ...//... I’d walk out the door, I would start changing my clothes as I was walking down the street and I’d be a totally different person. I’d come home, put my clothes back on again and come back in to Mum and Dad. They didn’t know that I’d be dropping LSD, or snorting or whatever else I was doing. (Rita)

At fourteen, Megan craved for her parents’ affection following the death of her sister in a car accident. Megan felt that her parents, who had turned to alcohol as a source of comfort, were not able to be close to her:

I remember that’s when Mum and Dad started going down. But they didn’t look after themselves. Not that it helps now. Dad did in the end but it was sort of too late. They had smoked like trains all their life, both of them. And drank, drank a lot ...//... They drank socially before she was killed. And then when she died it was every night and on weekends ...//... I rebelled. I was pretty rebellious as a child. Um, it was sort of like [my parents] buy me anything but they didn’t want to get near me, because something might happen to me ...//... After my sister died. When they didn’t want to be close. That’s when I really needed them ...//... So I was sort of out on me own there, too. I didn’t take that well and I went wild! ...//... We drank a far bit and smoked. I was with a pretty wild group of friends. And I met my first husband. Oh, he was a kid I’d gone to school with ...//... And my mother didn’t like him. He was a wife abuser! (Megan)

Marie described how both her father and stepfather were violent alcoholics:

My real father was an alcoholic and ...//... he was also used domestic violence ...//... my stepfather was an alcoholic as well and he started to beat [my mother] up as well. (Marie)

Janette expressed distress and concern for her adult son who was also having difficulties controlling his alcohol and other drug use. Janette said:

They’re both [husband and adult son] drinkers and ...//... I can’t change that ...//... I guess I worry a lot about [son] ...//... he is a lovely young man. It’s just the devil gets between him and he goes off on those other little trips ...//... I’m terribly worried about his drug taking and about his being irresponsible ...//... I get very concerned and very worried about him. (Janette)

As well as the stories of physical violence, often exacerbated by alcohol, many of the women in this study shared stories of sexual trauma.
Sexual trauma

*It’s that stealing of innocence and lack of respect or whatever else. It’s just not good* (Rita)

A common thread intertwined in many stories was the women’s survival of child sexual assault and incest. Other women shared stories of being raped as adults and one woman shared her horror when she discovered that her husband, the father of her six-week-old baby, was a paedophile.

Marie described an incident of sexual assault that she survived as an eight-year-old child. During a subsequent untaped interview, Marie explained that the reason why she felt so physically sick was probably due to forced oral sexual contact with the perpetrator of the assault. In the first interview, Marie described the experience:

*And then about eight years of age ...//... a work colleague of my stepfather’s ...//... he took me out on the boat and then he made out that the motor on the boat had overflooded with petrol ...//... So we were in the middle of [the lake] and floating around ...//... and he had an erection and he put my hand on top of his bathers ...//... and he said to me, ‘Just stroke it and do whatever ...’ and then he said to me, ‘But don’t tell your parents, because this is just something between you and I, this is our secret’. And I was absolutely – I could feel the discomfort of where this is going, this is not right! ...//... So when I got back, I was feeling really sick by this stage. So I said to me Mum very quietly, ‘Can you come up to the toilets with me? Because I’m feeling really sick. I’m feeling like I’m going to vomit’. ...//... So I told her what had happened ...//... she went back and very quietly pulled Dad aside and told him what had happened. And my Dad just went for this guy’s throat ...//... of course we left straight away and his wife was in tears and really upset with it all. And that was the end of the situation. We never saw them again.* (Marie)

Very early in her interview, in response to my prompt asking Rita to share some things about herself as a woman, Rita shared how she survived incestuous abuse between the ages of ten and twelve:

*I had had a sort of a strict upbringing, family of five, I was the youngest and during my childhood I was sexually abused by my brother. Um, the oldest, in a family where that had never been talked about ...//... that was ten till twelve ...//... the memories became very clear for me when I had a son and a daughter ...//... I couldn’t leave them alone in the bath or the bedroom or anything like that ...//... and I thought, ‘Well, what am I frightened of?’ And then sort of had some memories of that and fully understood why they were triggered at that time and having the boy and the girl and the boy being older than the girl. So, that was a particularly painful, difficult time for me going through that, those memories and*
healing and I confronted my brother with it. Um, felt like I was betraying him. (Rita)

Although Rita had repressed the memories of the incestuous abuse for many years, when those memories came to her consciousness as an adult, she confronted her brother, the perpetrator of the incest. Her brother confirmed the accuracy of her incest memories:

After my daughter, couldn’t quite get my act together, couldn’t work out what was wrong and that was when the incest memories started coming in and it was a whole range of things, I believe that got me to the point of not getting, getting on with my life. And I think it was the memories of the incest and I think it was confusion about my sexuality ... All of those sorts of things that added together – make for a very unhappy time in my life. Which I was sad about, because I really wanted children and I dearly loved having them and wanted to enjoy them and not mope around feeling shitty ... After I confronted him ... he was fairly obnoxious in the period of time I’d confronted him. He would ring me up at three o’clock in the morning, absolutely pissed off his face, begging my forgiveness and in the same breath saying, ‘but you’re so beautiful, if you weren’t my sister, I’d still be your lover’. And me saying, ‘I’m not your lover now, you never were’ and the absolute abuse that continued to happen I felt, over that period of time ... it’s that stealing of innocence and lack of respect or whatever else, it’s just not good, it’s not OK, regardless. (Rita)

At the age of thirteen and for about the next six years, Marie described how her stepfather, the same man who had assaulted his friend for molesting Marie as a child, frequently overstepped sexual boundaries with her:

When I was thirteen ... what had started to happen was that my father started to spend a lot more time with me. And I became the surrogate parent for my mother ... I don’t remember very much about what my stepfather did to me other than I knew that it wasn’t right and I knew that it was abnormal. And that he would take me out to the pub and he would take me, you know. Even if there was no physical penetration or anything like that, I knew that was creating a relationship with me that wasn’t normal. Does that make sense? ... And it wasn’t until I was about ... in Year 12 ... he was having affairs left, right and centre. And there was a lot of marital stuff going on ... I mean he was already beating her up then ... At nineteen I got my first boyfriend. And I thought I lost my virginity, OK? But I now understand that there were other things that happened to me in that time that I may of ... less of the penetrative intercourse [with my stepfather] but more of the oral stuff. Because I have a real aversion to oral intercourse or anything like that or anything to do with it ... There was some physical abuse in that space of time too, when I was growing up too. My Dad hit; my stepfather just hit me around quite a bit. I ran away a couple of times and when I’d come home, he’d smack me around a bit ... And then when I was nineteen ... he said to my mother, the comment he made was, ‘Jesus, if she wasn’t my stepdaughter I would have had sex with
Marie was nineteen years old but her stepfather refused to allow her to go out or dance with a boy. Marie explained:

'[Boyfriend] rang me on the Friday to ask me to go out. And my Dad said, ‘You’re not going out!’ And I said, ‘Why not?’ And he said, ‘Because you belong to me and you stay here’. ... [My Dad] took me out with everybody else and then every time that any guys came up and ask me to dance, he would say, ‘No!’ And I would say, ‘But I want to dance with these guys, they’re all my age. You’re my father, I don’t want to dance with you’. And Dad would say, ‘No, you’re with me and I have rights over you. You can’t dance with them’. And that was when I met [boyfriend] ... [He] was too frightened to come up and ask me so I went and asked him, and when I got home that night, my Dad smack, like he hit me, for, he said, ‘you have no right to ask that boy to dance’. ... he had ownership over me. And he also took great pleasure in the blokes that he met in the club ... he used to come and tell me ... ‘They think you’re my girlfriend, ha, ha, ha’. And it was really amazing what was going on in his head ... He said, ‘You will always be my daughter and I’ll always have ultimate control over you. You do not have control over anything when you come to this house’. (Marie)

Terry explained that both she and her ex-husband had survived child sexual assault. But she did not use her husband’s child sexual assault experiences as an excuse for his criminal behaviour as an adult:

And to me obviously, there were other problems, deep-rooted problems ... he had been molested as a child. He told me that ... It didn’t, it still didn’t occur to me that he might be a perpetrator ... I mean I know lots of people who are abused ... I’m one of them ... But it didn’t make me a perpetrator. It didn’t make me do bad things. (Terry)

Annabelle was eighteen years old at the time of her preliminary interview. As a child she was raised by her father and stepmother and explained that her biological mother would have very little to do with her. Annabelle was a survivor of child sexual assault and a number of vicious rapes that occurred during her adolescence. She had been hospitalised with pelvic inflammatory disease. Annabelle described trying to cope by attempting to become detached and distant from her memories. She often experienced flashbacks to the rapes and had a great deal of difficulty in trusting anyone but her boyfriend. Annabelle demonstrated symptoms suggestive of post-traumatic stress after she was raped. Petrack and Campbell (1999) found that almost 90% of women who survived sexual assault went on to exhibit post-traumatic stress disorder. Annabelle was homeless for a while after she was raped and said:
About two and a half years ago I was, I was raped quite a few times, um, I thought I was in a safe environment with my friends when I first moved out of home. But that wasn’t too obvious! I then moved out of that house and was homeless for a while ...//... I have no trust in no one ...//... It was really hard. Sometimes it still affects me ...//... Drains, certain touches, certain actions, sometimes you’re going along all right and it all comes back and it’s so hard ...//... I find if I put in the back of my brain, and try and forget about it, it’s right. I try to live my life as normally as possible ...//... There are so many little instances that it doesn’t ...//... people coming up behind me and scaring me. Say, um, if I’m at a pub and fellow just out of the blue, walks up and puts his hand around your middle, it really scares me. Sometimes bad days at work, or, or um, some of the fellows at work can come up, can come across the wrong way ...//... The supervisor! ...//... It’s just the way he comes across, it’s pretty bad sometimes ...//... he threatens me with my job at times, too. Without threatening, if you know what I mean? ...//... I’m the youngest in the factory, I’m only 18 ...//... and they think that they can bully me around. (Annabelle)

For Terry, the experience of being sexually assaulted herself was not as traumatic and devastating as when she discovered her husband was a paedophile:

And six weeks after she was born, I discovered that the fellow I had married was a child molester ...//... And then of course, all hell broke loose. And I fell in a very big, black hole ...//... And I stayed with him, for some time in the hope that he might get better – get rid of this sickness that he had. But discovered, um, that wasn’t to be. So when [daughter] was about fifteen months old, I left the family home and left him. (Terry)

Terry left her ex-husband, but contact and problems associated with him persisted and came to a head shortly before Terry had her second abnormal Pap test result. Terry’s ex-husband was urging their eleven-year-old daughter to have unsupervised time away with him. Her daughter, who had never been told that her father was a convicted paedophile, desperately wanted to go on holidays with her father, without her mother’s supervision. She would not accept Terry’s ‘no’ and Terry was, ‘The worst in the world because I wasn’t going to allow it’ (Terry).

Terry eventually shared with her daughter the reason she could not allow unsupervised access with her father:

I mean I’ve got the stress of my ex-husband ...//... He’s been coming to visit [daughter] here ...//... I should qualify that I have always supervised those visits ...//... I wasn’t going to let him harm my little girl. I’d seen him in action and he’s a sick man! ...//... I’ve always felt that [daughter] was too young to know the full story ...//... from the time she was two years old I always believed that she would have to know the story, but until she knew what sex was, I didn’t think she would be able to understand this sort of thing ...//... We agreed next day we sit down and
talk. Which we did and we sat down for two hours in the first instance, and I just basically told her the story of what had happened. I wasn’t too graphic and I was honest and open and then explained that he had been charged with indecent assault ...//... ultimately she decided that she didn’t want to see her father anymore ...//... Ten-thirty at night and I was lying in bed and I could hear her sobbing so I went in there and she’s crying her eyes out and she’s obviously confused and upset. And my biggest concern has always been, that [daughter] would not take this on as her own ...//... That she would not take this on as her own fault. Because children do that, they feel that they’re responsible ...//... I mean in some ways wives feel that they’re responsible ...//... The only anger I ever got from her, once she found out this story about her father, was why did I ever take her there in the first place ...//... I explained to her that well, really it wasn’t my choice ...//... That’s what the law says and she finds that very confusing ...//... But I’m not taking the risk with my daughter and if she doesn’t want to see him, she doesn’t have to see him. (Terry)

Sexual trauma included but was not limited to incidents of assault and/or discovering a partner is a paedophile. Many women in this study described instances in their sexual relationships that caused them a great deal of sadness, pain and distress. Having survived incestuous abuse, Rita from around the age of twelve described how she ‘dabbled’ in sex:

_I was in the age groups of ten to twelve when I can pin [incest] down to happening ...//... often from that time on I dabbled in sex ...//... it was inappropriate sexual behaviour, I know that now. When I see other young women having the same sort of things happening for them I get suspicious about what’s happening in their life ...//... I had sex for the first time with a male when I was fifteen._ (Rita)

Although Rita described some coercion in her first heterosexual relationship, at no time did she equate that coercion with assault:

_It was a loving relationship; it was the man who ended up being my children’s father. Um, there was some coercion, but I was quite promiscuous I believe for my age ...//... I was aware I was under age and all those sorts of things. Um, and, and experimented sexually with men and women or boys and girls, really wasn’t it at that age...//... I had become quite rebellious and I know now in hind sight that that’s not anything unusual for someone who has gone through trauma or abuse as a child. It was like you were forced into being much older than you are. And my attempts to have that noticed, I acted out really badly at school when I had been a model student ...//... So I got into trouble quite frequently at the new school um, I realised later it was a cry for help ...//... I couldn’t clearly enunciate what was happening for me anyway. And basically just lived with that shame, guilt, curiosity._ (Rita)

Marie specifically described two sexual relationships that proved to be very negative for her in the time prior to her having the abnormal Pap test result:
I started to have a lot of sexual relationships with lots of different, not lots of different guys, maybe three different guys. And, um one of the guys that I got involved with ...//... for me I describe him as ‘a grotty Greek man’. He was just awful, but he was very heavily involved in the drug scene and in prostitution – he knew a lot of prostitutes. And I didn’t feel good about myself at that time. I was exploring a lot of things. And I had a really bad relationship with a guy who nearly cost me my job in the Spinal Unit – a client that was in the Spinal Unit. And um, that was really an awful experience. So I wasn’t feeling really good about myself, so my choice of partners wasn’t really good. In terms of when I wasn’t around – [grotty partner] was often off with all these prostitutes and he was off with a lot of other people ...//... he got non-specific urethritis, picked it up from somewhere. Um, and he rang me on the phone and said that he’d picked up an STD ...//... They told him to tell anyone, any recent sexual partners. And I felt absolutely appalled, I was so disgusted with myself ...//... absolutely disgusted. (Marie)

Many women described incidents of their partners’ having had relationships with other women. For Janette her feelings of insecurity came to the fore when she said:

I know [partner] has had many relationships with other women in the past and at least one other relationship that I’m aware of since him and I’ve been together ...//... so, if it’s related, if the abnormal Pap smear is related to the changes in sexual partners, which it could be, couldn’t it? ...//... It might be I’m pretty unsecure with him, in that I know there have been a lot of other people in his life. A lot of relationships. (Janette)

Jayne described her sense of betrayal:

I knew at that stage that my boyfriend ...//... I knew that he had slept with another girl and that’s what made us break up ...//... I was an ignorant country girl who had been going out with a boy for three years, who I loved to death – it [HPV] was like another betrayal! From him! ...//... I guess he had slept with other girls and I knew that and we had broke up and yet, um, he had left me with not only the memories of that betrayal and hurt but also something a bit more physical! Um, and that’s how I felt at the time [the HPV was diagnosed]. (Jayne)

Some women discovered that their husband was having a sexual relationship with their close friend and this exacerbated their feelings of betrayal. Although feeling betrayed by her husband and friend, Megan also had a sense of relief that she felt she then had an excuse to leave her violent marriage:

It was a real relief when I did find out that he was sleeping with my best friend. It was an excuse to split up without Mum saying, ‘I told you so’. That’s the only reason I stuck with him. So she wouldn’t say, ‘I told you so’. (Megan)

For Megan, an unlikely partnership between pride and shame had kept her in a violent marriage. Her husband’s violence offered her no excuse or reason to leave him but
when she discovered his infidelity it provided her with an ‘out’ for which she was grateful.

Faye described intense feelings of betrayal when she found her husband was having a sexual relationship with her best friend. Faye had returned home from hospital a day earlier than expected, having given birth to their twins – their youngest child and stillborn baby:

Actually it was when I was having [youngest son]. I came home from hospital a day early, earlier than I expected to ...//... So I went home and caught my husband and my best friend there ...//... I came home and caught them together ...//... We sorted that out after awhile because I had nowhere to go with four children under five ...//... it was a big mistake according to him ...//... when my son was about nine and a half, I knew that this same girl was back in town um, so one night, being the suspicious wife after you find lipstick and all this sort of thing on the collars. I waited up the club one night and I waited, and him and her came out and got in the car and drove off. So when he came home, I just faced him with it and he went through all this again. Saying you know, saying the same. But I said, ‘No, that’s it!’ Actually Elaine, his idea was to live with her one week and me one week! ...//... I was very hurt, very hurt. (Faye)

Faye’s husband had been her only sexual partner. Many years later, Faye had an abnormal Pap test result and was given health promotion literature that discussed the link between abnormal Pap test results and a woman’s ‘promiscuity’. The hurt and pain that she had previously experienced was intensified by this link. She discussed her shock at reading that abnormal Pap test results were associated with being ‘promiscuous’ with the colposcopist. Faye related the colposcopist’s explanation and her response:

When I was saying to ...//... Dr [Gynaecologist], ‘promiscuous’. And he explained to me, that on a man’s penis, if there are any abnormalities like a mole or a wart, or something like that. That could go towards causing it ...//... And my husband did have a wart on the side of his penis ...//... I hope that the girlfriend that he went with has got it too! ...//... And anyone else that he’s gone with! ...//... Like he’s with a lovely woman now and I wouldn’t like to see her get it ...//... I might ring and tell her to ...//... he might have had other partners ...//... so that can cause the abnormal Pap test. (Faye)

Divorced and with a young child, at the age of twenty-three, Julie married her second husband:
Got married again. Don’t know whether this is a good thing, but anyway um, that didn’t end up so well either, he was seeing somebody else on the side. So it hasn’t been an easy road. Second marriage ended. (Julie)

Marie described the ongoing hurt she felt from her husband having had a ‘one night’ sexual relationship with her friend:

A woman who I called a friend around the corner ...//... [Husband] had an affair with her. He went out there and he came home about one o’clock in the morning and he started vomiting ...//... And I said, ‘oh shit, you’ve got gastro from the spaghetti I’d made!’ But in fact what he was doing, was purging her. Because he had had the affair with her, like he had the one night stand with her, came home and felt so guilty that he – and what I didn’t realise he was sobbing in the bed next to me and he’s never one for crying. Never! I’ve seen him cry since and/or before and he was sobbing. And I felt the bed moving and I woke up, I thought, ‘Oh you’re home, what’s wrong?’ Then he got up and he raced to the toilet and he vomited his heart out. And he came back again and he was sitting there. And then I turned the light on and I could see that he was crying. And I said, ‘For Christ’s sake, what is wrong with you?’ And he said, ‘Oh, I’ve done a really stupid thing!’ He said, ‘I’ve gone off and had an affair with [Name]’ ...//... I know that people say to me now, ‘Oh he was really honest because he told you straightaway’. And all that sort of stuff. But he did that to dump on me too. To make me nurture him, because I can remember being ...//... physically he was lying there sobbing. And I was holding him to the breast almost like to nurture him to make him feel better and he kept saying to me, ‘Hold me, have sex with me’. You know, ‘I just feel so terrible about what I’ve done to you’. But it was him appeasing his guilt ...//... I think I have forgiven him but I still have a broken heart. (Marie)

Marie believed that in his vomiting, her husband was trying to purge the adultery experience from his mind/life. Rita also described a time of vomiting – a great purging on one occasion after she had confronted her brother about his incestuous abuse of her:

I stayed with this brother, and ...//... we had a few drinks together actually and cried and cried and cried together. And I was sick as if I’d drunk an enormous amount of alcohol and I hadn’t. I vomited bucketfuls’ full and it was a purging of all this from my system. I realise this now ...//... that was a real turning point for him and I. (Rita)

As well as the experiences of violence, sexual trauma and alcohol/drug misuse described by Schover, Fife and Gershenon (1989) and outlined in the women’s stories above, many women in this study also shared their experiences of profound grief and loss.
Deep grief and profound loss

You’ve sort of got no one (Megan)

Melanie had left her homeland and came to Australia to live with her young son shortly before she experienced the abnormal Pap test result. Melanie grieved for all that she had left:

I have no family. You know, when you have someone that you can count on every day, every time of night, day or things like that, it’s easier. But here is different ...//... I didn’t come to Australia because of me, for my family but [son] ...//... he was little and it was terrible, terrible. I was afraid that without like, being aggressive or thinking that you are a better person because you belong to one religion ...//... that is why I came to Australia for [son] ...//... before in Yugoslavia, before war it wasn’t important who you are, it’s important ...//... then we came here ...//... very lonely ...//... so alone. You know ...//... you can’t build friends overnight. Friends are someone that you grow up with and you die with that friend, and I’ve left my friends all over the world, they are everywhere. (Melanie)

Megan described herself as a mother and a wife who still felt very much alone and yearned for her extended family:

I’m nearly 38. I have four children. I’ve been married twice. Um, I’ve lost both my parents, I’ve lost my sister, I’ve got no family left ...//... It is hard. You’ve sort of got no one, especially a sister. I find, you know, you sort of need someone to talk to, but there’s not anyone ...//... I only ever had a sister and she died when I was fourteen. (Megan)

Around the time Terry had her first abnormal Pap test result, she had not only discovered her husband was a paedophile but many close family members had died. Terry described this time:

It was devastating ...//... I mean my Dad died, my sister died, my grandmother died, my sister had a baby who died ...//... It was horrendous. It was an horrendous time ...//... I mean that’s a big part of my life and it causes me a lot of stress ...//... My sister had brain surgery ...//... she was twenty-one years old ...//... she had a tumour the size of an orange ...//... on the left side of her brain, where all the memory and all that stuff is ...//... they took the tumour out and with that they naturally have to take a lot of your brain cells ...//... After that she had radiotherapy. And then she had fits, then she degenerated. And she actually degenerated over a six, seven year period ...//... and died of weakness and frailty ...//... the tumour was actually on her spinal cord ...//... That was six weeks before we got married. That was when we got married in the September and then by December, Dad was in [city] hospital having two thirds of his stomach out ...//... Stomach cancer! But it got into his lymph nodes and he eventually died ...//... Dad sort of went into remission for eighteen months. He had chemotherapy and lost all his
hair. And [younger sister] was having the radiotherapy, the fitting was happening ...//... Like all this is happening. Um, [younger sister] has had this brain surgery and like two years later she is really starting to degenerate ...//... Dad’s like out of remission and he’s got very little time left. Um, [ex-husband] is in psychiatric care ...//... ended up having fifteen months off work ...//... so yeah, I was pretty stressed out I think, with all those things ...//... So of course, well, I had the abnormal Pap smear so you know, not that I considered anything to do with it then ...//... But now reflecting back, I look at that time and I think, Gee whiz, I had a lot of stresses ...//... So by the time [Dad] died, I’d had the abnormal Pap smear and what have you. But that was all leading up to it ...//... I’ve had half my family die from cancer ...//... I’ve watched people die. I’ve watched people die horrible deaths from cancer. (Terry)

Faye and Megan both experienced the death of their babies. In describing herself as a woman, Faye defined herself as a once married mother who had experienced a multitude of medical illnesses and the death of her baby. She described part of her life as a young adult:

_I had four children. Unfortunately my marriage ended in divorce when my youngest was ten. Um, I have had a lot of problems actually ...//... two operations for [endometriosis] ...//... abscess on my ...//... ovary, right. I had an operation for that. One ovary removed ...//... something the matter with my head ...//... bone growing in the main blood vessel of my head somewhere ...//... operated through my ear, a four hour operation thank you very much! And I was awake ...//... After that I went for another six months and then became pregnant. And, they told me after I was pregnant that the only thing that would cause it to happen again was pregnancy. So he wanted me to terminate. No, he didn’t want me to; he gave me the option because I wasn’t quite three months. Then I decided to go ahead and have the baby which I had twins! Which, what he was worried about was something to do with, with this thing that the child could be abnormal. Anyway, I had twins. One was quite perfectly healthy and still is today. But the other one was abnormal and born dead. (Faye)_

Megan also had a baby who died and she feared the baby’s death might have been related to something about her:

_I lost a baby then, a little girl and I had a nervous breakdown and I was always – and they couldn’t give me an answer why I lost it. There was nothing wrong with the baby and there was nothing wrong with me. But I figured there had to be something wrong with me. (Megan)_

An intense loneliness was Janette’s most vivid memory associated with the multiple miscarriages she experienced:

_I had many miscarriages ...//... so that was always very sad because [husband] and I both wanted a large family and there seemed to be no reason why physically I couldn’t have any more children, other that_
physically I just kept having miscarriages ...//... it was very lonely. I found it to be extremely lonely because nobody felt anything for you, when you perhaps have a miscarriage ...//... I did feel it greatly actually. And I look back on it now and yeah – it was a very serious time for me. (Janette)

Ann also experienced a sense of intense loss and described a miscarriage she experienced in the years before the abnormal Pap test result:

I then fell pregnant and it was like, like you wouldn’t believe the elation, and then I miscarried. So I sort of went from this incredible high to a really, really low. And in the back of my mind I was never really sure whether the kids’ father stayed with me because I had fallen pregnant and lost the baby. (Ann)

Just prior to Joyce’s first experience of post-menopausal bleeding, her 59-year-old, caring and loving husband suddenly died. Joyce related this sad experience to the onset of her post-menopausal bleeding:

From the time [husband] died ...//... it’s going back twelve years now ...//... I was 56 years of age! ...//... And then after that I started to haemorrhage ...//... D and C ...//... there were fibroids there at the time and polyps ...//... another six months, twelve months [the bleeding came] back again. And I kept doing this – back into hospital, had another curette ...//... To have all those bleedings, it just seemed so ridiculous, but you know what I mean. But I think when [husband] died, because he died at home in the bed, beside me. I heard this gurgling, something shocking, and I thought that he was just asleep or snoring or whatever you like. And uh, I shook him and I puts me arms around him and I kissed him and I said, ‘Come on [husband], wake up!’ No reply, just this horrible noise! And of course, it hit me like a van, you know. Oh my God, something is wrong here! ...//... But he was gone ...//... so I mean that was a big enough shock for me to have him die in bed like that. And uh, he was special. Special to all of us, you know. He was [husband] and he was my [husband]. But he was gone like that! ...//... He was only fifty-nine. (Joyce)

After her divorce, Faye met a man who became her companion. They were not in a sexual relationship but had plans to marry:

My life just went on, I was quite happy. I met a man. A very nice man, a perfect gentleman. We did discuss getting married but I wouldn’t marry him until the children were old enough ...//... Which he understood ...//... Anyway we just ended up companions, didn’t live together or anything but just really good friends ...//... and I think that would have still been going on, but unfortunately he died ...//... yeah, but those things happen don’t they? ...//... But I miss him a lot ...//... it was really good. But other than that, I’ve been in no other relationships. (Faye)

Rita grieved not for her husband, who was alive, but rather for their marriage and the pain she believed she had caused him. Rita shared her story and, in doing so, the
feelings of hurt were close to the surface. Her face was streaming with silent tears when she recalled:

_I started a relationship with a woman. Which my husband was very aware of and I told him from the very beginning about that ...//... he was supportive of the notion of me exploring that part of my sexuality, because he believed I would get it out of my system ...//... Unfortunately for him and really as a couple for us, that didn’t happen. And he still grieves for that, as I do. Sometimes it’s very hard [Rita sobs silently] ...//... I’ll be right till it comes up again. It will come up again periodically ...//... It was hell, absolutely hell ...//... we tried everything ...//... probably one of the most painful moments of my life ...//... there was a lot of genuine caring, amongst the genuine pain ...//... he was in so much pain ...//... And I just felt that I had caused such incredible pain for somebody who is such a good person, was just the worst thing to feel. Because I’m actually a really caring, compassionate person ...//... I couldn’t apologise enough to him for that dreadful pain ...//... he was my first lover, he was my best friend for so many years. And there was so much to lose in that process ...//... I took on a lot of the guilt at that point and felt responsible for a whole lot of what had happened. When in fact he’d had affairs when I was with her because he was hurting and because his manhood was being challenged in his eyes. So he screwed around a whole lot of people in this town ...//... But then had to come back and deal with the grief and loss of the dream of the relationship where I was going to you know, grow old with this person and we were going to sit on the verandah in our rocking chairs and watch our grandchildren play in front of us and those dreams that you do have and you hope ...//... so that was the hard part, as well as the pain that is still there. The hard practicalities of separating in a relationship is one thing but the pain of that loss is quite, quite big. (Rita)_

With the exception of Margaret, who had been diagnosed with adenocarcinoma, every woman shared stories of multiple and intense, stressful life events in the time preceding their abnormal Pap test results. As stated, these women were not asked to recall or share traumatic experiences, but rather to share a little of themselves as women and their experiences of having abnormal Pap test results. The participants spontaneously chose to define themselves according to the devastating life stressors they had experienced.

The nature of this type of research does not allow for generalisations to be made. Assumptions cannot be made as to any correlation between stressful life events and CIN. However, the women in this study have alerted us to the possibility that, because this was their experience, it is very possible that other women with abnormal Pap test results may have also lived very ‘troubled lives’. Another possibility is the stories that these informants have shared may be common to many women, whether or not they
have had abnormal Pap test results. It was the women who drew the association between the stress they were experiencing and their abnormal Pap test result.

The women in this study welcomed the opportunity to share their stories with another person. They experienced the violence as an integral chapter in their lives and part of what being a woman meant for them, it was their response to the simple prompt, ‘Please tell me about your “self” as a woman’.

Phenomenologically speaking, this ‘self’ that the women described could not be separated from the violence and trauma they had experienced. Sullivan (1953) described ‘the self’ as a social construct developed from experience, culture, societal influence, gender issues and spiritual and psychic components. For many of the women in this study, the experiences of violence, trauma, deep grief and profound loss had brought them to their present understanding of ‘self’.

The data showed a common thread of trauma weaving through the women’s narratives. When asked to describe themselves as women, the informants frequently saw and defined themselves in relation to the traumas and stressors they had experienced and which were described in this chapter. Knowing that this research was to focus on their experience of having an abnormal Pap test result, the memories and negativity of that experience would appear to have ‘awakened echoes of old traumas’ (Kristeva 1999, p. 1486). The women in this study continued to redefine and make meaning from the traumatic events in their lives, some which had happened decades earlier and some that were more recent. The question needs to be asked, ‘Could it be that a significant trauma or stressor, once experienced, continues to redefine women, predisposing them to vulnerability and to pathological cellular changes to the cells on their cervix?’ This study does not and cannot answer that question but instead alerts the reader to a possibility and urges further research in order to test this hypothesis.

Terry’s story is selected as a paradigm case to illustrate many participants’ belief that their abnormal Pap test result was a direct effect of trauma and stress. It illustrates how women in this study elected to define themselves in accordance with devastating life stressors they had experienced. In recalling the experience of having an abnormal Pap test result, memories of other life traumas surfaced.
Terry’s paradigm story

Terry was 45 years old and had had two abnormal Pap test results at the time of her preliminary interview. Her story exemplified the stressors women in this study experienced prior to and around the time of their abnormal Pap test result. Terry’s first abnormal result was in 1984 and the second in 2000. Prior to both occasions, Terry described a period of severe stress. In 1984, Terry’s father was terminally ill with cancer, her 28-year-old sister was dying with a brain tumour, her husband who she has since divorced was mentally ill with a bipolar disorder. Both Terry and her ex-husband were survivors of child sexual assault. In the years that followed, Terry’s young sister and her father both died as did a number of other close relatives. Terry had given birth to a baby girl and when her daughter was six weeks old, Terry discovered that her baby’s father, her husband, was a paedophile. This man was charged and convicted of indecent assault of minors.

In the few months immediately prior to Terry’s last Pap test result that predicted CIN 2–3, a high grade epithelial abnormality, her mother had been diagnosed with cancer. Terry’s new husband’s ex-wife had moved interstate taking Terry’s two stepsons without consulting Terry or her husband. This limited their access and contact with the two boys who she had loved and cared for since they were toddlers. Financial hardship as a result of high child maintenance payments by Terry’s husband added to her distress. Terry’s ex-husband wanted to have unsupervised weekend access with their daughter. In explaining the reasons why this could not happen, Terry’s daughter was informed of her father’s criminal history for the first time and as a result refused to have any contact with him. Terry expressed her belief on many occasions that there was a correlation between her stressful life events and the abnormal Pap test results.

Negative life events and devastating stressors had played a defining role when Terry considered herself as a woman. In addition to these external stressors, Terry’s distress was exacerbated by her sense that something grotesque was growing inside her that she just wanted to get rid of. Terry said:

_This is the point where I felt sick! I was just sick in the stomach, knowing that I couldn’t have this thing done. I just wanted to get rid of it._ (Terry)

Terry responded to and had an intense need to get rid of the cells that were growing on her cervix. Kristeva (1982) would have defined Terry’s response as ‘abjection’. It is the
informant’s description of the pollutant ‘abject’ – that which is absolutely abhorrent to them and poses a threat to their sense of self that will be discussed in the chapter to follow.
Chapter 5
Abjection

The disenchantment that I experience here and now, cruel as it may be, appears, under scrutiny, to awaken echoes of old traumas.
Kristeva 1999, p. 1486

Adding to the stress of their life context, all of the informants in this study found the experience of having an abnormal Pap test result frightening, a threat to their lives and to themselves. Julia Kristeva (1941–), a French-Bulgarian, psychoanalytic theorist defined such an intense response to something that threatened a person’s borders and/or their ‘self’ as abjection and she argued, ‘The abject has only one quality … that of being opposed to I’ (Kristeva 1982, p. 1; Kristeva 1987). Although Kristeva rejected the feminist label (Kristeva 1996), many feminist theorists and literary critics have found her ideas useful and she is often cited in the feminist literature (Oliver 1993). Kristeva developed the theory of abjection while working with the anthropologist, Mary Douglas, who in her analysis of purity and risk argued that something was seen as dirty, a pollutant and a threat when it was not contained in its ‘proper’ place (Douglas 1969).

The purpose of referring to Kristeva’s theory of abjection in this chapter is to illuminate the women’s fear that their self, their person was greatly threatened by the abnormal Pap test result. On multiple occasions this was felt due to their embodied boundaries being transgressed during gynaecological examinations. Considering themselves unclean and defiled, the abnormal Pap test result posed a serious threat to their very sense of self.

This chapter will explore the women’s feelings of abhorrence and abjection when they were informed of and treated for their screening detected cervical abnormality. The participants’ narratives are undergirded by the theoretical positions of Julia Kristeva and S.K. Toombs, a phenomenologist and woman suffering from multiple sclerosis. The overriding emotion relating to the informants’ sense of abjection was the fear they experienced on being informed that they had an abnormal Pap test result.
Absolute fear

I can remember thinking, ‘This is terrible, I’m too young to have cancer and die’ (Margaret)

Women attend for routine cervical screening with the commonly held belief that the result will be normal. Abnormality is not expected and fear is not anticipated. As Ann said:

I rang for the results, expecting it to be normal. (Ann)

The terms cervical screening, Pap test, Pap smear and cervical cancer screening are used interchangeably in both health promotion and professional literature. This is evidenced by reading the titles of the articles in the reference list of this thesis or statements from the NSW Cervical Screening Program, including the introduction to their article about cervical screening in migrant women, ‘Increased education through the ethn-o-specific media and targeted health promotion activities enhance cervical cancer participation in women from ethnically diverse backgrounds’ (Taylor et al. 2001a, p. 55).

As a consequence when the women in this study received an abnormal Pap test result, their first thoughts were usually of cervical cancer. Marie explained:

As a midwife, you know, the only understanding that I had about Pap smears was that they looked for cancer cells. That was my only knowledge of what Pap smears were all about. (Marie)

When the results were abnormal, many women experienced both shock and incredible fear. Megan and Janette recalled their shock when told of their abnormal Pap test result:

I was shocked! ...//... The only word I heard was probably pre-cancerous. And that, that really scared me ...//... If I had heard of the bit that it could have taken ten years to turn to cancer, that would have relaxed me a lot ...//... to know that it could take that long to go from one to the other, would have calmed me a bit. But I never heard that bit. (Megan)

It was a shock, heavens yes, it was a surprise ...//... I thought it was life threatening to start with and I couldn’t believe that Dr [GP] was saying what he was saying to me and it was so serious to me and wasn’t serious to him ...//... he was detached for it, I wasn’t! And I guess I only heard the first few words ...//... I thought it was cancer and I thought it was very, very serious ...//... I thought every abnormal test was cancer. (Janette)
Julie was rung by the doctor’s receptionist and told that she needed to return to the doctor:

_The doctor’s receptionist had rung me and told me to come back. And I thought, ‘Oh, hang on, what’s going on here, this hasn’t happened before’. So anyway, I went to see her, expecting just to have another smear test …//… And she said, ‘Oh no, you’ve got to go to [Regional city] to have a colposcopy done’…//… I had no idea what was in store for me …//… Not knowing! You know, like not knowing what this test was and not thinking that it could happen to you._ (Julie)

Julie’s original abnormal Pap test result was a CIN 1, but four months later it was colposcopically and histologically diagnosed as CIN 3. Julie did not consider the possibility that the Pap test might have been inaccurate, she believed the cells on her cervix had changed very quickly and this added to her fear and alarm:

_I think that’s what really scared me, was that something so minute, that started off only mild that it could get so severe in four months. You know, so, it’s only such a short time …//… it changed so quickly and I think that’s frightening in itself. To think that these things can change so quickly._ (Julie)

Rita described her fear and consequent vulnerability when she had to hand over control of her body to another person:

_There was the fear of cancer to start with. Then there was the feeling of, the fear of cancer was about, are they going to get them all, will it still develop into cancer? Oh my God, I’m getting something burnt! That’s part of me going. There is part of me you know that is being damaged here. That is obviously unhealthy to start with. What will I do? Obviously I’ve got to get rid of it but oh gosh, it being burnt off, burning. There is going to be scars and burnt tissue and I suppose, the whole thing …//… you’ve got to actually hand over all your control …//… you’ve got to actually trust a system that I don’t really trust. So I had to actually just hand over to somebody, my life and my body._ (Rita)

Rita’s sense of self was profoundly threatened by her need to hand over control of her body to a professional who belonged to a system that she did not trust. The relationship between herself and the medical practitioner was inherently unequal. The professional had what Rita did not: the knowledge, skills, technology and power to bring about healing. Toombs (1987) argues that this inequality of the relationship between medical caregiver and recipient accentuates the loss of control felt by the person in need of the medical service.

Megan and Margaret, like many of the informants, feared they were going to die:

_I think you look at your life, like, am I going to die?_ (Megan)
They usually say, ‘if you don’t hear anything from us it’s all right’. So.../... a few weeks after I had it I actually had a phone call from the GP who said that an abnormal Pap smear and that I needed to come down and see her and discuss it.../... And I thought, ‘Oh God, abnormal Pap smear – that’s absolutely awful!’.../... So I had that Christmas thinking, ‘I’ve got cancer! I’m going to die!’.../... ‘I’m going to die!’ I can remember thinking, ‘This is terrible, I’m too young to have cancer and die!’ (Margaret)

Many of the women who were mothers spoke of fear primarily for their children. Ann said:

I was worried that if it is something more, um, what would happen to my children? Because I was separated from their father, all of my family were interstate. (Ann)

And Megan, divorced from her older children’s father, said:

Am I going to die? Who’s going to look after me children? .../... That’s why when I walked in [to the colposcopy appointment], I burst into tears. And [colposcopist] said, ‘What’s wrong?’ and I said, ‘Well I’ve got three kids, I need to know if I’m going to live or die. You know, I’ve got a life to organise here’.../... I was always scared that I wasn’t going to live long enough for those two to grow up. Who did they have if they didn’t have me? (Megan)

Melanie, who so poignantly shares her story as a paradigm at the end of this chapter, described how she was no longer able to take her body, her health for granted. It will never be known if the abnormality detected on cervical screening spontaneously regressed prior to colposcopy or if her Pap test result was a false positive. Whatever the case, the abnormal cells reported on the Pap test result were experienced as a threat for her son as well as herself. Melanie prayed to God and asked:

And I said, ‘Oh God... help me’. And then I said, ‘Why me? [Son] lost his father and why me now?’ (Melanie)

Melanie experienced her perceived threatened mortality in concrete terms and not as an amorphous possibility that might happen some time in the future. The abnormal Pap test result not only caused Melanie to be concerned for the present but her whole perception of her future had been altered.

Like Melanie, Julie had also become painfully aware of her own threatened future:

The fear of the unknown as to what it was going to lead to, and you suddenly start assessing your life.../... I mean as soon as you think abnormal smear, you think oh no, this is it! I’ve got something really wrong and you just sort of think, does this lead to a hysterectomy? How far does it go? And at thirty-two I hadn’t had any other children, and I
wanted to! So it was a very bad scenario for me ...//... Still a bit scared, to think you know, have they treated it all, you know is it going to come back? ...//... Am I going to be all right after this? Am I going to have kids? All those things go through your mind. You know, my future has sort of gone off on a little side track. (Julie)

Melanie and Julie both confirmed Toombs’ (1987) argument that in health a person takes for granted that their future will be available to them but in illness, ‘the future is suddenly disabled, rendered impotent and inaccessible’ (Toombs 1987, p. 234).

Julie again discussed how this experience of having the abnormal Pap test result very clearly reminded her of her own mortality. The abnormal Pap test result had occurred eight years prior to interview but the scars to her psyche persisted and she cried as she recalled:

_I suppose everybody has it in the back of their mind that they are going to die ...//... I think that would be the worst scenario. But that’s what probably goes through your head ...//... eight years ago ...//... I think it is getting easier. I sort of try not to think about it ...//... It tells you that you are not invincible ...//... We’re human...//... you become very conscious of yourself not being immortal._ (Julie)

Marie spoke her fears aloud to the receptionist at the colposcopy clinic:

_I just really let off at this receptionist on the phone and said, ‘Don’t you realise I’ve got cancer in my body, and I could bloody well die and I’ve got two small babies and I’ve got a husband. And really I’m terrified out of my brain ...//... this is the third bloody time you’ve cancelled me and I could be having third grade cancer and I could be dying’ ...//... For me it was like I was sitting on a time bomb. That I had cancer._ (Marie)

Like Marie, Terry’s fears and her anxiety were exacerbated when further procedures needed to be delayed. In Terry’s case, because she was menstruating:

_We’re scheduling [the Lletz procedure] for the following week, the 29th. 28th that night I got my periods. So we then rescheduled for the 5th and I was, this was the point where I started to get anxious! This is the point where I felt sick! I was just sick in the stomach, knowing that I couldn’t have this thing done. I just wanted to get rid of it ...//... I just wanted it out of the way; I just wanted it finished! And this wasn’t a good sign._ (Terry)

Terry shared how she tried to keep her mind blank during the procedure and then she explained the reason why, and in doing so indicated her belief that the abnormal cells being removed from her cervix were cancer:
I try to keep my mind blank about it actually. I, I’ve had half my family die from cancer ...//... I’ve watched people die horrible deaths from cancer. (Terry)

Ann’s story was unusual when compared to the other informants’ in this study. Many of the other informants described how needing to wait for further investigations and treatment exacerbated their anxiety. Ann, however, described how she needed to give herself time before she felt ready to deal with the sequelae of having an abnormal Pap test result:

I rang and the receptionist said that you’ve had an abnormal result and you need to come back and have another smear done. I said, OK then, hung up and waited 6 months ...//... and then I got to the point where I thought, ‘OK. I think I’m ready to go and deal with this now’. I had no idea of the degree of abnormality or anything else but I didn’t want to have to deal with it. My mother and grandmother had both had hysterectomies as the result of abnormal Pap smears and fair enough that was in the days when, if anything was a bit abnormal they ripped it out. And yeah, I just didn’t want to deal with that ...//... I think at one stage I actually turned to drugs a little bit, um, marijuana main, no that was it ...//... I didn’t want to feel or think anything to do with the Pap smear thing. (Ann)

The contrast in Ann’s story was that she controlled the timing of when she sought out further investigations and treatment. Ann knew when she was ready and that was when she sought medical advice and not before. There was a strong family history of abnormal Pap test results and Ann’s biggest fear was not the abnormal Pap test result nor the fear of cancer but the possibility that, like her mother and grandmother, she would require a hysterectomy and not be able to have any more children. Ann gave herself six months before returning for further investigations following the initial abnormal Pap test result:

But it took 6 months to get to the point, where I went back to my own doctor ...//... I didn’t want to discuss it, I didn’t want to know anything about it ...//... They’re going to give me a hysterectomy! And I don’t want my choice or my decision for children taken away from me ...//... If it’s cancer, it’s cancer but it’s not going to change that much in 6 months or 12 months or whenever I decide – I’ll deal with it then. (Ann)

Fear for their future fertility was common for the younger women in this study. Annabelle, Julie, Ann and Megan’s fears, following the colposcopy and biopsies, related to their concerns that the results and consequent need for treatment may have affected their potential to have children:

After all this happened it was, there was a fear of not being able to have any more kids! ...//... And I really wanted another one ...//... But there
was a big fear that I couldn’t have any more children ...//... I always hated the thought that I couldn’t have any more. (Megan)

I was really worried ...//... whether it affected my ableness to have children ...//... I just had a whole heap of horrible thoughts ...//... being told that I would never be able to have kids. I couldn’t – one the pelvic inflammatory disease and then two, is what I’m scared of having this Pap smear too ...//... not being able to have kids. (Annabelle)

Annabelle and Ann’s fear was compounded by their family history of cervical pathology:

[My mother] also notified me that there is a history of cancer as long as her arm, which goes through to my grandmother – she had to have her breast removed. Um, my aunty, she had cervical, no sorry, all of my aunties have had cervical cancer and have had it removed. My mother had to have ...//... a hysterectomy to remove in her, on her cervix. (Annabelle)

My mother and grandmother had both had hysterectomies as the result of abnormal Pap smears. (Ann)

Very little research has been published in regard to CIN/cervical cancer and family predisposition to the disease. Hemminki, Dong and Vaittinen (1999) concluded that, while family clustering was consistent with a possible genetic causative component, it was impossible at this stage to differentiate between environmental and genetic causes. For example, common family lifestyle factors predisposed women to be exposed to HPV infection and to develop CIN/cervical cancer and this may have been the link to family clustering that Annabelle and Ann described, rather than, or as well as, a genetic cause. While of academic interest, the cause and effect of genetic versus environmental linkages was not of great importance to Ann and Annabelle, but rather the fact that members of their family were treated for abnormal Pap test results by having a hysterectomy. Both women had a desire for pregnancy and children in the future and felt extremely vulnerable to the possibility that this choice could be taken from them. Known treatment options for the abnormal Pap test result jeopardised Ann and Annabelle’s self-identity and led to feelings of abjection – their sense of self being integrated with their fertility was under threat.

The informants in this study described their fear when they learnt that their Pap test result was abnormal. That fear was exacerbated because many of them felt they had to endure the experience alone.
Loneliness

As sickness is the greatest misery, so the greatest misery of sickness is solitude ... Solitude is a torment which is not threatened in hell itselfe.
John Donne in Rhodes 1987, p. 106

These words written by the poet John Donne (1572–1631) were expressed at a time when he mistakenly believed he was dying of the plague in London. Many of the informants in this study also had the mistaken belief that their abnormal Pap test result was life threatening. For example, Annabelle, Margaret and Melanie shared:

Then I really stressed out ... I just had a whole heap of horrible thoughts. (Annabelle)

I had that Christmas thinking, ‘I've got cancer! I'm going to die!’ Basically, and ah ... it was just awful! (Margaret)

I thought I was going to die ... But I wasn’t ready, I’m not ready to die. I was scared, that was my thought. (Melanie)

Younger (1995) argued that all suffering, including the threat of cancer and death, brought with it loneliness or a sense of alienation from others. Suffering first alienated the person from themselves and then alienated the sufferer from others. Scarry (1985) concurred and added that suffering led to feelings of self-alienation, self-betrayal and self-hatred. Marie epitomised these feelings when she said:

All I felt was that I was cheap and dirty and disgusting. (Marie)

Some of the participants reflected self-alienation and disembodiment when they shared their desire to be rid of ‘it’. The sense that women needed to ‘rid’ themselves of the abnormal cells (‘it’) was a theme in many of the interviews. The abnormal cells had become an identity, an ‘it’ that the participants felt they needed to rid themselves of as soon as possible:

That’s what my concern was – to get this dirty thing off! (Jayne)

I just wanted to get rid of it. (Terry)

I’ve got to get rid of it. (Rita)

Janette’s vocal intonation implied that the changes occurred to her body rather than her self. Her voice had a detachment, almost as if she was relaying someone else’s story and the inflection was directed on the word ‘body’, rather than the ‘my’:
It was pretty scary stuff! I wondered how it all occurred. How it happened to my body. (Janette)

In mid-sentence, Faye contrasted her ‘I’ with the ‘it’ of the abnormal cells detected on her cervix:

*If I was having them every two years I wouldn’t have got as far as I did or ‘it’ wouldn’t have got as far as ‘it’ did I suppose.* (Faye)

The sense of disembodiment described by participants is also portrayed in gynaecological textbooks. Smith and Condit (2000) analysed the medical construction of the pregnant body in *Williams Obstetrics*, a textbook studied by obstetricians/gynaecologists and published continually from 1904 to 1997. They discovered that ‘normal’ pregnant bodies were virtually absent in the text and female bodies were fragmented and pathologised. Smith and Condit (2000) concluded that the resulting medical and social construction of the female body in the *Williams Obstetrics* textbook was one of disembodiment and abjection.

In contrast to Janette, Jayne was vividly aware that the area being burnt was her, the intonation and verbal inference was on the ‘my’ – the area being burnt was her, not a detached part. Jayne was unable to disassociate herself from the smell; the burning had become embodied. Leder (1984) argued that one of the flaws of the current medical system was the adoption of the Cartesian notion of embodiment. Taking Jayne’s experience as an exemplar, Jayne presented herself for treatment and the specialist treated the Cartesian or object body, which was her vulva that showed signs of HPV. To a certain level, Jayne experienced her body during the examination as a scientific object beneath the dispassionate gaze and the probing, palpating fingers of the specialist:

*Basically another set of hands and eyes peering inside.* (Jayne)

But once the treatment got to the stage where Jayne felt her very being was threatened – abjection, she realised that her body was her:

*It was my area being burnt.* (Jayne)

From Jayne’s story, it appeared that the specialist did not share this perception. He was intent on treating the HPV. Jayne described his neglect of personal communication in favour of the immediate medical task at hand, lasering her vulva. From Jayne’s perception, the specialist disregarded her needs and did not adequately take into account her life context and lack of knowledge about the medical treatment. Jayne believed there
was a direct correlation between the gynaecologist’s actions and the fact she later developed secondary vaginismus.

Jayne realised that it was ‘her area being burnt’ and Terry was shown ‘her’ cervical biopsy, which she was not interested in seeing. The biopsy was taken and Terry related this to her feelings of having been invaded. She reported feeling vague and empty. Terry had arranged for her daughter to be cared for by her grandmother the night of the biopsy. On many occasions during the interview, Terry likened her experience of colposcopy and treatment to her experience of childbirth and, symbolically, it was only the presence of her young daughter that was able to relieve her feelings of emptiness:

*I can see when he takes the piece out. It’s like a five cent piece and it’s a thing like this ...//... they get it and they put it in a jar and they show it to me ...//... why should I be interested in this? ...//... I was empty. It was that bit that they got out of me if you like! It was like I just felt, I felt invaded! ...//... That’s how I felt. I just felt invaded. I felt like, I felt like there was a great big hole. And it was gone ...//... I felt really empty ...//... vague and empty ...//... [The biopsy's] a good hunk of you ...//... Like a bit of liver! Not as red as liver, more pink ...//... Yeah, See I don’t think I needed to see [the biopsy specimen]. If I hadn’t seen that, I don’t think I would have had that feeling ...//... I just bawled my eyes out ...//... Still empty. Very twitchy that night, very twitchy in bed. Bad night’s sleep ...//... I’m used to my daughter considerably! ...//... And three o’clock in the afternoon ...//... I got up, I went to the bathroom, I put a face on, I got in the car, I drove down to the school, I picked her up ...//... I felt a lot better then. I felt a lot better with my girl with me. (Terry)*

‘It’, that is, the diseased cells, added to the women’s sense of abhorrence; they felt alienated from their ‘self’ and others and this alienation compounded their feelings of loneliness.

Loneliness can be trivialised or go unnoticed by nurses and other clinicians who might be focusing on the client’s physical needs or recovery process. Nurses may feel inadequate because they cannot cure the loneliness. However, Killeen (1998) argued that loneliness required awareness not a solution. No woman in this project expressed any expectation that any health professional would relieve their loneliness, what they longed for was an acknowledgment and validation of their feelings. Feelings of loneliness (isolation) exacerbated these women’s misery. Although loneliness for many women in this study preceded the experience of having the abnormal Pap test result, the experience heightened what John Donne poetically described above as their ‘torment of solitude’. The impact of loneliness was devastating and easily recalled even decades
later. Rokach (1990, p. 41) stated that ‘acute loneliness is a terrorising pain, an agonising and frightening experience that leaves a person vulnerable, shaken and often wounded’. Janette, Megan, Melanie and Marie described that acute pain of loneliness. Janette wondered if there was a normal way to feel after being told of her abnormal Pap test result. Janette and Marie described feelings of loneliness, of having to go through the experience on their own and unsupported:

*It was a pretty terrible feeling. It was pretty much like I was alone again. Alone like I was when I had the miscarriages. I felt so alone. I wasn’t sure if this was the normal way to feel. Or if it was just something more, more that I had to cope with on my own ...//... A real loneliness ...//... Feeling terribly alone.* (Janette)

*It was a very lonely time. Because I had to do it all on my own.* (Marie)

Megan’s sense of aloneness persisted:

*I still feel out on me own. That’s because I’ve got no, no family to talk to ...//... I just keep it to myself.* (Megan)

Melanie’s simple statements cannot possibly convey the depth of the hurt, fear and loneliness her silent sobbing and body language gave witness to:

*Very lonely ...//... you know, so alone.* (Melanie)

Melanie’s story revealed a profound loneliness that was made worse by the abnormal Pap test result. Killeen (1998), himself a sufferer of loneliness, suggested that loneliness is a condition that is both distressing and dehumanising. It causes a person to have feelings of detachment when they endure emptiness in their life due to unfulfilled social and/or emotional needs.

Marie found it difficult to explain to her partner what was happening to her when she didn’t understand it herself. Her husband was experiencing business problems at the time and this added to her sense of facing the problem of the abnormal Pap test result, investigations and treatment alone:

*It’s sort of – it was a very lonely time. Because I had to do it all on my own.* (Marie)

Marie’s feelings of loneliness added exponentially to her sense of guilt:

*Based on the guilt that I had about having had multiple partners prior to my relationship with [husband]. I felt guilt that maybe I had gave him HPV virus, ...//... you know, where did I get it off, who did I get from and the guilt around that.* (Marie)
Marie felt so disgusted with herself that she was hesitant to ask the colposcopist questions:

*But I never thought to ask more questions either ...//... Denial, fear, um, yeah, the obvious fear that if I learnt any more then I'd be more disgusted about, more likely to feel awful about myself about and also coming down on myself for choosing such disgusting, grotty partners as well ...//... The denial that I didn’t want to know that I had something like that inside me. (Marie)*

Feelings of self-disgust added to the loneliness and sometimes led the women in this study to believe that their abnormal Pap test result must have been punishment for past wrongdoing.

**Guilt, judgment and punishment**

*I definitely do think it is a punishment (Megan)*

Cervical screening creates links between a woman’s sexuality and medical dependency. Past and/or present sexual expression is medicalised during the cervical screening process and any sequelae when the Pap test result is abnormal. Oriel’s findings from 1988 remain unchallenged in the literature that the two key variables associated with cervical cancer, and by implication CIN, relate to early coitarche and lifetime number of sexual partners. Accepting assertions about the association between CIN and the number of sexual partners a woman has had, had devastating implications for some of the participants. Marie, Faye, Ann, Jayne, Megan and Rita, for example, expressed their belief that they must be to blame for their abnormal Pap test result. They and the literature tended to ignore or downplay any contribution that male sexual partners may have had in the aetiology of CIN. Women, like Faye, may have only ever had one lifetime sexual partner but the risk of CIN increased with the number of sexual partners their partners had (Buckley *et al.* 1981; Oriel 1988; Kjaer *et al.* 1991; Lovejoy 1994).

From the beginning of recorded time in Judeo-Christian-Islamic cultures, it is the female who has been blamed in Scripture interpretations for bringing disease and death into the heterosexual relationship. More recently, in the Victorian era, female prostitutes were blamed for the increase in sexually transmissible infections (Oriel 1988). Today, CIN continues to be linked with female ‘promiscuity’, however that is defined (Lovejoy 1994; Whelan 2000). The adverse effects of male sexual behaviour continue to be largely ignored. However, male sexual activity is an important risk factor, and in many
instances the woman’s risk of developing CIN depends more on her male partner’s sexual behaviour than her own (Oriel 1988).

Health education literature perpetuates the concept that it is primarily female sexual activity in a heterosexual relationship that causes CIN. Health promotion pamphlets read by some of the women in this study linked the number of sexual partners a woman had with CIN. Faye was disturbed to read a pamphlet that implied her abnormal Pap test result was linked to promiscuity. She said:

_I read a book, a pamphlet [WHN] gave me once, that it said, um, most women get this if they’re promiscuous ...///... And I thought that’s a downright lie! ...///... That’s a damn lie that is! ...///... Because I’ve had one partner and one partner only._ (Faye)

Megan, having read health promotional material, felt that she must have been responsible for causing her abnormal Pap test result:

_In the books I was reading ...///... I had a few partners. Probably um, about three I suppose. I don’t know whether that had any effect or not ...///... [The books] keep telling you, it’s your own fault for sleeping around or something, that’s sort of, that’s how I took it when I read it ...///... I really don’t think you need to read that when you are going through something like that._ (Megan)

As a consequence, many of the women in this study shared their feelings of self-loathing and guilt that they had been responsible for the changes to the cells on their cervix. Rita and Megan both perceived that their abnormal Pap test result was a punishment. Megan shared how, on leaving her violent marriage with two toddlers, she found she was pregnant and could see no alternative but to have an abortion:

_I had an abortion. This would have been my third child. Because I had a two-year-old and a one-year-old and uh, my doctor, who happened to be a really good Catholic. I know I could have coped but, you know, and I do think that you know, that it has had some bearing on this bad Pap smear too ...///... in one of those books that I read, um, it said, having an abortion might cause it. That was another thing I didn’t like to read. Because nobody knows, only my mother and father and you now ...///... I um, I read that ...///... this friend of mine, I was telling you about, she had an abortion, um, last year, and now she has got the same thing ...///... Dr [Name] told her it could be the abortion, too ...///... I mean you wear enough guilt with an abortion, without that! ...///... It is a terrible thing to live with, especially when I love kids and I wanted to, but you know, my marriage. And I lost the next one, a little girl. I was six months pregnant with her when I married [second husband]. And um, I do, I definitely do think it is a punishment._ (Megan)
Megan’s sense of guilt and blame was perpetuated when she read the assertion that abnormal Pap test results were linked with having had a termination of pregnancy. Other women who had terminations of pregnancy also voiced their concern that there may be a relationship between cervical cancer and abortion (Tankard Reist 2000). Oriel (1988) argued that there is no association between abortion and cervical pathology and, in a Taiwanese study that associated a history of two or more induced terminations of pregnancy (TOP) with CIN, no consideration was given to stressful life events that led to a woman having a TOP that may have acted as confounding variables (Wang & Lin 1996). However, the link between abortion and abnormal Pap smears continued in both the health promotional materials Megan read and the rhetoric she heard from a medical practitioner. This information exacerbated Megan’s feelings of guilt and sense that she was being punished.

Rita believed she was being punished because of incest and her subsequent sexual ‘acting out’:

> Because of the timing about having the [abnormal] Pap smear, I think I felt a little bit like I was being punished for some of the promiscuity. Um, and some of the perhaps, punished for incest ...//... So there was a whole lot going on for me at the time and then the [abnormal] Pap smear came and it was similar thing. Oh God, this is all about this and how come it’s my sexuality, all my sexual organs that are being constantly under attack. (Rita)

Rita described the process of having a colposcopy and laser treatment to her cervix as:

> It was traumatic on one level ...//... but it was more about what it brought up for me in terms of the previous stuff and what that might have actually meant. (Rita)

For Rita the adverse effects of the colposcopy and treatment added to her discomfort, feelings of guilt and fear of judgment in relation to her sexuality. The guilt experienced by many of the informants in this study related to their interpretation that an abnormal Pap test result indicated to them and others that their sexuality having been exposed, meant that they were somehow dirty.

**Feeling dirty**

> It’s sort of dirty, you know, you feel like scrubbing yourself (Faye)

Rita spontaneously raised the subject of feeling unclean, but said these feelings were more at a subconscious level than a conscious one:
I didn’t feel unclean consciously but I think that’s part of it. The punishment stuff was probably because I felt I needed it which means I’d been naughty or whatever ...///... So I suspect I felt some levels of uncleanliness although I wasn’t consciously aware of that. (Rita)

For other informants the feeling of being unclean was at a more conscious level. Faye felt dirty and needed to wash when she learnt of the abnormal cells on her cervix:

I’ve always been a clean sort of person. I mean I’ve always showered and everything like that ...///... Yeah, I felt a bit dirty ...///... I felt like I wanted to go and have a really good bath ...///... I needed to go and wash me hair and have a bath and scrub myself ...///... It sort of reminds me of venereal disease ...///... It’s sort of dirty, you know, you feel like scrubbing yourself. (Faye)

‘Rubbish’ was a word Joyce used six times during her preliminary interview and she used the term in a number of different ways. When her beloved husband died suddenly in bed beside her, Joyce went on to experience frequent episodes of post-menopausal bleeding for twelve years and had innumerable gynaecological investigations before she was eventually diagnosed with adenocarcinoma of the cervix. Joyce described this persistent post-menopausal bleeding as ‘rubbish’ – she saw her bodily response to such profound grief as a trivialisation. Joyce reflected on the medical practitioner’s comments who also described her uterus, her self as full of ‘rubbish’ in the context of being full of garbage or dirt. Following her hysterectomy, Joyce had a severe infection that led to her wound dehiscing and again she described the ‘rubbish’ that came from her. Whatever the context, Joyce – her self and the ‘rubbish’ were inextricably linked during all of her descriptions:

I mean, what do you want me to say? Back when I started all this rubbish? ...///... To have all those bleedings. It just seemed so ridiculous, but you know what I mean. But I think when [husband] died, because he died at home in the bed beside me ... (Joyce)

I, you know, had that awful time them in [Base Hospital]. Cos they reckoned I was just full of rubbish. That’s the word he used, rubbish! ...///... They had to give me two or three blood transfusions to get it all, because of all the rubbish! (Joyce)

Although Joyce was the only informant to use the term ‘rubbish’, both the participants and others commonly perceived HPV as something dirty. Jayne recalled having discussed the concept of HPV during a women’s health education session:

We were talking about human papillomavirus and the wart virus, and one of the ladies, her reaction ...///... ‘Oh my God, you know, what’s that?’ ...///... The same ignorance but you know, the look on her face was,
'Oh my God, that’s a dirty thing!' ...//... Wart virus, it’s passed on from people to people and it’s probably perceived as an unclean thing. (Jayne)

When Jayne consulted the specialist for the colposcopy, he confirmed HPV as the diagnosis, assumed it had been sexually transmitted during a previous sexual relationship and told Jayne so. Jayne felt dirty and her feelings of dirt were compounded by a sense that she was being judged by the gynaecologist. Later in Jayne’s story, we hear that feelings of dirtiness and shame combined with the medical practitioner’s attitude to cloud her ability to make informed choices. At this stage Jayne was not angry at the gynaecologist for his moralistic and judgmental overtones, but rather with her own ignorance. Ignorance in not having practised safe sex and ignorance in her acceptance of medical treatment that was to have serious iatrogenic effects:

[The Specialist] said, ‘you have human papillomavirus’. I said, ‘What’s that?’ And he said, ‘It’s a sexually transmitted disease that you’ve probably picked up from a previous boyfriend’ ...//... and I knew that that [my previous boyfriend] had slept with another girl and that’s what made us break up and we had problems, and you know it was just so ignorant with me at that age not to have been more careful ...//... When [Specialist] told me that’s what the problem was, that’s what I focused on. I focused on that I had this wart virus that I had picked up from a previous boyfriend, um, which made me feel very dirty ...//... it was mainly feeling very dirty ...//... And of course I was very upset and of course I was very worried for [husband]. I thought, ‘Oh my God, what have I given you?’ ...//... And once again due to my ignorance and lack of knowledge and I guess feeling very insecure at the time and feeling the way I did. [Specialist] suggested he could just you know, laser it off. And I had no idea what he meant, no idea! ...//... He suggested that I have this laser surgery and I said fine ...//... All I was concerned about is, is it going to make it go away? ...//... That’s what my concern was – to get this dirty thing off! And really afterwards I found out, I think [female gynaecologist] told me, you know even nuns get it and you know when you’re young and something described to you like it was – made you feel very dirty! ...//... The worst part was – my ignorance! ...//... You know I never questioned [Specialist]...//...I guess because I was so vulnerable. (Jayne)

Marie described feeling dirty and recounted a flashback experience to another time in her life when she felt dirty and disgusted with herself:

It made me feel dirty ...//... I didn’t understand what HPV virus was ...//... The sense of feeling dirty came after the gynae explained to me what HPV virus was. And it was all in the context of sexually transmitted diseases ...//... One of the guys that I got involved with ...//... He was just awful, but he was heavily involved in the drug scene and in prostitution ...//... and I didn’t feel good about myself at that time ...//... And what happened was he got um, he got non-specific urethritis – picked it up from somewhere ...//... And I felt absolutely appalled, I was so disgusted
with myself ...//... That whole thing about having an STD, and my God, you know, I’ll never have another sexual life, sexual in my life again ...//... the way I was treated at the Sexual Health Clinic was pretty poor too ...//... all I felt was that I was cheap and dirty and disgusting ...//... So then when the gynae told me that I had HPV virus and that it was sexually transmitted disease. It was like – ‘Oh shit!’ You know, so you felt, all those feelings that happened to me when I went to the STD clinic came back to me again and made me feel really disgusting and dirty all over again. (Marie)

Kristeva (1982) described how women continue to define and redefine themselves according to traumas they have experienced. Marie’s experience of feeling dirty during the colposcopy experience was compounded by her earlier experience of feeling cheap, dirty and disgusting at the Sexual Health Clinic and in response to her stepfather having overstepped incestuous boundaries with her. Marie’s reliving of her feelings from being screened for a sexually transmissible infection and living through her stepfather’s abuse echoed Kristeva’s theories:

I actually found a whole lot of pornography in his place, that was all to do with incest and so that was kind of the end of the wall for me, the fantasy that was going on for him ...//... You know, it’s all about feeling dirty and where did I get all this from. You know my choice of partners and my own self-esteem ...//... I’m not worthy and it comes up in my relationship with [husband] now ...//... I’m not worthy to have someone as good as [husband] or as compassionate as [husband] ...//... feeling dirty about the diag – you know something wrong with my cervix or whatever. (Marie)

Marie’s esteem, her sense of worth, was threatened because of her stepfather’s incestuous abuse and her previous choice of sexual partners. She felt ashamed and damaged by the incest and her sexual history. Whether or not they shared a history of sexual abuse, the overweight women in this study also shared similar stories of feeling ashamed.

**Body dysphoria**

I’m feeling like a monstrous sort of person (Annabelle)

In contrast to feelings of blame that another had damaged them, the women who were overweight in this study felt ashamed of their body size and shape and their stories reflect self-blame. Feelings of abjection and self-loathing were exacerbated for the women in this study who felt alienated and unaccepted by society because of their body shape.
Annabelle and Ann, like the vast majority of overweight and obese women in American studies (Sarwer, Wadden & Foster 1998; Pesa, Syre & Iodes 2000; Goodman, Hinden & Khandelwal 2000), expressed body image dissatisfaction and low self-esteem related to their weight and body image.

Ann’s sense of awkwardness, shame and embarrassment was compounded because the gown she was given to wear did not fit her:

_They had the gowns that lace up the back but being bigger, those gowns don’t always fit and they’re very tight in the arms so you have to have it really loose around the neck and sort of half way down your arms to get it to – so you don’t feel like you’re choking ...//... I was more embarrassed about the fact that the gown didn’t fit properly than what I was going to have done. So it was more a thing about my weight ...//... I became much more conscious about my weight ...//... I’ve always had a problem feeling that I was much more overweight than I should be and self-conscious of that ...//... it was just the self-conscious._ (Ann)

Annabelle, already feeling embarrassed by the presence of four people being present for the procedure, expressed intense relief that the hospital gown she had been given to wear for the colposcopy was big enough:

*I had one of those sort of surgical gowns ...//... it went all the way around thank God._ (Annabelle)

Annabelle’s body dissatisfaction surfaced during the interview. At one stage she said:

*I hope to join [boyfriend] soon and then I’ll look alive again! And I’ll lose all my, all this, all this yucky weight! ...//... I hate being the size I am ...//... I know I can’t lose it in my shoulders, because they’re from shot putting and athletics and wood chopping and all those things I used to do when I was younger. Which I still do at times now ...//... It bothers me when my boyfriend pervs at skinny people ...//... I wish I could be that size again. I wish I could be skinny again, but, I used to be a size 14 and now I’m a size 22 or 20. I’m slowly going down which is good. I’ve lost a little bit of weight over the last couple of weeks. I feel like a, like a beached whale at the moment ...//... so I’m feeling like a monstrous sort of person ...//... it’s always being asked, ’why can’t you go back to the same size you were?’ (Elaine: who asks you that?) ...//... My parents, my nan, my brother, my boyfriend, everyone! ...//... Sometimes, sometimes it really hurts._ (Annabelle)

Annabelle and Ann felt shame and stigma. Their above average body weight disqualified them from feeling socially acceptable.

The extent of body dissatisfaction can be life threatening and Carpenter et al. (2000) reported that being overweight is associated with major depression, suicide attempts and
suicide ideation. The correlation between obesity and psychological morbidity is to be expected in a society preoccupied with thinness and where the overweight person, especially the overweight woman, experiences stigma because of her body shape and societal and media pressure to be thin (Tiggemann, Gardiner & Slater 2000).

Goodman, Hinden and Khandelwal (2000) argued that obesity is socially constructed and has inherent psychosocial implications and meanings for the individual woman. The social construction of obesity is evidenced in medical advice given to obese women. Medical discrimination against the obese woman reflects societal attitudes and prejudices. Illich (1976a) argues that medicine is both influenced by and influences what is deemed socially acceptable. The abjection that the overweight women in this study felt was compounded iatrogenically and confirmed the argument that medicine is an agent for social control over women’s bodies (Illich 1977; Miles 1991; Oakley 1986). Wright (1998) found evidence that medical practitioners, reflecting society’s abhorrence to female fat and the lack of acceptance of the female shaped body, subjected overweight women to humiliation and discrimination. Adipose connective tissue or fat and, by implication, the ‘fat woman’ are considered unhealthy. No regard is given in medical discourse for the physical benefits of fat, including fat as a provider of heat, as a store for oestrogen and for immunological functioning and the fact that risks from dieting outweigh any physical risks from being overweight (Wright 1998). Ann and Annabelle saw nothing positive about their body size and they blamed themselves for being overweight. Self-blame, however, was not confined to those women who were ashamed of their weight.

**Self-blame**

*Perhaps it was my physical shape …/… that caused him to make the mistake* (Janette)

Whatever their body shape and size, the informants in this study who were suffering from the iatrogenic effects of their treatments knew that the gynaecologist had made mistakes and yet they blamed themselves for the errors that had been made. The gynaecologist had erred in his biopsy technique but Janette made excuses for him and blamed herself for his error:

*I trusted this person to do what he was trained to do. And I’m not sure, maybe my physical shape is so difficult to everybody else’s, perhaps it*
was my physical shape, I don’t know, that caused him to make the mistake. (Janette)

Jayne blamed herself for not questioning the gynaecologist who attended laser surgery to her vulva:

The worst part was – my ignorance! ...//... You know I never questioned him ...//... I guess because I was so vulnerable. (Jayne)

The tabloid press (Whelan 2000) blamed women for not attending follow-up appointments when they had an abnormal Pap test result and Terry blamed herself for not seeking out the results. A number of weeks after the Lletz biopsy procedure, Terry had received the bill but no biopsy results. Terry blamed herself:

I suppose I should find the results. That’s a bit poor isn’t it? (Terry)

Self-blame took many forms. Rita believed that the abnormal Pap test result reflected what was going on for her emotionally at the time and was the legacy for not living naturopathically:

I didn’t feel that abnormal Pap had anything to do with what I put into my body in terms of food and perhaps, it had something to do with what I was doing emotionally and mentally, probably did! But um, I felt it was more than that and I felt it was from times like the wart virus and herpes and those things were from times when I didn’t understand anything naturopathically and didn’t live it and this was the legacy. (Rita)

A few years after the abnormal Pap test result, Rita developed unrelated gynaecological problems that necessitated the removal of her uterus. A woman who was extremely careful about taking care of her own health, Rita described her feelings of failure. She was no longer able to take her body’s compliance for granted:

I’d failed naturopathically, because I was having invasive surgery. Parts of me were being removed that I had never expected and had never had hoped would have happened ...//... Because of living holistically and believing in all those things, it was never what I wanted. I was very proud of the fact that I had never had appendix and tonsils or anything else out. So I went through quite a lot of, probably feeling guilty unnecessarily, of course! About that and then, I grieved for my nest, I grieved for my babies’ home, first home. I grieved for that, this part of me, that was one of the things that made me clearly female and clearly a woman and I was very proud of being a woman ...//... I love being a woman and it was one of the things, I’m not saying it was what determined me as a woman, but it was one of the many rich and complex things that made me a woman. (Rita)
Faye repeatedly blamed herself for the abnormal cells on her cervix:

*I was diagnosed with CIN 3. Now that was entirely my own fault! ...//... Because I was under the impression that you didn’t have to have Pap smears if you weren’t sexually active. Where I got that idea from, I don’t know. I just thought that! ...//... I thought, well, you silly woman, it’s your own fault! For not having had one [Pap test]. ...//... If I’d been having those Pap smears, I mightn’t have had to have those colposcopies every year now ...//... And then I go back to saying, well – it’s your own stupid fault! ...//... You lose track of time ...//... it’s no excuse. You see it on the TV now.* (Faye)

The informants in this study blamed themselves for the sense of abjection they experienced. This abjection was verified by the assault on their senses that took place when they had further investigations and treatment for their abnormal Pap test result.

**Bleeding**

*Bled like a stuffed pig!* (Marie)

For many women, the sights, smells, sounds and sensations that accompanied further investigations and treatment for their abnormal Pap test result added to their distress and the sense they were under threat. For example, many of the informants expressed surprise at the amount of blood lost during treatment.

Jayne, Annabelle, Marie and Megan described their bleeding:

*I had this big pad stuck between my legs because I was just bleeding – profusely!* (Jayne)

*Then they said, ‘Oh, we’ll have to take the blood out’ – What blood? ...//... That freaked me out! I thought, ‘I’m bleeding!’ ...//... then they had troubles stopping the bleeding afterwards.* (Annabelle)

*It bled like a stuffed pig.* (Marie)

*I had to have the surgery ...//... and I haemorrhaged. So I had to stay in overnight, because I lost a lot of blood ...//... I was unconscious. I was under anaesthetic. But yeah, when I came round I was in the hospital ward. I was supposed to be only in and out, so it was when I woke up and found out what was happening ...//... when I bled, they packed me to stop the bleeding and they took me to a room.* (Megan)

The informants had not been adequately warned to expect bleeding during the colposcopy and biopsy. They felt surprised, frightened and threatened by the unexpected blood loss and what had been done to them.
The smell

*That’s your flesh that you can smell burning* (Rita)

As well as surprise at the amount of blood lost, many of the informants discussed the ghastly smell of the laser or diathermy treatment. Julie found the colposcopy process reassuring, but like almost all of the informants she vividly recalled the smell of the laser treatment:

*The worst part of it for me, I think was the burning skin smell .../... that was horrible. Even [husband] said, Oh the smell of that was, no, really horrible .../... I mean it was horrible the smell.* (Julie)

Jayne described the experience of laser treatment to her vulva vividly. She likened the experience to something she had done to animals:

*I had the laser surgery done. I had many needles in the lobe area, um, to numb it obviously .../... on the outside, on my vulva .../...And the smell, I mean I get my horses hot shod, or I used to in Sydney which is basically burning off a shoe and burning it into their foot. And that is a ghastly smell and it was a very similar smell. I mean it was my area being burnt .../... I really didn’t have to go through what I did and I think being on the outer area, like it was just burnt to a crisp! .../... I had it done and walked out .../... he just burnt it to a crisp! I looked like a sun-dried tomato that’s burnt!* (Jayne)

Rita, like Jayne and Ann, had embodied the smell of the laser treatment. Rita used the word ‘wonderful’ in a sarcastic way:

*The wonderful smell, as you’re lying there knowing that the cells, that’s your flesh that you can smell burning.* (Rita)

Ann described the nauseating smell involved with having the laser treatment, made worse by the realisation that it was her body burning and the fear that if she moved, she risked serious injury from the laser:

*I think it was with the laser, I just wasn’t sure what they were doing .../... the smell made me sick! .../.... The pain was really uncomfortable but the smell made it worse! I mean I think I could tolerate that smell, if it wasn’t coming from me! .../... I was holding the nurse’s hand and I know that it hurt a considerable amount because I had tears rolling down my cheeks while she was doing it. And um, and I think a combination of the pain and the apprehension, that yeah, it was um, I just kept shutting my eyes or keeping my eyes shut and I was trying not to cry. Because I thought if I cry, I’m going to be jerking around here and I don’t want them to hit something that they’re not supposed to hit.* (Ann)

The smell was more horrific because each woman knew that it was her cervix, her flesh, her self that was being burnt. Burning usually causes irreversible damage and it is not
possible to resurrect something from the ashes. Some of the women in this study feared they would be permanently and irreversibly damaged by the procedure, that they would be:

    Burnt to a crisp! (Jayne)

The smell of the laser and their flesh burning were reminders of that threat as was the unexpected pain some of the women experienced.

The pain

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Women, including Ann, Terry and Marie in this study, experienced pain when traditional physiological understanding dictates that cervical procedures should not be painful unless they involved dilating the cervix (Malzack & Wall 1988; Mazza 1999). On occasions when the participants did experience pain, their report was negated, denied or they were blamed for the pain experience. This mirrored what Webb (1986) described when she was informed by the gynaecologist that she was experiencing a purely psychological reaction to the cervical procedure, because the procedure was painless.

Terry didn’t expect to experience pain. She experienced excruciating pain during the ‘Large loop excision of the transformation zone’ (LLETZ procedure). Both Terry and the colposcopist blamed her lack of relaxation on the fact that the wire loop touched her vagina. Terry described her experience:

    And then he starts working away .../... maybe ten or fifteen minutes into it – I just! Enormous pain! I just almost went through the roof [scream]. And what had happened is the wire loop had touched me on the vagina. Which was not anaesthetised and um, only the cervix was anaesthetised .../... And he was, you know, don’t get me wrong, he was really, really nice and like, ‘You need to relax Terry!’ Apparently I’d tensed up. But I mean I’m not aware of that .../... When it touched! Like I’m like this is worse than having a baby! .../... It was just like somebody had stuck a knife in me .../... I could see myself rising up through the roof .../... And you know, like I tried really hard .../... I’m trying really hard. And I’m really focusing on being relaxed and, and of course I’m terrified that that is going to happen again .../... I was just scared that it was going to happen again. And I’m trying really hard to be relaxed, because that is why it happened. Because I was all tensed up. How can you not be tensed up? .../... How can you not be tensed up when somebody is fiddling around in your fanny for half an hour? .../... I’m trying really, really hard and thinking, ‘God I wish this was over .../... this is not what I
expected at all! ’ .../... It’s scary, isn’t it? I mean you know, what happened to me was not nice! (Terry)

Many of the informants had been advised by health care professionals that the cervical treatment would not be painful. Written information explaining the treatment process to women claimed procedures such as a punch biopsy were painless or only mildly uncomfortable (Wilson 1994; Mazza 1999). The women then felt shocked when they experienced pain. Ann described the sensation of a frozen cervix as revolting and laser treatment as a sharp pain:

A frozen cervix which was horrible .../... revolting! Apart from just being completely yuck .../... it was uncomfortable .../... sickening feeling in the pit of your stomach .../... really deep, low sickening pains .../... just that sickening sort of feeling. (Ann)

A real sharp sort of pain sensation .../... I’ve had the freezing, I’ve had the laser and I’ve had the cone biopsy .../... I think the sharp pain was the laser. (Ann)

Marie felt betrayed as she had been informed by the gynaecologist that she would not experience pain during the biopsy procedure because, she said, there were no sensory nerves in the cervix. Marie explained:

[Gynaecologist] said to me, ‘Now I’m going to take four. I’m going to divvy it up into four, and take four biopsies and they won’t hurt, you won’t feel anything because the cervix, you have no sensory nerves in your cervix, you can’t feel anything’. And I fainted. I don’t know whether I fainted because I saw it up there on the screen and it bled like a stuffed pig or whether I fainted because, I mean I physically felt pain. I don’t give a shit what anybody tells me and it doesn’t make sense to me because the cervix has to have nerve endings in it .../... For her to tell me that I wouldn’t feel it. And then for me to still actually feel it – they were two different things! So I got really upset with that. (Marie)

The bleeding, smells and pain experienced by the women in this study heightened their sense of vulnerability and abjection.

**Vulnerability**

_I was like a canary with a broken leg .../... only hanging on with one (Janette)_

Sometimes vulnerability was accentuated by the woman’s consciousness of being reliant on others. Joyce’s reliance was on the nurse to provide adequate pain relief before removing the drainage tube from her hysterectomy wound but the analgesia wasn’t administered. During the retelling of the experience, Joyce referred to the ‘damn
mess’ that exuded from her body and she visibly paled when she described the pain she felt:

They were supposed to give me an injection to take that drainage tube out. My God, they didn’t! There was five seconds that, I held my breath I can tell you! But anyhow, I’m lying there in bed and this nurse came in ...///... it was only one thread ...///... She grabbed that end and she pulled it – oh my God! [wound dehisces]. You should have seen the eruption that came out of it. It was just blood and this watery looking stuff. And of course she looked panicky and she went and got the head sister on, on the floor. ‘Oh’ she says, ‘It’s better out than in’. And I thought well, that’s some consolation! And I went home see, and [daughter] came and got me and I came home. And I had all these pads and that, the whole way home, you know all this mess! ...///... They cut me right across there. And when they pulled the thread out, all this damn mess came out. (Joyce)

What Joyce described, in her understated way, was being discharged home (100 plus kilometres from the Base Hospital) in a private car with a wound breakdown that took many months of hospitalisations and twice daily packing by the district nurses before adequate healing took place. The nurses attending Joyce at the time of the wound dehiscence did not provide the prescribed pain relief and then negated the seriousness of the wound breakdown. Joyce’s focus on the retelling of the story was not on the nurses’ inadequate care but on the mess that she had made. Toombs (1987) described the type of situation Joyce was in when she wrote that, although the client may intuitively know the course of action recommended by the professional was not in their best interests, the person felt powerless to resist or fight the proposed action. To do so would seem irrational in the face of their perceived inadequate knowledge base compared with the health professional’s. In this instance, Joyce did not insist on pain relieving medication prior to the procedure or to remain in care after the wound breakdown; to do so would have meant alienating herself from the nursing profession that also had the power to alleviate her distress.

Janette’s reliance was on family to physically enable her to access health professionals. Health facilities are often inaccessible for someone with a physical disability. Janette was humiliated and distressed that she had to rely on other people in order to access health services and treatment for CIN:

Doctors are usually very hard for me to get to. When [estranged husband] and I were together and I used to have to get to the GP, he used to have to take the day off work to take me to the GP ...///... Used to physically have to carry me up those stairs and take me into, into the doctors ...///... The examination table was always terribly hard to, to get
onto physically. It meant that [estranged husband] or somebody who could lift me had to come with me and lift me from the wheelchair and up onto the table ...//... that meant somebody had to miss work to do that and it was always a bother for me to ask them to do that for me. It was always very difficult. Very difficult to ask for that. I found it hard ...//... I had parted with [estranged husband], so I asked my oldest son to take me there ...//... Pretty awkward, because it was like having a Pap smear, and having my son take me to have a Pap smear, having my son take me to that was pretty uncomfortable ...//... [Older son] had to physically lift me out of the chair and sit me on the table ...//... it meant he lost a day’s work and I had to ask for help, again! (Janette)

Janette experienced the gynaecological examination as ‘undignified’. A Microsoft Word thesaurus check provided synonyms for undignified that included ‘shameful, degrading, offensive and humiliating’. Janette perceived that the examination procedure was for the specialist’s comfort rather than her own and recalled that the nurse, ‘the doctor’s nurse’, was slow to assist her. Janette did not expect the specialist to assist her and said:

The examination, which was an extraordinary thing – on half a table, with my legs in the air, what an undignified arrangement! ...//... What an extraordinary thing to do to a person! ...//... Unbelievably embarrassing! Unbelievably uncomfortable physically ...//... The embarrassing – having your clothes off, sitting on what appeared to be half a bed with the bottom end missing and I wasn’t sure I was going to be able to actually physically stay there ...//... I guess it was a lot easier for the specialist to examine you in that position ...//... Unbelievably uncomfortable! ...//... Physically it was pretty bad, because I had to lift up one leg and put it in the cradle ...//... I can’t support my weight without hanging on with my hands. I’ve got to hang on with both hands to sit in that down position that I was in and try and put my leg up. So I think the nurse eventually put my leg in the cradle. Then it was a little bit more comfortable physically but it was a dreadfully uncomfortable feeling ...//... Very embarrassing! Your body totally exposed to the other two people in the room ...//... it was certainly unpleasant ...//... the doctor’s nurse was there ...//... he probably needed instruments handed to him ...//... But having had that dreadful experience in the examination, um, I was terrified about having to go back again ...//... I had no idea it even existed – that kind of examination and I felt so exposed ...//... It’s pretty unusual thing to have all your clothes off and be exposed in that way and to be in that position was awful for me and so the second time wasn’t quite as bad. I was still very embarrassed and still very unsure of my position of hanging on – I was like a canary with a broken leg ...//... only hanging on with one. (Janette)

Julie also described the gynaecological examination as undignified:

Embarrassed! Even though I had had a baby ...//... it’s sort of undignified. Sitting up there with all the world seeing whatever you’ve got. I think that is the big thing. Because I mean I was still, as I said, I wasn’t a really promiscuous person. And sort of, when somebody says to you, ‘sit up there, put your legs in these things and put your knees apart’. 160
You think, hang on there. I don’t know if I really want to do this! ...//...
But more or less you have to go through it ...//... at the time I was embarrassed and a little bit shy. (Julie)

The process of Pap testing, colposcopy and treatment reinforced a sense of dependence on medical professionals and exacerbated the participants’ feelings of vulnerability. Their powerlessness and emotional distress were embodied in needing to be undressed and lying in an exposed position for the procedures. Being physically laid open on the examination table metaphorically depicted and perpetuated the women’s sense of emotional subjugation.

Ann had two different and distinct emotional responses when she contemplated whether her abnormal Pap test result was linked to a genetic component or environmental causes – anger and guilt, both of which reflected her feelings of vulnerability:

I was a bit angry at first ...//... yeah, well it happened to my mother and my grandmother. Well, I was thinking, there’s got to be a gene there and it’s their fault for passing it on. Um, but it didn’t stop my thinking that I still wanted to have children and therefore if it was a hereditary thing then I would be passing it on ...//... there was a bit of guilt ...//... because in all the clinical bits of paper you get, it says if you start sexual relations at any early stage you have an increased risk. If you have more than one sexual partner, you have an increased risk. So I was in a high-risk category. I had been on the pill, I smoked, I’m overweight, um so, there was all the just, feeling a bit guilt about all of that. (Ann)

Ann internalised the stigma felt by many of the informants when they read about the links of CIN with sexual activity:

I know that someone who has been monogamous, has been a virgin until the day they’ve married, and has had only one partner can still have an abnormal smear, there’s a lot more of the others that get them! So there was that sort of thing ...//... The literature you get, it says that if you have sex at an early age, if you have this at any early age, if you do that, the earlier or the younger or the more, um, the chances of it happening are greater and I just thought, I knew that I had started sexual relations at a reasonably early age ...//... Sixteen ...//... and I had more than one partner. I mean I had had two that I lived with full time but there were others. And um, so naturally it was like OK. I just don’t want anyone surmising anything to do with this. (Ann)

Many of the informants shared Faye and Terry’s feelings of resigned vulnerability about the need to expose their bodies, particularly their genitalia to others:

I mean it’s just the thought of having to bare everything, you know, you, you’ve got nothing on from your waist down ...//... I hate this part where you’re laying in, so open. But you then you know, he comes in and he sits
down and talks to you and you sort of just look around. And you just think, ‘Oh well it’s got to be done anyway’. And I, I don’t feel uncomfortable once he starts, it’s just the getting up there, and you’re so open when he walks in! Sort of thing, um, you know, I know all women feel the same way. It’s an invasion of privacy isn’t it? In a way, but well, it just has to be done, doesn’t it? (Faye)

You’ve got your feet up in stirrups and flapping in the breeze. And feeling dreadful really, it’s not a pleasant thing. (Terry)

The vulnerability expressed by the women in this study has historical roots. The Pap test is possible because the clinician is able to use a speculum to visualise the cervix. Although there are accounts of the vaginal speculum being used in Greco-Roman times (Hughes 2001), it was rediscovered and popularised in the nineteenth century and again in the early twentieth century. In the first instance, J. Marion Sims, also known as the Father of Gynaecology (Kapsalis 1997), used a spoon to visualise the cervices of slave women on whom he was performing experimental surgery without anaesthesia in an attempt to repair vesico-vaginal fistulae. The spoon evolved into the vaginal speculum and Sims became famous for inventing a tool to visualise a woman’s cervix, not infamous for his abuse of disempowered women. Moscucci (1993) described how the vaginal speculum came to be used as a tool that the police used in Paris in the early twentieth century to examine female sex workers to ensure they were ‘clean’ and would not infect potential clients. This sense of using the vaginal speculum as an instrument to yield power over women persists into the twenty-first century. Hughes (2001) argued that the vaginal speculum continues to reflect a relationship where knowledge can be used in a manner that disempowers women and reinforces their vulnerability.

As well as describing their vulnerability during gynaecological procedures, the informants shared other instances of feeling vulnerable in their lives. They employed deliberate strategies to try to reduce their feelings of vulnerability, to try to protect and preserve their sense of self. When her sense of ‘I’ was threatened or she was feeling particularly vulnerable, for example to protect herself from her husband’s unwanted sexual advances, Janette feigned sleep:

*When it came to sexual, our sexual life, um, I can honestly say many nights I pretended to be asleep when he came home from the club. I guess that was a self-preservation thing as much as anything.* (Janette)

And describing an earlier time in her life Janette said:
I used to wear a lot of make up once upon a time; a lot of eye make up, because with eye make up in the old days you couldn’t cry. You would make an awful mess of your eye make up if you cried. And most of the time if I, if I had eye make up on I knew, I knew I wasn’t going to cry ...//... there’s a lot of things we do isn’t there, a lot of self-preservation things. (Janette)

Janette’s description of having to ‘put on a face’ to pretend to be strong and invulnerable was a theme echoed by the informants in this study in the context of their abnormal Pap test experience. Following laser treatment to her vulva, Jayne’s need to appear capable in front of her colleagues outweighed the intense pain and discomfort she experienced. She did not believe that she could share the nature of her medical treatment with anyone at work. Jayne felt that she had no choice, she could never admit that she needed a rest or a break from riding horses:

I needed to be riding the horses in my job – I had no choice ...//... So imagine trying to go back to work and saying, ‘Oh, I’m sorry I can’t ride’. ‘Why?’ ‘Oh well...’ so I did ride ...//... so then in a very male dominated job and it was, there were only two women in the whole field of about forty to fifty men working in the place, so I couldn’t really talk to anyone about it, so of course I rode ...//... I stuck a whole heap of cotton wool down my pants to try and give myself some padding and when you ride, doing what I was doing, you sit, you don’t do a lot of trotting or cantering. So for about three hours I just sat on a very hard with a very hot, you know, jodhpurs, nylon, tight, you know. (Jayne)

Rita described needing to protect herself from possible judgment over her evolving sexual identity at the time of the abnormal Pap test result. She protected herself from being judged and protected the gynaecologist from feeling embarrassed, but felt negated as a person and rendered invisible as a result:

The gynaecologist I went to at the time was, was a local fella who was also a Catholic ...//... I almost intuitively knew there was enormous barriers between us ...//... So I had a real protective reserve, and a reserve about me in terms of what I was going to disclose to him ...//... it was a really awkward and funny thing ...//... Not really any conversation, the smell and the sounds and things were uncomfortable ...//... I remember then leaving there and just feeling a bit, well, what do I do now? And you know, what happens next and asking him about how long it could be since, to um, have sex, and wanting to clarify what that actually meant ...//... he said no sex for such and such a time and I’m then, I’m then thinking how can I actually ask him, what he means by sex? ...//... I didn’t want to see his disapproval ...//... or judgment or anything else ...//... So I asked him what that actually meant, ‘Do you mean no penis in vagina sex?’ Because that was about as specific as I could get because he surely he was a gynaecologist and he could handle the words penis and vagina. And he said something like, ‘Yes, that’s right’. So then I actually plucked up the courage and asked, ‘What about
orgasm? Are you talking about orgasm or are you talking about contact with the cervix?’ And um, he was a bit taken back by that. And [he] just said, ‘Look I think it is just you know, just best if we just leave it alone and when, leave it alone and when you feel more comfortable, you can sort of, you know, when it’s been the period of time and the healing has happened’. So I left feeling um, totally invisible, I was invisible. I hadn’t disclosed anything of what I might have wanted to do. (Rita)

Some of the informants including Marie, Megan and Jayne described actually fainting, or feeling like they were going to faint during the colposcopy and subsequent treatment. The women inferred that it was a self-protection mechanism. Their sense of self and safety was so threatened that they lost or feared they would lose consciousness.

Megan said:

I had the colposcopy and ...//... I felt like I was going to faint when I had that, even though I was lying down ...//... Whether it was stress related I don’t know ...//... when I was in the chair, I said to them, I said, ‘I’m going to pass out’. To stop myself fading. And [Colposcopist] said, ‘You can’t, you’re laying down’. And I said, ‘Well it feels like it’ ...//... Because it was my first colposcopy – the unknown is even worse you know, and the embarrassment ...//... the first time is always embarrassing isn’t it? ...//... Very undignified! In that chair! Yes, pretty embarrassing ...//... I was frightened of the unknown ...//... I just thought I was going to pass out. (Megan)

In Jayne’s description, her previous experience was so frightening and traumatic that during a repeat colposcopy with a different gynaecologist she fainted:

Yes, that’s when I fainted! ...//... [Colposcopist], she was fantastic, very sensitive, like it’s OK, take your time. I still fainted but, I said, ‘[Given name of colposcopist], I’m going to faint, going to faint!’ I mean having the big screen there was probably enough to make me faint I think. I’d turn around and here was this big, huge, hairy looking thing. It was a bit frightening. (Jayne)

The primary interview with Jayne took place in a women’s health clinic at Jayne’s request. Behind a screen was an examination table and Jayne said:

You know it’s funny because if you got me up on there, I’d be, I’d feel terrible. I’d feel vulnerable again ...//... [I’d] tell [myself] it’s going to be OK, even if [I] faint ...//... I think that’s probably why it’s hard to get women to have Pap tests. And especially when they’re older, because you do, you turn into, as you know, you become very vulnerable ...//... You don’t make yourself vulnerable so you don’t have to face it! Easy! (Jayne)

Jayne dreaded the thought of being made vulnerable again through cervical screening. For many women in this study, their past experience of having an abnormal Pap test
result heightened their feelings of present and future vulnerability as fear of recurrence remained ever present.

**Fear of recurrence**

*Sitting on a time bomb (Megan)*

Many of the informants shared their ongoing fear that the abnormal cells would return. They described an inability to control the abnormal cells, a powerlessness that was only in part reduced by ongoing medical surveillance. Joyce did not even consider the possibility of a missed diagnosis when she had frequent gynaecological investigations for protracted post-menopausal bleeding. She blamed herself and said:

> I hope it doesn’t recur. It shouldn’t on the cervix. But you wouldn’t know, would you, if it came back. So I’ll just keep going back and having check ups. All the time and that. But I was a misfit for sure ...//... to have all those bleedings. It just seems so ridiculous, but you know what I mean ...//... I mean I don’t worry about it that much. But I mean if [gynaecologist] keeps a check on me, but you never know, do you? (Joyce)

Margaret knew that she was at ‘low risk’ for developing CIN because she had no identifiable risk factors. Crawford (1994) argued that the healthy body, or at least efforts made towards that goal, has become increasingly important in determining the moral worth of the person or, as Margaret described, ‘a risk group’. ‘Healthism’ is a term coined by Metcalfe (1993) and is evident in health promotion philosophy, policy and practice. Healthism infers that everyone has a responsibility to work towards maximising their health and those who do not are criticised for their perceived lack of self-control. The healthism ideology results in intolerance from health professionals and the community for those who cannot or do not strive towards the prescribed health goal. It can also bring about a sense of abjection or anger for the person who esteems healthism but then experiences ill health or pathology such as an abnormal Pap test result. A woman who esteemed healthy lifestyles and self-responsibility for health, Margaret felt especially undeserving of the abnormal Pap test result:

> Why me? ...//... Because I knew enough at that stage to know that I was not in any of the risk groups. Why me? Shouldn’t be happening! Not fair! ...//... After the surgery that although they were pretty sure that they had um, what they thought were all the cancerous cells, that there was no guarantee that there wouldn’t be a recurrence ...//... I think it’s something that once it’s happened though you’ve always got it in the back of your mind ...//... particularly with being at a very low risk group to start off with, you think well, it could happen again any time ...//... it’s
just always there. You know that the risk of it happening again is there.
(Margaret)

The health promotion discourse has been particularly effective in communicating to women like Margaret that health can be accomplished through conscious creation and deliberate actions that involve self-control, self-denial and will power. Such beliefs are common in many Westernised countries including Britain, America and Australia (Lupton 1995a). With no known risk factors, Margaret could amend nothing in her lifestyle to prevent recurrence and this made her feel particularly disillusioned and served to heighten her feelings of vulnerability and susceptibility. Margaret’s fear that the abnormal cells could recur was always present.

Julie also had internalised the belief propagated by the health promotion ideal that a healthy lifestyle and regular medical surveillance would protect her from illness:

I’d always had my regular smear tests done. I didn’t neglect anything. I was pretty healthy; I always played sport and you sort of think, hang on, why is this happening? You know, I’m a healthy person ...//... I wasn’t sort of somebody that sort of went out and got with anybody that I felt like. I wasn’t a very promiscuous person. I probably haven’t had very many relationships ...//... You sort of think of those terms if something like this happens to you. Like what have I done to cause this? And I couldn’t really think of anything that I might have done ...//... Because I mean I ate sensibly, as I said, I played sport. I still play sport. And you know, and I looked after myself. So I sort of think, what caused it? (Julie)

Faye considered it unfair that she has had abnormal cells develop on her cervix because she had only ever had one sexual partner and she was a clean woman:

I read a pamphlet ...//... It said, um, most women get this if they’re promiscuous! ...//... I thought, that’s a downright lie! ...//... Because I’ve had one partner and one partner only! ...//... I thought, well here am I, I’ve done everything right, you know. I’m a clean person; well I think I am. I shower every day ...//... And I did think, ‘Well how, how did I get it?’ You know, what caused it? ...//... Why should I get it? ...//... Haven’t I been washing myself enough or haven’t I been, you know I kept going back to cleanliness. (Faye)

For Margaret, Terry, Joyce, Megan and Julie the fear of recurrence invaded their present and thoughts of their future:

Although they were pretty sure that they had um, what they thought were all the cancerous cells, that there was no guarantee that there wouldn’t be a recurrence ...//... I think it’s something that once it’s happened though you’ve always got in the back of your mind ...//... particularly with being at a very low risk group to start off with, you think well, it could happen again at any time ...//... It’s just always there. You know
that the risk of it happening again is there ...//... no guarantee that it wouldn’t recur. (Margaret)

I don’t want this to have to happen again ...//... but it could do. (Terry)

So I hope it doesn’t recur. It shouldn’t on the cervix. But you wouldn’t know would you, if it came back. So I’ll just keep going back and having checkups, all the time and that ...//... But I’m one of the lucky ones aren’t I? They’ve got on to it, they’ve closed it off and I just hope it never recurs again ...//... I mean I don’t worry about it that much. But I mean if [gynaecologist] keeps a check on me, but you never know do you? (Joyce)

And is it going to come back? That’s another thing that I sort of live with ...//... just waiting there, just sitting waiting there for it to come back ...//... sitting on a time bomb waiting for it to come back again. (Megan)

I’ve never gone back to my two yearly check, because I am absolutely petrified, so I have one every year ...//... just that it could happen again. Because I mean, I didn’t do anything! That sort of caused it or made it to happen ...//... so therefore you sort of think in the future, well it could happen again ...//... I still have my smear tests every year. So it’s still a bit of a worry ...//... It still comes to mind yes. Yes, that fear that it could happen again and it may be worse next time ...//... And it’s been a while now, so you know, every time I go now I am getting better and better. But you sort of always have it in the back of your mind that you’ll have another bad one ...//... I think it’s a subconscious thing, that’s there in the back of your mind for the rest of your life really ...//... I mean it’s there, and it’s part of your past and therefore I think it is part of your future ...//... I think it is there all the time. I think it is something that you live with. (Julie)

No matter how hard they tried, participants could not escape their thoughts that they might experience another abnormal Pap test result. The experience of having had the abnormal Pap test result was etched into all the informants’ memories. Julie articulated the idea that it was part of her past, present and therefore her future. As Fox (1989) described, the memory of what once was, fed into the continuity of how a person perceived themselves. As humans, memories form bridges between what we were, what we are and also our image of the future self.

The women in this study shared many memories and experiences of abjection. They described how their very sense of self had been threatened by the experience of having an abnormal Pap test result. They recalled the fear and guilt that the abnormal Pap test result had brought to the surface in their lives. Their esteem had plummeted into an abyss because the result made them feel dirty and ashamed. The sight of blood, feelings of pain and the smell of their own flesh burning had assaulted their senses during
cervical treatment. These memories were recalled in vivid detail during the preliminary interviews and their vulnerability to a recurrence of the cervical pathology shadowed the women’s future.

On many occasions, prior to and during her abnormal Pap test experience, Melanie experienced abjection. Her life, her future had been threatened and her story is shared as a paradigm of the interconnectedness between having an abnormal Pap test and abjection.

**Melanie’s paradigm story**

Melanie shared her harrowing story of having an abnormal Pap test result. It was not horrific because the result indicated serious pathology but because Melanie believed that any abnormal result must mean that she had cancer and was going to die. Melanie was a Bosnian woman in her thirties, who had immigrated as a war refugee to Australia. She was a woman of courage and strength who had survived horrific war experiences, including the murder of her husband. Melanie shared her story of abjection with me and sobbed as she recalled her experience of having an abnormal Pap test result:

> I get a call from the nurse in the women’s health clinic and she said, *Something is not normal, showing like some abnormalities .../*... And I was very scared. The first thing that, I wasn’t scared for me, I’m not too scared to die or those sort of things. I was just so scared for [son]. Where he would stay by himself and this is strange country and no friends or family and oh, it was hard /*... it was so hard /*... I thought, I thought I was going to die. But I wasn’t ready; I’m not ready to die. I was scared that was my thought /*... And leave [son]. I thought I would die. I thought that yes, I would be finished. I thought that /*... When they said that I have something, some irregularity. I thought you know, this is the end of the world /*... I cried and said, ‘I came long way here to die. I don’t want this!’ Yeah, and still, talking about it, even talking about it, it still really /*... [son] was sleeping, I know that. And I come into his room and I was watching him and I was crying and crying and crying. Poor my son /*... I couldn’t believe it, I think I was in shock /*... In the morning when survived that night /*... The hardest thing for me was I dying and who will look after my son. I have not anybody to leave him [Melanie continues to sob silently] You know I was thinking, what will they do with [son]. How, and then I think OK, I will not leave him here by himself, if he was older it would be OK, but nine years old. He is too young. How can I afford. And I said, ‘Oh God, help me’. And then I said, ‘Why me? He lost his father and why me now?’ /*... I didn’t come to die here, I came to live here in Australia /*... When you find that something is not normal with you then you start building your future so quick. And thinking what will you do if you have to die next week. And you know, I already made plans like, if there
is something wrong, I am going to send [son] back home. I am going back and spend the rest of my life with my family but [son] will be there. And things like that. You are just trying to, now its slowly and you play it slowly, your future. And suddenly you have to hurry, to make all that in a hurry. (Melanie)

Melanie’s sense of self, her identity as a woman, her role as a mother and her very life she believed were threatened by having the abnormal Pap test result. Pap tests can and do save lives because they can detect changes to the cells of the cervix that may, at some time in the future, become malignant. Cervical cancer is a preventable disease and amenable to the benefits of a screening test. However, health promotion strategies to encourage women to avail themselves of a Pap test have emphasised the connection to prevention of cervical cancer. Promotion strategies have worked on the premise of encouraging women to have Pap tests and ongoing assessment and diagnosis through the use of fear strategies. The links between cervical cancer and Pap tests have been medically constructed in an endeavour to maximise compliance with Pap testing and follow-up when necessary (Somerset & Peters 1998).

There are adverse effects from focusing attention on the link between Pap testing and cervical cancer. Women like Melanie who might have an abnormal Pap test result, endure unnecessary anxiety and pre-emptive grief. Other adverse effects relating to the medical construction of cervical screening and treatment of women when they have an abnormal Pap test result will be discussed in the chapter to follow, entitled ‘The Nocebo Effect’.
The ‘Nocebo Effect’ or ‘I shall do harm’ – was described by Odent (1994) as the opposite to the placebo effect (to do no harm). For the purposes of this study, the Nocebo Effect was considered an umbrella term and included direct iatrogenic concepts and other, more hidden influences such as the effects of inadequate communication and power imbalances between women and health professionals. The term, Nocebo Effect, came into popular usage in relation to pregnancy, birth and obstetrics, having been ‘rebirthed’ by Odent (1994). Prior to Odent, theorists had used the term in their critical analyses of the medical system (Wolf 1950; Pogge 1963; Herzhaft 1969 cited in Illich 1976a).

Even with the best of intentions, medicine is not always healing and helpful and, on occasion, causes harm. When the women in this study experienced an abnormal Pap test result, the health care system’s ‘Nocebo Effect’ was pervasively evident. The literature describes how many women feel dehumanised by health professionals’ insensitivity when they are informed of an abnormal Pap test result, leaving many women to believe they are being blamed and judged for their cervical abnormality (Posner & Vessey 1988; Gregory & McKie 1991).

When the woman with an abnormal Pap test result attends for a colposcopy, she is often instructed to undress and replace her own clothes with an institution gown and lie up on the couch to await the arrival of the colposcopist. While the women are unlikely to know or to have met any of the health professionals present, the staff have visual and tactile access to the most intimate parts of their bodies. Women are often asked information about their personal circumstances and social and sexual history that has no bearing on treatment options or therapeutic outcomes, but which they feel obliged to
disclose. They have to endure a vaginal and colposcopic examination and sometimes painful cervical biopsies or treatment in the presence of strangers. Their consent to have other people present during the colposcopy is not always informed. They may then wait many weeks for the results of these procedures.

Every participant in this research project shared stories illustrating the Nocebo Effect. Some effects were comparatively minor such as the need to wait for weeks to get an appointment, hours to see the medical practitioner and then further weeks to get results, all the time exacerbating the anxiety they felt. Other effects were catastrophic including the iatrogenic development of secondary vaginismus for one woman and a recto-vaginal fistula in another. Both women directly associated these problems with the time of their treatment for CIN. As with the previous interpretive/discussion chapters, this chapter will conclude with a paradigm story: a summary of Jayne’s experience to encapsulate what the Nocebo Effect meant for an individual woman.

The participants in this research study provide the principal voices and their stories are dialogued to a greater or lesser degree with the literature and the discursive works of critical theorists. The works of theorists to be introduced in this chapter include those of Michel Foucault, Ivan Illich and Jurgen Habermas, all of whom questioned the relationship between power and knowledge and how that relationship was evident in medical and health professional practice (Cheek et al. 1996). Foucault (1980), Illich (1976a; 1976b) and Habermas (1971a) all implied that, as long as the practitioners remained the dominant players in the patient-doctor relationship, women with an abnormal Pap test result will be at great risk of experiencing the Nocebo Effect.

**Waiting**

*You’re just a number aren’t you really? (Joyce)*

[Critique functions as] a process of self-enlightenment of socialised individuals about what they could want if they knew what they could want.

Habermas 1971b, p. 281

Waiting is critiqued as an example where participants perceived that the health system valued itself above the people whom it was meant to serve. There were many ways women waited – waiting to get an appointment, multitudes of women waiting in the waiting room, waiting to see the health professional, and then waiting for results.
Waiting is such an established component of health care that it is seen as inevitable and accepted without question. Waiting to see a medical practitioner is a taken-for-granted process – the ‘waiting room’ an essential component in any medical or health facility. Inequality of status between health care provider and recipient is reinforced by the need to wait. Frankenberg (1992) argued that the health professional has become the principal actor in the performance (consultation). The professionals, though scarce, have a symbolic value above and beyond their scarcity value that is reinforced by the subordinate member of the dyad, the client, always waiting for the clinician. The message received by women waiting for care is that their time, and by implication themselves, is of little value compared to the health professional’s. The health system and its professionals are seen to value themselves above all else. The purpose of sharing the informants’ stories of waiting for care, is to make their waiting visible and, in so doing, strip away some of what Cheek et al. (1996) described as the taken-for-granted, invisible aspects of the health professional’s power.

Waiting months for an appointment

Valueless in terms of who we are as human beings … (Marie)

Margaret had an abnormal Pap test result and was told that the ‘Grade 4’ (Adenocarcinoma in situ) result was ‘pretty bad’ by her general practitioner in November. She was advised by the general practitioner to see a gynaecologist as soon as possible. The earliest available appointment was in two months. Margaret described the waiting as a time of high anxiety:

>This was in about November, round about my birthday and I was booked into see the gynaecologist in January! So, I had that Christmas thinking, ‘I’ve got cancer! I’m going to die!’ Basically .../... it was just awful! The wait to see the gynaec. Just absolutely dreadful. (Margaret)

Megan’s abnormal (CIN 3) Pap test result also came back before Christmas. The GP informed her that he didn’t know whether she would ‘live or die’ from the predicted cervical abnormality and booked Megan in to have the colposcopy in January. Megan contacted the colposcopist herself and managed to get an earlier appointment. Even the week she waited was a long time for Megan as she explained:

>It was an awful long week .../... It must have been early December or something that it happened. And the medical centre here booked me in with Dr [Colposcopist] and never got me in until January, which was a month later. Any way I thought, ‘How am I going to live for this month, not knowing whether I am going to live or die?’ .../... So I rang him and
in, in a week!...//... It was a long week, yeah, not knowing anything. That’s why when I walked in there, I burst into tears. And [colposcopist] said, ‘What’s wrong?’ And I said, ‘Well, I’ve got three kids, I need to know if I’m going to live or die. You know, I’ve got a life to organise here’. And [Colposcopist] said, ‘What do you mean?’ And I told him and he said, ‘Well, he’s got no right to say that because he knows better’.

(Megan)

Marie believed she had cancer of the cervix. She was a young mother and midwife working night duty at the time of her abnormal Pap test result. On three occasions Marie made arrangements to attend a colposcopy clinic in the city, one and a half-hour’s drive away. Three times her appointment was cancelled by the colposcopist:

[GP] said, ‘I’ve made an appointment at the public clinic for you’ and I said, ‘OK’. And he gave me the date and the time and that was fine. So I rearranged my night duty schedule and made sure that I had the kids in childcare for that day and the ...//... [Afternoon before] I was at home, the telephone rang and it was the public clinic ringing to say that the clinic had been cancelled and that they had rescheduled me for a month’s time. And I went, ‘Oh, OK ... yeah fine’. So I rearranged my schedule again and made sure that I was available for that appointment that they gave me for that month’s time. And then the day before that next, that second appointment in a month’s time, the telephone rang again and they cancelled the clinic again. And I went, ‘Oh, this is not good’. I said, ‘Do you realise that my Pap test is abnormal and I’m really nervous about that’. And she said, ‘Look I’m sorry but there is nothing I can do about it’. So she rescheduled me for a third time a month later. So that’s sort of like three months down the track. And then lo and behold the third time, I picked up the phone, they rang me the day before and said, ‘Sorry but we’ve cancelled the clinic again – you’ll have to be rescheduled’. And I just lost the plot at that point in time, I was sleep deprived, I’d been working full-time night duty trying to bring in cash flow for [husband’s] business. Things were not going very well there and I had to rearrange the kids’ appointments again ...//... And I just stacked my turn, I just really let off at this receptionist on the phone and said, ‘Don’t you realise I’ve got cancer in my body, and I could bloody well die and I’ve got two small babies and I’ve got a husband. And really I’m terrified out of my brain ...//... This is the third bloody time you’ve cancelled me and I could be having third grade cancer and I could be dying’. She said to me, ‘Are you, have you got private health insurance?’ And I said, ‘Yeah, well what bloody good is that? ...//... It doesn’t help me in this situation’. She said, ‘Yes it does, you can come in tomorrow’. (Marie)

Marie was in private health insurance and once that was known was able to see the gynaecologist the next day. Marie’s status had changed from a dependent client to a purchasing consumer. Fraser (1989), in discussing the North American social welfare system, described how women were considered either deserving or undeserving recipients of services such as health care. Women who could afford to contribute
financially to their own care were seen as deserving while women who relied on a public funded health system were seen as undeserving. Aspects of the American system were reflected in the stories shared by women in this Australian study. Once it was known that Marie was contributing financially to the cost of her colposcopy, it was deemed that she deserved an appointment the following day rather than wait for what then would have been four months. Joyce was very conscious of this two-tiered, private/public health system and expressed her concern:

But I suppose they’re busy, and you’re only a patient aren’t you? ...//... I suppose they’re dealing with people all the time and you’re just a number aren’t you really? ...//... I reckon you feel like a second rate, especially if you’re not in medical schemes. (Joyce)

Joyce believed that she was second rate and considered less deserving of health care services because she was not privately insured. She had intuitively picked up on the stigmatisation and the undeserving/deserving client ideology described in the literature (Fraser 1989). Joyce was experiencing what Oakley (1993) described as the tendency of health professionals to present different faces to patients/clients from different social class groups.

Melanie had been contacted by the women’s health nurse to say that her Pap test result showed some irregularities. English was Melanie’s second language and non-use of interpreters by the nurse at the clinic compounded the barriers. Melanie described her fear, especially when she was informed she would need to wait over a month to see the gynaecologist:

Just a little bit harder to understand in English than if they, if they told me in my language. It is so much harder to understand what has happened ...//... I get a call from the nurse in the women’s health clinic and she said, ‘Something is not normal, showing like some abnormalities’. And I was very scared ...//... I wasn’t scared for me [Melanie sobs silently], I’m not too scared to die ...//... I was just so scared for [son]. Where he would stay by himself and this is strange country and no friends or family and oh, it was hard ...//... it was so hard ...//... I thought I was going to die. But I wasn’t ready; I’m not ready to die. I was scared, that was my thought ...//... In the morning I rang Dr [Gynaecologist] ...//... and I made appointment and the woman, secretary she said, ‘The next appointment is on May the 12th.’ And I said, ‘Oh, for God’s sake I’m going to die till May’. (Melanie)

Having waited for up to four months from the time of the abnormal Pap test result to the time of the colposcopy appointment, the informants then found they had to wait with many other women in the ‘waiting room’.

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Waiting with many others

One more cervix in a long line of cervixes (Ann)

Jayne and Ann both described the dehumanising effect of having many women sitting in the waiting room waiting for their gynaecological appointments:

*We’re talking doors thinner than this, and then he had twenty people, because he was a gynaecologist wasn’t he, twenty women, maybe more, thirty women sitting out in the area ...//... It was my area being burnt. Apparently I was screaming like nothing else and so everyone would have heard.* (Jayne)

Leder (1984) argued that the Cartesian notion of body objectification was evident when the person sought medical investigations or treatment. They experienced their body as a scientific object beneath the medical gaze and the probing, palpating fingers of the doctor. However, this was not the only experience described by participants. Jayne for example said, ‘*it was my area being burnt*’ and the fact that the other women waiting to see the colposcopist would have heard her scream, added to her humiliation.

Ann’s experience was more in keeping with the objectification concept and she described feeling dehumanised in the process:

*I just felt that mine was another cervix, just one more cervix in a long line, because I mean there’d be about 20, 30, 40 people there for the same types of things ...//... every time you went ...//... Like you were just another cervix in a long line of cervixes ...//... I’m sure they could recognise people much more if they spread their legs than by the look on their face ...//... Just a production line ...//... Which I suppose is a bit dehumanising or, but I think that they had just become so desensitised by the whole thing that ...//... they had got to the point where they didn’t really acknowledge, or didn’t ...//... know that the patients were individuals.* (Ann)

In contrast, Julie was an exception to the other informants and felt reassured that there were many other women who also required treatment:

*I mean they were busy. They had lots of people coming in to have laser surgery, and I think that puts your mind at ease as well. Because I mean when you do have that happen, you think, ‘Oh, I’m the only one that this has happened to’.* (Julie)

Women who had waited months for a colposcopy appointment, then waited with many other women, sometimes for hours to actually see the colposcopist.
Following the cone biopsy and diagnosis of adenocarcinoma in situ, Margaret needed to have regular and frequent colposcopies. This proved to be time consuming and frustrating for her:

*The worst thing about them is the bloody waiting! You always have to wait! ...//... Always, always had to wait! And of course I had to travel to get there. And it always had to be a day that you had to take. Because you might be waiting for an hour or so ...//... well, two or three hours, depending on what they were doing ...//... I always found that galling really! Particularly when I was back at work and thinking that, they either have to be a little bit better at scheduling people and have a little bit more idea about how much time you are taking and not double book and all that sort of stuff.* (Margaret)

Janette described sometimes waiting for hours to see a health professional and then waiting again for the actual procedure:

*I would be undressed and just lying on the table waiting for the doctor to come, with the sheet over me.* (Janette)

Janette, like most women, accepted without question that the doctor’s time was so valuable, that she must be lying there waiting. Graham and Oakley (1981) argued that the woman’s ability to both reason and question was reduced when lying horizontally rather than sitting upright. Oakley (1986) observed that time spent talking with women during the consultation was significantly shorter when they were lying on the examination couch waiting for the clinician than when they were introduced to the practitioner while dressed and sitting in a chair. The fact that women are more likely to ask questions of the practitioner if they are sitting in a seat is at best not considered by the clinician or, at worst, considered beneficial in an encounter where time equals money for the professional.

Faye also felt very uncomfortable and vulnerable, lying exposed on the colposcopy table, waiting for the colposcopist. She accepted that this was the way it had to be:

*I mean it’s just the thought of having to bare everything ...//... you’ve got nothing on from your waist down ...//... And I get there and I hate this part where you’re laying in, so open ...//... He comes in and he sits down and talks to you and everything and, you sort of, just look around. And you just think, ‘Oh well, it’s got to be done anyway’ ...//... It’s just the getting up there, and you’re so open and then he walks in! ...//... I know*
all women feel the same way. It’s an invasion of privacy isn’t it? ...//...
But, well, it just has to be, doesn’t it? (Faye)

Having developed vaginismus after her treatment, Jayne reported seeing many different specialists in an effort to resolve the problem. Jayne’s story reflected on the invasive and intrusive nature of ‘eyes peering inside’, what Foucault (1976) described as the medical gaze. Jayne eventually lost faith that the clinical gaze of medical practitioners would heal her. Foucault (1976) discussed the myth of the medical gaze where the medical practitioner was thought able to see the cause of a problem through the vast array of observations conducted. He argued against the assumption that the medical practitioner’s ability to look with a clinical gaze meant that they could diagnose problems, design solutions and speak about all things with wisdom. Foucault (1976) further argued that the doctor’s experience and skill became unchallengeable when allopathic medicine became dominant. However, with time and hindsight, Jayne did come to question the assumed medical sagacity associated with the clinical gaze of the gynaecologist.

Gilbert (1995), borrowing Foucauldian concepts, argued that individuals were made ‘object’ through three interrelated processes and they included hierarchical observation, normalising judgments and examination, all of which Jayne indirectly referred to during her preliminary interview. Jayne felt tired of the objectification, the focused attention on her vulva and sexual difficulties and that tiredness was exacerbated by the devaluing effect of having to wait many hours to be the recipient of the medical gaze. Jayne described one specialist visit in particular:

_I wouldn’t have called her a sensitive doctor, she was very direct, very much straight to the point ...//... Up there, open your legs ...//... oh yes, you’ve had human papillomavirus, oh yes, it’s slightly still there, oh yes, you’ve had laser surgery – so what’s the problem? Mind you, we’d waited two and a half-hours for that and many hundreds of dollars later! ...//... I was in there for ten minutes ...//... we had waited two and a half hours to see her. Travelled from Sydney to [2 hours drive away] ...//... [Husband] was three hours late for work and I was with her for ten minutes! ...//... I said to [husband] – I will never go back to another doctor and that’s what happened! I said, right that’s it! No more looking in my areas. No more medications. No more, forget it! And that’s what happened [for a number of years]. (Jayne)_

It was expected that clients needed to wait, sometimes for hours to see a health professional. Marie contrasted the experience when exceptional circumstances meant that she and her family were 15 minutes late for an appointment with a general
practitioner, to discuss treatment for Marie’s daughter who had a serious eating disorder. She described the situation (the emphases belong to Marie):

*We were 15 minutes late and [GP] happened to come out of her office at the same time we got to the desk. And the reception staff were so rude! She said to us, ‘You’re 15 minutes late!’ ...//... she didn’t even ask us for an explanation. She just said, ‘You guys have to reschedule because the doctor’s so busy that she can’t fit you in’. And I said, ‘Look, we’re desperate, we need to see this GP, and she’s been referred to us by the Mental Health Worker’. ‘Oh, you’re that family are you?’ And by this stage the GP had come out of her office and she said, ‘What’s going on?’ And the reception staff member turned her back on us and said, ‘*They’re late!* They’re 15 minutes late for their appointment!’ And she said, ‘Well, I can’t’, the GP looked at us and said, ‘Well I can’t possibly fit you in now, because I’m already behind time! I’ll give you ten minutes maximum! You can just sit over there and stay there until I’m ready to see you!’ And we just, we were so stunned that we went and sat down ...//... I thought it was just so disgusting the way she spoke to us ...//... the GP would be half an hour late and we’re still expected to sit there and tolerate that, but it doesn’t work the other way around.* (Marie)

‘Good’ patients wait for whatever length of time it takes for the health professional to be ready to see them and do so without complaining. Marie’s circumstances had inadvertently challenged the position and power of the medical practitioner. In doing so Marie brought upon herself and her family the wrath, not only of the medical practitioner but also of the workers who support the hierarchical medical structure. Fahy and Smith (1999) argued that deliberate or even accidental confrontation with the health care system is dangerous, the person risks negative labelling, sanctions and even punishment for their perceived rebellion. As a consequence, participants expected and accepted that they would wait, sometimes for hours, to see the clinician. It was a taken-for-granted process. Having waited months for the appointment, hours to see the colposcopist, some informants then described waiting for weeks to hear the results of that encounter.

**Waiting weeks for the results**

*Biggest five weeks of hell … (Annabelle)*

Terry received the bill for the colposcopy and the biopsy within days of the procedure but six weeks later had still not received the results. Annabelle described waiting for the results of a colposcopy and punch biopsy – results that took five weeks to reach her, when they were available many weeks earlier to the health professionals:
I had to wait another five weeks for the results .../... the biggest five weeks of hell .../... it was really a big blur at times .../... I thought what would happen if it came back positive. If ... I had to go in for other surgery, I was really worried about that. Whether I could, whether it affected my ableness to have children .../... A lot was going through my brain .../... a whole heap of horrible thoughts .../... being told that I would never be able to have kids. (Annabelle)

The colposcopist had communicated the results to the referring health professionals, but no one had informed Annabelle. Accepting that ‘doctors are doctors’ and not expecting any better service, Annabelle described how waiting five weeks for the results was the hardest part of the whole experience for her:

I believe [Women’s Health Nurse] got a letter, but I didn’t! .../... The most difficult part .../... just the wait I think .../... Yes, just the wait! That’s it. The waiting to get the results, I think that was about the hardest .../... It was just those five weeks that I had to wait for the results, that was about the hardest out of the whole lot .../... Doctors are doctors; they don’t look at people’s files unless they have to. (Annabelle)

Annabelle was disappointed that the women’s health nurse, the general practitioner and the colposcopist had not considered that contacting her about the colposcopy results might be therapeutic. Annabelle did not contemplate the possibility that she could act as an assertive consumer and contact one of the health professionals for the results. Lupton (1995b) described situations such as Annabelle’s inaction as a deep-seated need to invest trust in the professional, modelled on the parent-child relationship. The inaction on the part of the health professionals was not deliberately malicious, but rather an oversight or an assumption that it was the duty of one of the other professionals to contact Annabelle. The lack of malevolent intent on their behalf did not negate the adverse effect on Annabelle and the five weeks of hell she suffered. Annabelle’s needs had not been adequately met. Practitioners within the health care system had communicated between themselves; the needs of the system had been served but not the needs of the woman.

Health professionals serving the system

We’re just the cattle that come in and see them … (Marie)

Providing physical and emotional support, education and encouragement or counselling are considered to be at the core of nursing care (Gibb 1998). Some of the women in this study perceived that the nurse was present not to provide them with quality nursing care
but to assist the medical practitioner. Janette mentioned the inadequate nursing support she received:

Yes, the doctor’s nurse was there ...//... Unbelievably uncomfortable! Cause, as I said, physically it was pretty bad, because I had to lift up one leg and put it in the cradle. And then I had to jiggle a little bit to stay in this position I was in, without ... Because I can’t support my weight without hanging on with my hands. I’ve got to hang on with both hands to sit in that down position that I was in and try and put my leg up. So I think the nurse eventually put my leg up in the cradle. (Janette)

It will never be known if the nurse who was present at Janette’s colposcopy aligned herself more with the colposcopist or in caring for Janette. Where the nurse is employed by and therefore financially renumerated by the gynaecologist, there may be a conflict in her loyalties. Many nurses esteem advanced technical skills over relational care and nurses have unquestioningly and eagerly taken on advanced clinical skills without considering whether they advance nursing caring-healing practices or better serve the public (Watson 1999). When nursing becomes clinical task focused, the person receiving care may be confused and uninformed as to what nursing is. In this case, Janette perceived the nurse to be the doctor’s assistant but not to have a caring role.

Janette described intense physical discomfort, embarrassment and fear that she would fall off the examination table. She discounted her own needs and identified:

I guess it is a lot easier for the specialist to examine you in that position.
(Janette)

When a colposcopy is attended at a teaching hospital, the need for student education may take precedence over the attention given to the woman. Ann described how the specialist’s attention focused on the students present during her examination, she felt negated by the experience:

He’d be chatting to the students and it was sort of like, you didn’t exist! And just sort of felt, like, well this may be standard for you but this is pretty important to me and I would have appreciated a little bit more, I don’t know whether compassion is the right word. But, yes, just a bit more acknowledging that I was there. (Ann)

Marie was angry in her assessment that the medical/health system was there to serve itself. Constant waiting for professional attention was seen to dehumanise the person and further increased Marie’s perception that the client was there for the convenience of the professional but not to receive a quality service:
We’re just the cattle that come in and see them as far as I’m concerned ...//... we’re valueless in terms of who we are as human beings! We are just an income source for that particular GP, and the way she runs her business ...//... we’re there for her convenience, not the other way around. And the same with the dietitian as far as I’m concerned. We’re just a stat! ...//... And, as far as service delivery is concerned, without being flexible when the need is required ...//... it’s about people disempowering other people, basically. (Marie)

Inaccessibility and inflexibility of health professionals

| Somebody who could lift me … (Janette) |

Physical inaccessibility caused problems for women, especially for those who have or care for a person with a physical disability. This inaccessibility heightened their dependence on others and served to disempower them further. Janette described:

The health system – not very [accessible]! ...//... Doctors are usually very hard for me to get to. When [first husband] and I were together and I used to have to get to the GP, he used to have to take the day off work ...//... still the same surgery today ...//... three steps up the front. So [first husband] used to physically have to carry me up those stairs. (Janette)

Once into the examination room, Janette was once again dependent on family members (or others) to assist her:

The examination table was always terribly hard to, to get on to physically. It meant that either [first husband] or somebody who could lift me had to come with me and lift me from the wheelchair and up onto the table. To have the examination to start with, now that meant that someone had to miss work to do that. And it was always a bother for me to ask them to do that for me. It was always very difficult. Very difficult to ask for that. I found it hard ...//... I had parted with [first husband], so I asked my oldest son to take me [for the colposcopy] ...//... Pretty awkward, because it was like having a Pap smear and having my son take me to have a Pap smear, having my son take me to that was pretty uncomfortable. (Janette)

Having to ask for assistance and causing financial and work inconvenience for others was a demeaning experience for Janette. There were at least two able-bodied health professionals in the examination room but Janette did not question why they did not assist her. It could be surmised that the health professionals found it a demeaning experience to physically assist Janette in such a basic way, or the two minutes it would have taken to assist her may have been too time consuming for the medical officers and nurse to assist her. On one occasion Janette described being assisted on to the table by two wardsmen, when two medical practitioners and a nurse were present:
[General Practitioner] had arranged for me to have the examination up at the hospital …//… and that meant …//… two wardsmen actually physically put me onto the table. A nurse came in and I would be undressed and just lying on the table waiting for the doctor to come, with the sheet over me. And then [General Practitioner] would come along and on this occasion [Gynaecologist] came along as well. (Janette)

In a different context, Marie described the difficulties she experienced trying to get her daughter, whose health was rapidly deteriorating, help from professionals:

[Dietitian] …//… only works between 9 and 2.30 …//… [Daughter] just hates missing school! She is terrified …//… So I said to [dietitian] could you be flexible …//… after work some day …//… And she too said, ‘No! If she can’t come in my work hours, I’m sorry I can’t help you!’ …//… the system was very inflexible in terms of support. (Marie)

We started the round of GPs …//… at one point I actually had [daughter] in the back of the car, and I said to this GP, ‘Would you please come out and have a look at her?’ And she said, ‘No! If [Daughter] cannot physically walk in here to my office, and have a physical assessment done by me, I am not getting out of this chair and going to the car and doing a visual assessment. That is not enough’. But I said, ‘If you do a visual assessment you will be able to see …//… she is terribly underweight and we need help, and I am asking you to please help us’. But she wouldn’t get out of her office to do it. (Marie)

**Omnipotence, omniscience and infallibility – Medical dominance**

*It’s the stuff about the patient/professional role …* (Margaret)

Janette described how her trust in the medical profession was betrayed by the first gynaecologist whose mistakes were only revealed by the second gynaecologist she consulted:

*I trusted [first gynaecologist] and felt that he would know the right medical things to do …//… I’d lost my feeling of trust – heaven’s they’re not always going to do it right. The medical services and decisions are not always going to be right.* (Janette)

Prior to this experience, Janette had believed that the gynaecologist’s training, knowledge and experience meant that he would always know what to do and would ‘do the right thing’ by her. Janette assumed that in matters related to gynaecology that the specialist would know all that needed to be known, that he would be omniscient gynaecologically speaking.
In former times it was the high priest who had this ‘all-knowing’ or omniscient role. Since the French Revolution, the medical practitioners have taken this role of dominance from the high priests in the secular society (Illich 1976a). Willis (1989) advanced the concepts proposed by Illich and argued that medical dominance was achieved firstly through political power and only secondly through scientific authority. Foucault (1976, 1980) argued that, once scientific authority was established, power was then reinforced and reinforcable through the process of medical governance. Governance esteemed professional knowledge and expertise and by implication denied legitimacy to all other forms of knowing (Culpitt 1999). If the healing knowledge was not medicalised it was devalued as ‘lay’ and considered, at best, worthless and, at worst, harmful. Expert medical knowledge continued to be seen as the only legitimate healing knowledge. It was formulated and categorised through its own language and paradigms and was then given to society as reality that needed to be accepted on trust (Gibb 1998). The trust/faith had been transferred from the high priest to the medical practitioner and represented a new form of power, a power based on healing and knowledge (Culpitt 1999).

To expect one human being to have the monopoly on healing knowledge, to know all and be always right is unrealistic. It is unfair and yet the ‘Doctor knows best’ attitude is one often perpetuated by the medical practitioners themselves. As Janette described the response she received from the first gynaecologist:

*It was such a shock for me to learn that he had done what he had done wrong and then said it was OK and I just needed to give it time to heal. For me sitting all the time and for me not being active all the time might take longer for me to feel better – he told me that ...//... But he must have known and he must have been able to see what was wrong.* (Janette)

The question remains unanswered, whether or not the gynaecologist was genuine in his belief that he had not erred and it was Janette’s particular situation (paraplegia) that led to her difficulty in healing. The process of medical governance does not imply a power-seeking motive for any individual practitioner. Like the past power of the high priest, medical power is pastoral in nature and naively accepted as well meaning, by provider and recipient alike (Foucault 1983; Fraser 1989). The Foucauldian concept of power is not centralised or static but involves one group’s regulation of time, space, desire and sanctioned authority over another (Foucault 1984; McKie 1995). Using Foucauldian concepts in the context of cervical screening, McKie (1995) argued that cervical
screening programs inadvertently used women’s sexual and cervical health as mechanisms to maintain medical hegemony and power over women.

Women are encouraged to have Pap tests at regular two-year intervals. Targets (percentage of women to receive cervical screening) are set and surveillance mechanisms are set in place to ensure they are met. General practitioners are financially rewarded by the state for attending Pap tests. Women have cervical screening in a medical institution in which power relations between health professional and the woman are inherently unequal. Women provide details of their sexual history that have no bearing on therapeutic outcomes and then, having given their history, risk being judged for not sharing the same moral values as the clinician. Women are assumed to be heterosexual, and lesbians may feel either invisible or too vulnerable to challenge heterosexist attitudes. Women enter the cervical screening process asymptomatic, believing they are healthy but risk being informed that their healthy self-concept is incorrect. McKie (1995) argued that cervical screening is surrounded by discourses that reinforce medical superiority, make assumptions and can result in demeaning the woman’s view about herself and her now commodified cervix. It is highly unlikely that any gynaecologist described by the women in this study deliberately set out to harm them or was even consciously aware of the discourse described by McKie (1995).

The Nocebo Effect was experienced in part because the professional concerned had been socialised through homage to the education and medical systems to believe in their considered expert knowledge and skills at the expense of any seeming contradictory evidence. Baker, Yoels and Clair (1996) argued that, throughout medical school, the medical student learnt that appearing knowledgeable was paramount and in the interests of instilling confidence in patients; they learnt to conceal any uncertainty or anxiety with a mask of confidence. However, Matthews (1995) argued that any analysis of power should not be concerned with intentions but the effect that that power has in practice. Whatever the intention of the gynaecologist who attended Janette’s cervical biopsy, adherence to the primacy of medical opinion had potentially life-threatening effects.

Many feminist theorists such as Oakley (1980) argued that gynaecological medical styles relating to women are predominantly masculine and women are categorised as being especially ‘troublesome’. Janette in this situation may have been seen by the first
gynaecologist as being particularly troublesome. He may have genuinely believed that it was her ‘troublesomeness’ rather than the adverse effects of the procedure he had attended that was responsible for the problems Janette was experiencing. However, the gynaecologist’s unwillingness to admit his mistake reinforced the myth that the medical profession may somehow be above common humanity, that he was able to fix anything and everything.

Oakley (1980) further argued that because the obstetrics/gynaecology specialty originally developed as a challenge to female modes of midwifery care, its ideology has its roots in anti-feminism. The achievements of obstetrics over midwifery were propagated throughout the twentieth century. However, they were rarely, if ever, argued empirically, but always a priori, from the double premise of male and medical superiority (Oakley 1980). Female obstetricians and gynaecologists continue to be a minority force. Oakley (1980) argued that this gender imbalance would continue for as long as gynaecological practices continue to exercise a social control function over women’s lives. The legacy of tension between obstetrician and midwife continues between general practitioner and women’s health nurse. In the exemplars to follow, Joyce and Megan both shared stories illustrating their awareness of the tension sometimes evident between the professions.

Joyce expressed her surprise that the general practitioner read the women’s health nurse letter of referral and took immediate action. She was aware that, in this small rural town, the general practitioner was overtly antagonistic about women opting to see the women’s health nurse for gynaecological screening, counselling and education. Joyce said:

And then [General Practitioner] didn’t hesitate .../... when [women’s health nurse] sent him that note, because he’s not all that keen is he? On, you know [women’s health nurses (WHN)]. Because I’ve heard other women say to me, ‘My God, he went off the air!’ [GP] says, ‘My God, what are you going up there to [WHN] for?’ .../... And this particular woman, she’s a friend of mine, and I said, ‘What did you say to him?’ And she said, ‘I told him to get stuffed! I’ll do what I wanted to!’ She’s really outspoken this woman and I roared laughing. (Joyce)

Like Joyce, Megan also described the hostility held towards the women’s health nurse by the general practitioner in her town. But, unlike Joyce, Megan did not find it amusing. Megan believed the medical practitioner was motivated by financial greed:
I found [WHN] were really good, when I did find out. But the medical profession wasn’t very good. Here, locally, they were sort of very cold and abrupt with me. And I think that was because I had come here to the women’s health clinic instead of going to the doctor to have the Pap test in the first place. But I feel much more comfortable here. Especially with a woman I think ...//... I went to the doctor here, he just said to me, ‘Oh I don’t know whether you’re going to live or die!’ ...//... He was angry! He was angry! He was angry! ...//... It really upset me, because I was in a big enough state as it was. He wasn’t going to give me any answers. And I went to [regional city] and Dr [Colposcopist] was pretty upset about that! He said, ‘He knows darn well that there’s a lot we can do!’ And uh, he put me mind at rest, he was really good ...//... He listened! Yeah, he was really um, disgusted in the way I was treated over here ...//... I was in tears when I got there. Because it was sort of a week later and I, it was an awful long week ...//... Because it never came back that it was cancer, straight off. And [GP] would have known that. He was just, as far as I’m concerned, he was just money hungry. Because he didn’t get the dollars for doing it, that’s how I look at it. Because he didn’t get the money for doing the Pap smear, he just turned into a pig! (Megan)

Financial considerations may have accounted for the general practitioner’s attitude, in part. It was, however, unlikely to be the sole motivation.

Willis (1983) argued that medical domination of the health industry was completed in 1933. Since that time, medicine has been the most powerful health discourse in industrialised countries such as Australia (Chard, Lilford & Gardiner 1999). Medical dominance is evidenced by medical practitioner professional autonomy, control over patients, determining resource allocation, determining direction of high technology treatment, influence over nursing and allied health occupations’ realms of practice, administrative influence and through the collective influence of medical associations (Bates & Lapsley 1985; Phillips 1996). Medicine dominates other health professions, in this instance nursing, through subordination, limitation and exclusion (Willis 1983). Nursing has traditionally been depicted as the ‘silent partner’ within this dominant medical relationship, taking the role of assistant or chaperone during the gynaecological consultation. For many decades and still in some areas, cervical screening and women’s health have been the domain of the medical profession; the nurses’ role is one of subordination. In 1984, the Women’s Health Policy Review Committee was set up by the NSW State Government to investigate women’s satisfaction with the state of health services. In response to community demand the Review Committee made the recommendation that a special category of registered nurse be established to provide gynaecological health screening, counselling and education for well women, that is, the ‘Women’s Health Nurse Practitioner’ (Coxhead et al. 1992). In response to this report
and State Government initiatives, in the late 1980s some registered nurses elected to do post-registration training to become specialised women’s health nurses and in so doing were certified to undertake cervical screening as well as holistically focusing on well women’s health education, counselling and clinical services.

Prior to the advent of women’s health nurses and other autonomous nurse/midwife roles, medical dominance had been maintained in part through the medical officer deciding which tasks should be the domain of medicine and which should be the domain of nursing (Willis 1983). In contrast, the women’s health nurse program had been established in response to community demand and the nurses’ willingness to meet this need. Many medical practitioners, nurses and the women who consulted them saw this ‘women’s health nurse’ role as one that was complementary to that of the general practitioner (Barclay et al. 1993). This innovative, government-backed, women’s health nursing initiative had been reported on in extremely positive terms and had had unprecedented success (Coxhead et al. 1992; Reynolds & Foote 1990). Recommendations were made by the NSW Department of Health in 1989 for it to be both maintained and expanded (Coxhead et al. 1992; Reynolds & Foote 1990).

However, not all medical practitioners were prepared to see the women’s health nurse as a health professional who complemented their own role in women’s health, and a significant proportion of medical officers saw the women’s health nurse model of service as a threat and unnecessary competition (Leach 1998). One small area of medical dominance was now under threat and medical practitioners were no longer able to exclude nursing from the women’s health arena. The Australian Medical Association mounted a media campaign to discredit the program, limit its growth and where possible exclude nurses from practising in this autonomous nursing role. Newspaper headlines at the time included, ‘Danger of Nurses Doctoring’ and ‘Women Attack the Basis of Practice’ (Coxhead et al. 1992). Willis (1983) would have argued that the medical establishment and the general practitioner, described by Joyce and Megan, were in effect trying to reclaim the power that the general practitioner perceived was being eroded, as well as the financial remuneration he was missing. He was doing this not by confronting the women’s health nurse involved, but rather by venting his anger during medical consultations with the women who had elected to see the women’s health nurse for well women’s services.
Hierarchical relationships exist between medical officers and nurses. They also exist between all health professionals and clients/patients. A health professional herself, Margaret expressed amazement at the unspoken pressure to maintain the status quo in a hierarchical relationship between professional and patient/client. Margaret said:

*You take on the patient role. No matter how knowledgeable or assertive you are. And I would consider myself reasonably assertive most of the time. You do take on the patient role very much ...//... The most overwhelming thing for me, particularly looking back ...//... it’s the stuff about the patient/professional role and how even, no matter who you are, you tend to put yourself into that role and how strong that pressure is. Even though you don’t feel it at the time ...//... [Health professionals] have the power of the knowledge. And therefore that makes you a bit more important to me, and more important than me in the process ...//... so therefore I’m going to subjugate what I know to your professional knowledge. Whether the professional actually has that knowledge or not, you assume it of them, perhaps ...//... the knowledge is the power! The assumption of the knowledge is the power in that relationship.* (Margaret)

On a catastrophic note, Margaret described a horrific obstetric experience – premature birth, recto-vaginal fistula and a colostomy for nine months. She was experiencing contractions early in labour but her experience was completely negated by the midwife aided by technology. Margaret described the situation:

*The fetal monitoring stuff. They had the whiz bang machine here and I kept on saying to the person um ... that was putting the monitor on and [them] saying, ‘Oh no, no, no, you’re not getting too many contractions’. And I’m saying, ‘Well look, not feeling them down there where you’re getting the monitoring. I’m getting them ... It’s all back ... and it’s all really low’. Oh no, no, no, you can’t be having them because um ... the monitor says you’re not! Which is really interesting sort of situation! I’m thinking, OK! And it’s interesting to spite the fact of how much you know about the process, that you still submit yourself to comments like that and that you accept it.* (Margaret)

Peacock and Nolan (2000) argued that the legacy of the scientific tradition of modern medicine is that human beings, once they seek medical attention or health care, become committed to the cult of the expert being more knowledgeable about them than they are about themselves. The fact that Margaret was an experienced health professional offered her no protection. Margaret said:

*It’s interesting to spite the fact of how much you know about the process, that you still submit yourself to comments like that and that you accept it ...//... You take on the patient role. No matter how knowledgeable or assertive you are ...//... you do take on the patient role very much so ...//... it’s really interesting how much you submit to other people and how much you let them take over that role ...//... how damn difficult it is to actually make known what you want and what you don’t want and...*
what you think. I guess it’s probably a lot about the way we see medical treatment in general and the medical model of things and the fact that the people work in a facility, just because it’s called a hospital must be experts ...//... it’s that feeling I think. And even when you know they’re not, you still go along with it! ...//... I’m not really sure why ...//... as soon as you come into a hospital, it means that you are a patient and therefore you are expected to act in a certain way ...//... that you basically go along with what is being told to you ...//... you like to think that you would voice your opinion more but you might be more likely to just let it go. (Margaret)

The concept of ‘submission’ that Margaret used indicated recognition of a hierarchy of power between the professional and the client/patient that was present in the medical encounter but may not have been evident at other times. Margaret knew that she was in early labour, she knew she was experiencing contractions and yet this knowledge, this truth was worthless. Bluff and Holloway (1994) illustrated how women believe that health care professionals, in their and Margaret’s instances, midwives, know what care is best for them and, as a consequence, find it difficult to communicate their needs.

Health care professionals are in a position of authority. As evidenced by Margaret’s narrative, authoritative professionals may fail to acknowledge that a woman has her own form of expertise arising from intimate knowledge of her own body (Salmon 1999). The health professional’s knowledge is considered legitimate (especially when that knowledge has technological backup). The woman’s knowledge is not legitimate and, at best, is considered inferior to ‘scientific’ knowledge (Roberts 1992). The dominant medical model is left intact and further esteemed; women are left feeling degraded and stupid, until their knowledge is ‘proven’ right. Then, like Margaret, they are left angry but with little or no means of expressing it. A number of years later, Margaret remained angry and shared:

_I guess I probably still retain some of the anger about it all ...//... and in some ways I don’t think that is necessarily a bad thing! Because I think I was hardly done by! ...//... Why shouldn’t I be angry about it and why should I be accepting._ (Margaret)

Language in everyday use reinforces the same hierarchical power structure and the woman’s loss of ownership of herself. This loss of self-ownership and passivity was reflected in Margaret’s simple description of when the gynaecologist she had originally seen returned from leave:

_He had taken me over as his patient once again._ (Margaret)
Offensive language and communication

Jayne equated effective communication with procedural skills. She argued that gynaecologists should be required to be proficient at both but implied that procedural competence was easier to obtain than communication adeptness. Jayne questioned if gynaecologists had lessons on communication as part of their training:

> And obviously we need gynaecologists ...///... like doing colposcopy and things that are practical ...///... but that is a service that once taught, they can do ...///... I presume when gynaecologists do their studies, surely they have an aspect of communication in their course? (Jayne)

Communication skills may be taught to medical students at university. However, Oakley (1993) argued that the health system actually worked to reduce effective communication between the practitioner and the client/patient. In her observations at antenatal clinics, she observed that the new medical officers would start by coming early to the clinic and were willing to spend time with women. The new medical officers observed the consultant obstetrician invariably running late and spending less and less time with individual women. Within a short period of time, the new medical practitioners would also attend late, timing their arrival just before the consultant obstetrician would arrive, and spend less and less time with individual women. They had been effectively socialised by the health system to provide a service that devalued effective and reciprocal communication.

Time is considered by the health professional as a scarce and highly valued resource that needs to be controlled by the physician (Fox 1990). In their ethnographic study at outpatients clinics, Yoels and Clair (1995, p. 46 cited in Baker, Yoels & Clair 1996), quoted one second-year medical resident advising a first-year resident, ‘If you let the patients talk, you’ll be there all day’. The second-year resident appeared oblivious to the concept that inadequate communication prevented the ‘patient’ concerned participating in their own health care. The young resident who had been taught at university that listening to patients was therapeutic was soon socialised into believing that listening to a patient’s story was an optional extra, to be indulged in only after the real work of medicine was complete (Baker, Yoels & Clair 1996). It is highly likely that the nursing profession is similarly affected. Attempts to limit the woman’s input into the medical dialogue appeared to Jayne as bluntness and had tragic, unforeseen consequences.
In Jayne’s experience, the gynaecologist’s bluntness exacerbated her feelings of self-loathing. Jayne shared that her self-loathing was associated with being made to feel diseased and dirty by the gynaecologist’s insensitive communication. His bluntness dehumanised him in Jayne’s perception until he was reduced to just another set of hands and peering eyes. Jayne described his manner and the effect it had on her:

Very blunt! This is the problem! This is what you have to do! .../... He said, ‘you have papillomavirus’. I said, ‘What’s that?’ And he said, ‘It is a sexually transmitted disease that you’ve probably picked up from a previous boyfriend’ .../... when [he] told me that’s what the problem was, that’s what I focused on. I focused on that I had this wart virus that I had picked up from a previous boyfriend .../... which made me feel very dirty .../... That’s my first consultation I recall ... very cold, very blunt .../... basically another set of hands and eyes peering inside me .../... it was mainly feeling very dirty .../... and if [gynaecologist] had been slightly more sensitive, it wouldn’t have had to make me feel that way. (Jayne)

The ‘peering eyes’ described by Jayne had the effect of compartmentalising her into a physical body and a less important socio-emotional self. Compartmentalising seemingly provided the gynaecologist with a tool to manage his own emotions and his time. Fox (1990) argued that the clinical workplace and medical subculture, with its focus on controlling time and talking to rather than listening to people, may explain why efforts to ‘humanise’ medical training meet with little success in the medical environment. Jayne could only describe in negative terms how the gynaecologist communicated with her:

He wasn’t ... he wasn’t ... I can think of things that he wasn’t! He wasn’t understanding, he wasn’t .../... considerate of your feelings, it was just a job! He didn’t have very good communicating skills. Every word he said was offending .../... I don’t think men should be allowed to be gynaecologists when they have attitudes such as his. (Jayne)

Jayne believed that consideration and understanding were sadly lacking in the communication repertoire of the gynaecologist she consulted. His inadequate communication exacerbated the difficulties she was experiencing. Jayne went on to describe multiple consultations with many other specialists who also seemed to trivialise her problems and offered her no assistance with the iatrogenic sexual difficulties she was experiencing.

The women in this study have reiterated the need for warm communication, consideration and understanding in any professional consultation. Trust that a health
professional will hold all information confidential is also at the core of therapeutic communication.

**Confidentiality broken**

*It’s a gossipy place … (Terry)*

Instances of overt broken confidentiality were fortunately rare in the stories the participants shared. Rita described one instance:

> Chiropractor was pretty bloody awful, in terms of telling another client who knew me, about something or other and said, ‘Of course that is why they split up, because Rita is a lesbian’. .../... totally out of line .../... he had no right to acknowledge that I even came to see him, so I was pretty upset about that one .../... I’ve had minimal contact with health professionals. (Rita)

After living in her rural town for a few years, Terry decided that she never should have had the HIV test there. She feared that the receptionist staff at the medical centre might break her confidentiality:

> I did have an AIDS test when I first came here to [rural town] .../... if I had known what [rural town] is like, I never would have had an AIDS test in [rural town]. It’s a gossipy place .../... I have heard of things that have got out, yes. So hence I’m pretty reticent to go to the medical centre here. (Terry)

Some women described the health facility’s geography as being incompatible with confidentiality, even when no words were spoken. Megan described the medical centre in the small town where she lived:

> At the medical centre they walk out with their, thing they use, Spec? .../... Speculum. Yes, they walk out to the other part with it, so everyone knows why you’ve been in there don’t they? .../... I’ve seen it when I’ve been sitting there. Like you’ll be sitting there waiting to have a blood test and down the side and they walk past with it. They don’t treat you very good; I don’t think. (Megan)

Megan’s description illustrates how a Nocebo Effect was not deliberately inflicted on women. It more often resulted from the professional’s inadvertent focus on the task at hand, rather than on possible implications for the person concerned.
Professional coolness

He was detached for it, I wasn’t … (Janette)

The informants often described their expectations of what should happen in their relationships with health professionals. Having described some neutral experiences with male health professionals, Janette identified herself and I as ‘us’ in comparison to the male ‘other/them’. In doing so, Janette stated her expectation that being with a female would be a positive experience:

> Females are just so important. It’s wonderful, it’s like turning over and finding it’s a clean page. You can start anywhere you want to start on that page and tell them what’s happening to you physically, what’s happening mentally .../... I’ve had some lovely females in my life, including yourself! You’ve worked to my advantage .../... I guess we’re both females .../... I’d probably expect a female to understand how I feel more .../... I don’t expect a male to understand .../... They don’t understand us very well, I don’t think. (Janette)

> I can talk to women’s health nurses. I can expect that they will hear what I’m saying – it’s not just talking to them. It’s like they hear what you’re saying! .../... I suppose because they’re females I expect them to hear the way I hear other people’s concerns .../... it’s like that you’re switched on to your work .../... women’s health nurses seem to me as though they’re switched on to their work – so they’re doing their job and not just attending. (Janette)

However, Janette’s experience with women’s health nurses had not been universally positive:

> I wouldn’t be able to have [named WHN] do the tests that [other WHN] do for me. I’d be really uncomfortable .../... Probably a coolness. Usually there’s a warmth but with [named WHN] it’s the opposite. It’s a coolness for [her] and I .../... I’d been coming along all those times and I’d, and it was a big shock to find that I couldn’t do that any more. (Janette)

Janette’s description was congruent with the work of Drew (1986) who argued that health care recipients described their caregivers as cold and lacking emotional warmth when they felt excluded or not cared for by the professional.

Women like Rita, Marie and Megan, whose stories have been previously shared and who felt guilty or felt that their abnormal Pap test result was a punishment, desperately required warm health professionals. Detached coolness on the part of the professional reinforced the idea that they were indeed guilty and therefore deserved punishment. It is not argued that this was the clinician’s intent, rather that their need to appear
knowledgeable and in control caused them to exhibit what Fox (1963) described as ‘detached concern’. The participants noted the professional’s detachment and it was not therapeutic.

Janette described the general practitioner who she recalled giving her the information that the Pap test result was abnormal:

[General Practitioner] was saying ...//... and it was so serious to me and wasn’t serious to him ...//... it was just like he was reading it off a piece of paper, which he was. But it was detached ...//... He was detached for it, I wasn’t. (Janette)

The detached and dehumanised scientist-technician was able to read Janette’s results as if all that mattered was the piece of paper on which they were written. Janette’s general practitioner neglected personal communication with her in order to complete the immediate scientific task at hand – informing her of her abnormal Pap test result. Illich (1976a) argued that, before sickness became perceived as an organic or behavioural abnormality, the sick person could find in the eyes of their carer, a reflection of their anguish and suffering. Now the medical encounter was one of a biological accountant engaged in input/output calculations, and the sickness had become the raw data for a diagnostic equation. The expertise of the physician and the power of their gaze have been enhanced by the invention and acceptance of nosology, a system of disease description that makes it appear that all illnesses fit within a definitive network of disease classification, based on how the organs are affected (Foucault 1976). The epistemological acceptance of nosology requires the physician to be detached and demands objectivity as a pre-requisite to efficient diagnosing. However the medical practitioner’s detachment was perceived by Janette as an uncaring attitude and reinforced the loneliness she felt when told of her abnormal Pap test result:

Yes, it was a pretty terrible feeling. It was pretty much like I was alone again. Alone like I was when I had the miscarriages, I felt so alone ...//... I found it to be extremely lonely because nobody felt anything for you. (Janette)

Ann felt ignored and negated by the medical practitioners and the students present to observe her colposcopy procedure:

There’d be students in the room and the doctor would – while you were getting undressed and ready, he’d be chatting to the students and it was sort of like, you didn’t exist! And just sort of felt, like well this may be standard for you but this is pretty important to me and I would have
appreciated a little bit more, I don’t know whether compassion is the right word. But yes, just a little bit more acknowledging that I was there. (Ann)

Ann conceded:

They probably thought that they were giving me privacy by sort of moving over to the side of the room and they were just discussing a couple of things. Um, I think I would have been just as offended if they had left the room ...//... I just wanted a bit more personal attention. (Ann)

However well meaning their intentions might have been, without reciprocal communication Ann interpreted their actions as neglectful, disrespectful and offensive. Ann described having difficulty understanding how females with technical expertise and who have probably had Pap tests themselves could be cruel:

[WHN] the only female I’ve ever had do a Pap smear that doesn’t hurt! And sometimes, it’s just in putting the duck thing in, but quite often they put it in and it would be shu, shu, shu [shu, shu, shu implies a very quick, abrupt almost aggressive technique]. And it was sort of like ...//... you’ve had these done, surely, and occasionally they’d get a hair caught in the thing ...//... and like you’d try and sort of try not to move so the hair doesn’t get any more tension on it! (Ann)

Just as medical and nursing staff set up barriers with their coolness and detachment so too do some administrative staff and requirements. Bureaucratic form filling exacerbated the difficulties faced by some informants. Joyce described her admission procedure:

You go over to that [Base Hospital] and only for [Daughter] filling out those stuffing forms and going through all that rigmarole ...//... it’s a headache ...//... I’m sixty-eight but there’s a lot of people in their seventies and eighties who aren’t as ...//... coherent. And you know, if they’ve got to fill them out, it must be dreadful. And some of those people in those offices aren’t that helpful! ...//... They ask you all these questions ...//... we sat around that hospital all day long ...//... it’s ridiculous ...//... this is bloody stupid! ...//... I said to [daughter], ‘[Clerk’s] a sour faced bitch isn’t she?’ I said. But that’s how I feel ...//... I thought, ‘Oh God, they’re not very helpful!’ (Joyce)

Already nervous about her need to receive health care, Rita was made even more anxious and her sense of vulnerability and aloneness was exacerbated by the coolness of the attendant anaesthetist:

You’ve actually got to trust a system that I don’t really trust. So I had to actually just hand over to somebody, my life and my body. I didn’t know internally what was happening to me. I therefore had to trust somebody who might have known more. And I actually don’t trust the health system
very much. Too often they reduce us – it’s a reductionist model anyway, but it reduces us to that part of our body. And this guy didn’t have a bedside manner, he wasn’t awful, he just didn’t have any. So there was not warmth about him ...//... I was totally alert and just started trembling and said, ‘I’m feeling very anxious, I’ve got the shakes’. Because it helps to say it ...//... But I often don’t get much response. And I was there on my own and I think I would have liked to have a friend. Or a friendly nurse ...//... to hold my hand, to talk to me, to reassure me. (Rita)

Rita did not desire the nurse to be a competent technician but an empathic human companion. This was in keeping with the concepts espoused by Habermas (1971a) and Sarvimaki’s (1988) analysis of holistic nursing practice as primarily a form of communicative rather than skills-based action. A focus on technological skills, no matter how advanced, has the effect of being reductionist in nature.

Reductionism

Too often they reduce us ... (Rita)

Rita described the health system as reductionist. Reductionist trends are seen in this study as one of the flaws of medicine. Reductionism is directly related to medicine’s acceptance of the Cartesian notion of body, which is seen to represent an ‘object’ body rather than a ‘lived body’ or person. Leder (1984) argued that in Cartesianism, the human body is a machine, driven by mechanical causality and susceptible to mathematical analysis, medical fragmentation and reductionism. The body has no intelligence, rather the mind, the essence of self is accepted as a discrete entity (Leder 1984). However, Lawler (1991) counter-argued that Descartes may, in actuality, not be as dualist as reported. She described how Descartes (1986 cited in Lawler 1991) argued in his Sixth Meditation that bodily feelings such as pain and hunger indicate a close body-mind union.

Whatever the roots of Cartesian dualism, combined with nosology, it serves medical hegemony well. Stanley and Wise (1993) believed that patriarchal dominance is maintained by Cartesian binary ways of understanding. They argued that Cartesianism, in the form it is propagated in medical philosophy, sees reality in two opposing principles, maleness and femaleness and their working out through such concepts as science and nature, reason and emotion, objectivity and subjectivity. Reality becomes presupposed and expressed in binary and gendered terms. These oppositional principles coexist in relations of super- and subordination with the feminine supportive of the
masculine. Stanley and Wise (1993) rejected this notion of Cartesian ontology and argued that the needs of women would be better served if it were replaced by an alternative ontology that recognised differentiation, but saw this as neither oppositional nor dualistic. There needs to be an appreciation of, rather than an antagonism towards difference, and women need to be perceived as an interconnected whole person (Stanley & Wise 1993). Medical fragmentation and reductionism founded in Cartesian dualism and nosology do not serve the needs of women or their sexuality well. When health professionals consider female sexuality, it is often from dualist heterosexual/homosexual terms with heterosexuality considered the norm.

**Heterosexism**

\[I was invisible \ldots (Rita)\]

Rita described heterosexist assumptions made by health professionals that had the consequence of negating her sexuality as a lesbian and her visibility as a person. The gynaecologist’s discomfort in discussing sexuality was obvious to Rita and as a consequence her desire for answers needed to be put in abeyance to protect the gynaecologist. The need for Rita to be approved of by health professionals inhibited her conscious desire to challenge heterosexist and/or homophobic communication, or even to ask for clarification from them:

*Asking [gynaecologist] about how long it could be \ldots to \ldots have sex. And wanting to clarify what that actually meant, in terms of him saying \ldots ‘No sex for such and such a time’\ldots I’m then thinking how can I actually ask him, what he means by sex? \ldots I didn’t want to see his disapproval \ldots probably because I was feeling sensitive about some of that stuff anyway. So I asked him what that actually meant, ‘Do you mean no penis in vagina sex?’ \ldots And he said something like, ‘Yes that’s right’. So then I actually plucked up the courage and asked, ‘What about orgasm? Are you talking about orgasm or are you talking about contact with the cervix?’ \ldots He was a bit taken back by that. And just said, ‘Look I think it is just you know, just best if we leave it alone and when, leave it alone and when you feel more comfortable, you can sort of, you know, when its been the period of time and the healing has happened’. So I left feeling um, totally invisible, I was invisible. I hadn’t disclosed anything of what I might have wanted to do. (Rita)*

Family Planning Associations play a major role in educating health professionals in areas such as sexuality and homophobia. However, even in family planning clinics, heterosexist assumptions are evident. Rita explained that on occasions she challenged heterosexist attitudes but, when she did not, her well being was affected by both the
health professional’s ignorance and her own perceived weakness in not promoting the rights of lesbians:

*I still get annoyed when I go to family planning or anywhere else and they talk about your partner ‘he’ and make all those assumptions which they do. Now they may well do that because I have children. It is irrelevant and I get annoyed about it and I challenge them on it even though I am not necessarily comfortable with saying, ‘But I am actually a lesbian’. And I don’t know why? I probably would be comfortable saying it I suppose. But I don’t know why I don’t say it ...//... One particular time I went into family planning, it might have been the last time I went there ...//... I didn’t actually correct this woman and was really annoyed with myself for not correcting her when she was talking about sex. And I can’t remember what it was now but it was clearly indicating contraception and sex and then saying, ‘But you don’t need contraception of course, because you’ve got no uterus and do you need to use lubricant with the penis?’ ...//... And I remember feeling quite annoyed with myself for not correcting her on this.* (Rita)

Two issues are evident from Rita’s description. The first is that organisations such as ‘Family Planning’ and ‘Women’s Health Clinics’ become more conservative in their approach as they become accepted as ‘mainstream’ health services. The second issue relates to Rita’s feelings of annoyance, not so much with the health professional’s heterosexist attitudes but with herself for not challenging those attitudes. When a woman is in receipt of a health service, she is in a vulnerable position and it may be in the interests of self-preservation to focus the attention of anger on herself rather than the health caregiver.

The Nocebo Effect is evident when health professionals express anger during consultations or when they evoke anger in clients. It is also evident when they do not provide adequate, plain-language information. Adequate information is required by women if they are to be able to make sense of what is happening to them or to make informed choices as to treatment and/or non-treatment options.

**Information withheld and consent uninformed**

*He wouldn’t tell me anything ...* (Jayne)

Cervical screening continues to be promoted as a means of providing reassurance for women but, as the participants shared, the experience also provokes anxiety and fear. Lupton (1995a) argued that screening for any disease has psychological costs and participants are not informed of this. While told that the Pap test procedure is ‘low risk’
they are not informed of the high risk of psychological distress. In the context of cervical screening, a false positive result can be rectified through further investigations and is not considered as serious as a false negative where the woman might unknowingly go on to develop serious disease or even invasive cancer. However, as Melanie described, a false positive result can also have serious psychological consequences and she had not been informed of that possibility.

Information may not be withheld but may be so jargonised that it is meaningless or intimidating for the woman. Whorf (1956) described the language barrier that technical terminology creates between the professional ‘in’ group and the clients ‘out’ group. The acquisition of medical terminology is seen to be an important step in the health student becoming an ‘insider’ to their profession (Crawford, Nolan & Brown 1995). Having an extensive technical language proves powerful and serves to consolidate the power of the health professional over the client (Ng & Bradac 1993). Illich (1976a) argued that because medical language is in the domain of the health profession and is constructed by them, the person consulting the health professional is deprived of meaningful language to describe their anguish or experience. The person attempts to describe their pain or experience and the health professional transforms the description into a medical or nursing diagnosis. In so doing the health professional lowers the status of the person, by reframing their experience into one that can be explained through a medical paradigm (Crawford, Nolan & Brown 1995). Health professionals using medical jargon that is not understood by the woman, or intentional or unintentional withholding of information that the woman requires to make a meaningful interpretation of her situation, is a common theme in many of the informants’ narratives and contributes to their powerlessness. Jayne perceived that the health professional’s use of jargon and medical terminology was deliberately used to limit her understanding and intimidate her:

*I visited her and many, many other specialists ...//... Talking about things in such a scientifically medical way that is intimidating and she knows it is.* (Jayne)

Many participants described consultations during which information was withheld from them. Jayne described how her questions were ignored:

*I went to my GP and he ...//... said, ‘I’d like to refer you to a specialist’. And he, he wouldn’t tell me anything. He wouldn’t even say it was human papillomavirus, he wouldn’t say a thing – just that he wanted me to go to a specialist! ...//... It was terrible. I thought, oh my God, what’s wrong?"
And he wouldn’t tell me! He just said, ‘No, I just want to confirm it – you go and see the specialist’. So he wouldn’t even give me any feedback, so of course that was enough to worry. (Jayne)

Marie believed that she was disadvantaged by the inadequacy of the information she was given but did not ask questions because stressful life circumstances ‘took over’:

How disempowered I felt and how even the GP didn’t give me very much information ...//... He never explained to me about what sort of abnormality it was that I had. He just said to me, ‘You’ve got an abnormal Pap test, I’ve already done all these things for you – all you need to do is to rock up for the investigations’. And that was it, that was the beginning and the end to the phone call. And I never thought to ask any questions either, because my stuff that was happening in my daily life took over. (Marie)

During the interview, Jayne wondered why her vulnerability meant she accepted without question the gynaecologist’s recommendation to laser her vulva:

The first time I went in he observed the cervix and he put a vinegar type base on it to see where it comes up as white and he said, yes, you have papillomavirus ... and on the outside ...//... [Gynaecologist] said, ‘This is what we do’ and I thought if you do this I’ll have this [dirty] thing away from me ...//... [Information] ... what I should have asked for when I went to the doctor but I didn’t! So why didn’t I? ...//... I just kick myself for not saying, ‘Why?’ ...//... And I think it’s sad that so many women would have been in a similar situation and felt just as vulnerable. (Jayne)

Joyce had a hysterectomy for treatment of the adenocarcinoma of her cervix. On six separate occasions during the preliminary interview in this study, Joyce wondered aloud if her ovaries had been removed. She was not sure and never recalls being informed if they were removed at surgery. The first time Joyce mentioned her ovaries, she said:

And of course, I say to [daughter], now I wonder if I’ve had ... I think he did take the ovaries ... I think he took the lot. (Joyce)

Joyce’s experience mirrored the experience of the participants in the study by Webb (1986) who did not know whether their ovaries had been removed at the time of their hysterectomy. Such knowledge, or lack of knowledge, indicates women’s lack of involvement in decision-making processes about their body once they are admitted into the health system. It also demonstrates a devaluing by the health professionals, of women’s right to know what had happened to them during treatment. By deliberately or inadvertently withholding information from women about their treatment, the balance of power is maintained with the health professions (Ehrenreich & English 1974, 1979; Rowland 1988).
When inadequate information or no explanations are given it means the consent is not informed and is therefore invalid (Beauchamp & Childress 1994; Armstrong, 1995; DeLuca et al. 1995). Had adequate information been given, Jayne believed she never would have consented to the treatment:

And I had no idea what he meant, no idea! ...//... I think if the doctor had provided me with more information and alternatives, I never would have had it done ...//... He just said, ‘Laser treatment’ and I thought, ‘I wonder what that is?’ All I was concerned about is, is it going to make it go away? (Jayne)

Ann, like Jayne, was not aware of what would be involved with laser treatment:

I just wasn’t sure what they were doing ...//... yeah, they were going to laser my cervix ...//... laser surgery was pretty, to me it was fairly new, it wasn’t a common practice thing and I wasn’t getting knocked out ...//... I mean the only lasers I’d seen were on ‘Star Wars’. So the imagination sort of went overtime. I mean if they’d come in dressed like ‘Darth Vader’ I’d have had a problem! (Ann)

Annabelle described her distress and embarrassment when she discovered that, instead of seeing the female colposcopist she had been expecting, she was also being observed by a male medical student. She was asked permission for this student to be present, but her consent was ambiguous:

I thought that it was only going to be a female team and there was one male there, which sent me very red faced ...//... after the rape, I don’t really like, except for my boyfriend, I don’t really like anyone else seeing me, no pants on or naked or any of that sort of stuff. I just don’t like it! ...//... I only go to the male doctors if I really have to ...//... there was a red-faced learner doctor ...//... he was very red faced – poor, poor bugger! ...//... Yes, one of the learner doctors was a male, and he was very red faced. He came from the Children’s Hospital in Sydney. I saw it on his little tag thing ...//... They just said, ‘So this is our learner doctor ...//... do you mind him being in here?’ And I thought, ‘Ha, ha, what can I say?’ ...//... I was a bit iffy about it. (Annabelle)

Annabelle described giving ambiguous consent to the presence of the male medical student, but her expressed consent was not requested for him to participate further. She was reduced to a body part on an examination table and was offered up to the medical student’s gaze:

They’re saying, ‘Have a look, you have a look’ with the binoculars to the male doctor and he’s gone even more red. (Annabelle)

Withholding information such as that the procedure would be used for teaching purposes may not be intentional on the part of the health professional. It does indicate
neglect to ensure that the woman fully understands the process. Julie and Megan both expressed their distress because they did not know what was going to happen:

You know, like not knowing what this test was and not thinking that it could happen to you ...//... And the fear of the unknown as to what it was going to lead to, and you suddenly start assessing your life! ...//... I mean as soon as you think abnormal smear, you think, ‘Oh no, this is it. I’ve got something really wrong’ and you sort of think, ‘Does this lead to a hysterectomy? How far does it go?’ And at thirty-two, I hadn’t had any other children, and I wanted to! So it was a very bad scenario for me. (Julie)

Because it was my first colposcopy, the unknown is even worse you know. And the embarrassment ...//... the first time is always embarrassing isn’t it? ...//... I was shocked. Because it is only that I had trouble getting in that I went seventeen months instead of twelve. I didn’t understand CIN 3. That meant nothing to me. I had no idea what [WHN] was talking about ...//... I was in, shocked, and I probably couldn’t have understood. They only word I heard was probably pre-cancerous. And that, that really scared me ...//... If I had heard the bit about it could have taken ten years to turn to cancer, that would have relaxed me a lot ...//... Because I had no idea. I’d never even heard of it ...//... And the colposcopy, I was frightened of the unknown. (Megan)

Faye found the need for further investigations very expensive. She was on an aged pension and was told she was to have an automated cervical screening process (Thin Prep) for which she received no financial remuneration. Faye was not informed that automated cervical screening processes such as Thin Prep and Papnet remained in the realms of quality control and were yet to be proven to reduce the incidence of cervical cancer (Farnsworth, Chambers & Goldsworth 1996; Bosanquet et al. 1999). Faye described her financial difficulties:

I mean it is fairly expensive, petrol the way it is ...//... it costs me, um, about $160 for it, you take $80 for the colposcopy, which you get a refund but I don’t know how much ...//... Because I haven’t got it yet, $20 for petrol and then you have the Thin Prep that you get nothing back for ...//... $29 I think it was, which in itself isn’t much but then you add the $35 for the what? The results of the Pap smear, the smear test or whatever ...//... about $160 it costs me ...//... next time I have to have that estpos? Oestrogen cream? (Faye)

Faye was dependent on the ‘expert knowledge’ of the health professional to recommend treatment options. She did not feel able to question the advice or ask for more information and suffered considerable financial distress in following their prescribed therapy. Other women did attempt to inform health professionals about their own ‘knowing’ of a situation. But the information they shared was often ignored.
Not listening negates a person’s ‘knowing’

But I knew there was something wrong … (Rita)

When the health professional doesn’t listen, the client is left feeling depersonalised and negated. Peacock and Nolan (2000) argued that, when a person complains that they have not been ‘heard’ by their medical practitioner, nurse or carer, it demonstrates a breakdown of ‘care’ and the caring relationship. Margaret described a seemingly minor incident, when the general practitioner, attending a Pap test, continued to explain the process step-by-step, even though Margaret had requested she not. Margaret said:

*I remember thinking afterwards, ‘God, does she think I’m a complete idiot?’ …//… It means you don’t take into account any of the other person’s experience or how they are feeling or anything.* (Margaret)

Margaret contrasted two examples, one where she wasn’t listened to following surgery to have a colostomy to repair a recto-vaginal fistula and another where the health professional took note of what she was saying:

*And I said to [the surgeon], ‘Look I don’t know what it is but I think I can smell it’. And he sort of said, ‘Oh no, you probably can’t …//… you might be a bit too sensitive!’ or something like that …//… When [stomal therapist] came along, I said, ‘Look I mentioned it to the doctor but I think I can actually smell it’. She said, ‘Let me have a look’, and she said, ‘Of course you can, it’s not clipped on properly!’ …//… she was really good.* (Margaret)

Listening to and taking note of the person who is being cared for, is a vital component that is given little credibility in the health professional’s repertoire of skills. The health professionals, who Margaret described, endeavoured to categorise her reported symptoms according to their experience and pre-existing knowledge base. This limited their ability to make sense of what Margaret was describing. Farber (1966) in the context of describing phenomenology reported the same occurrence when he said that as researchers we are limited by the ‘blinkers’ we wear. He argued that we see the world according to an already interpreted phenomenon, resulting from past scientific inquiry and fixed traditional conceptions. Margaret, contemplating both her experiences as a woman who was not listened to, and as a health professional, provided some invaluable insights into the perception that professionals were hampered by those same blinkers, when they focused primarily on their own experience and knowledge:

*It’s a really interesting …//… our attitudes to medical care and childbirth and issues that seem to require some sort of ‘specialist’ …//… attention …//… And how much health professionals actually do listen to the patients/clients whatever you want to call them …//… Working as a*
health professional, you’re going to have a number of experiences that explain for you what is going on in a particular situation. And I guess, probably like everybody we draw on our experience more than anything else I suspect. And if someone comes along that is saying something different to what we have found before, it is easier perhaps to negate it.../... than to put it into the rest of your experience. And to say well, that might be something different to what I’ve come across. Particularly if it’s someone who might have been working in the field for a long time.../...
And I guess they probably think well, I’ve seen everything! (Margaret)

Health professionals frequently negated Margaret’s ‘knowing’ that she had a problem. They saw things through their own blinkered understanding and Margaret reported:

There was a lot of negating things.../... After a couple of days.../... I started to get a really sore perineum again. And I mentioned it was sore and they had a little look and they said, ‘Well, it’s not too bad’.../... And then I had a bath.../... I was getting discharge.../... I said, ‘Look I’m getting a bit sore, I’ve got this strange sort of discharge’ and I was having a bath and it was faecal stuff, of course coming through. ‘Look it’s really strange, it smells horrible, I don’t really know what is going on here’. And they said, ‘Oh no, well, it should be all right!’.../... They looked but not very well!.../... It got to [a couple of days later] and I was much sorer then.../... Finally I got to the stage.../... as soon as I stood up, a bit more would come through. And I actually soaked a pad. Got a nurse and said, ‘This is what the discharge is’. She took one look and took off to get the doctor. So she knew what it was.../... I think maybe I should have complained more. But then I think, no, I shouldn’t have. They should have been doing their bloody job!.../... They obviously weren’t listening carefully. They were listening but not putting it into context.../... Another time when you think, hell, they just didn’t listen to me!.../... They were listening and putting it into their experience of what was normal, but I obviously was not normal and that didn’t fit into, to the way they did things. (Margaret)

Joyce had experienced at least six episodes of post-menopausal bleeding. She knew it was not normal and had multiple gynaecological investigations that detected no abnormality. Frustrated, she described how the doctor must ‘know’:

And [Gynaecologist] said, ‘Look I’m sorry I never got back to you’. Dear he was nice. And he said, ‘I never found anything unduly there, you know you’ll be right’. And all the rest of it. And I thought, ‘Oh well, he would know!’ And I come home and I start [bleeding] again! I thought, ‘God, this is ridiculous!’.../... And then I came up to [clinic] and [WHN] discovered that [cervical polyp]. Well then, from then on he had me in [Base Hospital] and everything.../... To have all those bleedings, it just seemed so ridiculous.../... And when [gynaecologist] examined me that time when I went to hospital, he said that there was nothing there that he could see and yet that came on.../... and I came back to [WHN] and I’ve had a Pap smear again. But you see [Adenocarcinoma] developed in oh, I’d say less than 12 months. (Joyce)
Joyce had negated her own knowing but valued the knowledge of the specialist, especially as he had been nice to her. Joyce perceived this specialist as caring but not all health professionals mentioned by the women were seen in this way.

**Uncaring professionals**

*Well he didn’t seem to be interested in me much …* (Faye)

In Heideggerian phenomenology, caring (sorge) forms the basis of our being-in-the-world (Heidegger 1962; Kaelin 1988; Benner & Wrubel 1989). This is not to say that all human beings are either ontologically or intentionally caring of others (Edwards 2001). Heidegger (1962) argued that care (sorge) meant caring for self as well as caring for others or being with that other person. Faye had previously described only caring experiences from being with nursing and medical staff:

> Getting back to nurses and doctors, you know I don’t think I could ever fault any of them, they were wonderful. (Faye)

However, she then described two negative experiences. The first was after she had been diagnosed with a life-threatening illness and was being transferred, acutely ill from the small district hospital to a metropolitan hospital in a care flight:

> I said to [the nurse] that I had to use a pan because I was on the drip and she said, ‘You can’t use a pan!’ And I said, ‘Well I’ve got to’. And she said, ‘Well you shouldn’t have drunk so much!’ I said, ‘I’m on a drip!’ So that is why she, she took the drip off! I said, ‘That doesn’t make any difference, I need a pan!’ Anyway, we were called back to [regional city], we were nearly at Sydney and we were called back to [regional city] because there was an accident or something, or a young child .../...That was the only reason I got the pan! Because we stopped .../... I needed a drink of water, you see my throat had all fungus. (Faye)

The philosophy behind sorge is not so much what is done to indicate caring, but rather how a person goes about caring (Kaelin 1988). Bradshaw (1995) would have argued that Faye required the nurse to be competent, knowledgeable and skilled but also to treat her with kindness, sympathy, comfort and reciprocal communication. This was not forthcoming and, as a result, Faye became distressed and unnecessarily dehydrated, Nocebo Effects of inadequate nursing care.

The second negative experience Faye described related to a consultation with a general practitioner. Faye described his officious attitude that has implications for the *New South Wales Cervical Screening Program Strategic Plan 2000–2004* that promotes
opportunistic screening by general practitioners as the primary strategy for increasing the cervical screening rates:

"The doctor I was seeing at the time ...//... I didn’t want to get undressed in front of him ...//... he was too sort of, abrupt! ...//... I sort of didn’t feel comfortable with him ...//... well he didn’t seem to be interested in me much. You know if I went for two things, he would say, ‘Make another appointment for the second’. ...//... ‘You’ve only booked in for ten minutes! You haven’t booked in for the second, or if you want to see me for two things, you book for two things’ ...//... I remember I went in there one time, for one thing and he asked me all about my leg and everything and I told him. Then I said what I’d came in for and he said, ‘No, you’ve had your time’. And I said, ‘That’s not what I came in for, you asked me about it’ ...//... And he said, ‘No, you make another appointment’. (Faye)"

In the two instances Faye described, the Nocebo Effect was evident in that the health professionals were more concerned for their own interests than ‘being with’ her. Being with someone requires an active involvement in the life-world of the other person (Walters 1995b; Draucker 1999).

As stated in the introduction to this chapter, iatrogenesis is a component of the Nocebo Effect. Many instances of social and cultural iatrogenesis have been described under the umbrella term of the Nocebo Effect. A number of participants also shared stories related to clinical iatrogenesis.

**Clinical iatrogenesis**

*He hadn’t done it right ... (Janette)*

The word, iatrogenesis is derived from the two Greek words, *iatros* meaning physician, and *genein*, meaning to produce, and relates to ‘physician generated’ disease and illness (D’Arcy & Griffin 1986; Anderson, Anderson & Glanze 1998). An iatrogenic disorder is caused by health professionals/procedures or through exposure to the health facility environment.

Having been diagnosed with CIN, Janette was referred to the first gynaecologist who attended a cone biopsy. Janette was very slow to recover:

"I was bleeding and I was still feeling very unwell ...//... I was feeling really ill for some months. [Gynaecologist] was ...//... telling me I was OK ...//... he had done wrong and then said it was OK and I just needed to give it time to heal. For me sitting all the time and for me not being active all the time might take longer for me to feel better – he told me"
that! ...//... But he must have known and he must have been able to see what was wrong. (Janette)

Janette continued to feel very unwell and made an appointment with a women’s health nurse who examined her and urged Janette to see her general practitioner and request a referral for a second gynaecological opinion. Janette was referred by her general practitioner to a second gynaecologist. The second gynaecologist told Janette that the first gynaecologist’s treatment wasn’t correct:

The treatment that he’d given me, evidently wasn’t correct ...//... he had not done it right! Was how it worked out from [second gynaecologist] ...//... The damage was not completely doing the operation correctly. The biopsy hadn’t been done correctly, that’s what [second gynaecologist] said ...//... it needs to be redone. (Janette)

A number of years after having laser treatment to her vulva to treat subclinical wart virus, Jayne consulted a sexual health physician in regard to her protracted vulvodynia. As was common, from the informants’ stories, the second consultant specialist did not try to protect the first medical officer whose treatment had caused iatrogenic harm. The sexual health physician described to Jayne that laser treatment to the vulva:

Was experimental at the time and they don’t do it now because they’ve proved, well that it doesn’t solve the problem. Because it grows back. (Jayne)

Following the laser treatment to her vulva, and experiencing difficulties with vaginal-penile intercourse, Jayne returned to the doctor who had treated her:

I go back to him, he said, ‘Well, if you’re having trouble with penetration, you can cut this way and stitch that way and make it better!’ (Jayne)

Surgical attempts to cure vaginismus are detrimental to sexual well being (Dietsch 1997). Women undergoing surgical procedures prior to sexual therapy have a failure rate double that of women with vaginismus who have never undergone surgery (Barnes 1986). Having attended vulva laser treatment that resulted in Jayne developing secondary vaginismus, the gynaecologist now recommended surgical reconstruction. Rowland (1988) would have argued that this was an example of male dominated medicine mutilating women in the name of repair and healing. Jayne shared her story:

Slowly and slowly, sexual intercourse was less and less to the point where, I had seen many doctors in Sydney and I just gave up ...//... I said it was about twelve months but it was a few years I think, in between [attempting penile penetration] because I just wanted to forget about it. (Jayne)
Julie did not experience sexual problems following her cervical treatment. She experienced both mental and physical difficulties and did not believe that it was coincidental that her illnesses followed on from an abnormal Pap test result. A year following the abnormal Pap test result, she was becoming increasingly more agoraphobic and susceptible to panic attacks and infections that did not respond to a plethora of prescribed medications. Julie described her emotional difficulties:

>Not long after the smear test, that I got really ill and sort of, I virtually couldn’t even go shopping and I sort of had these feeling that I didn’t want to go out places. And um, that when I went shopping, the aisles were sort of closing in on me ...//... And I wouldn’t go shopping without [husband] – I’d take him with me, because I just thought that I was going to fall over or pass out. And I don’t know whether it was because I was sick or whether I was just you know, imagining it ...//... that was a very harrowing experience as well ...//... I probably went through that stage too, where my emotions were very raw and I’d burst into tears and things like that! And you do, you become very conscious of yourself not being immortal. (Julie)

Julie’s emotional reaction to the experience of having an abnormal Pap test result and consequent treatment developed and became exacerbated over a period of time. In contrast, Terry described the aftermath effects of having a cervical biopsy as more immediate. Biopsies taken at the time of the colposcopy are often shown to the woman, in the interests of client education. Terry was shown the cervical biopsy but she recalled this as a distressing experience that exacerbated her sense of having been invaded:

>I can see when he takes the piece out. It’s like a five cent piece and it’s a thing like this. And I can see it and I can see it when it’s really quite pink and raw and it’s got all the blood around it and everything around there. But then they get it and they put it in a jar and they show it to me. And I mean, I wasn’t interested in my placenta, why should I be interested in this? ...//... It’s just the way I am ...//... I had the procedure and it’s all dreadful and everything ...//... We get home and I’m really feeling wasted, very, very wasted ...//... So I get into bed ...//... And howl! Cry, cry, cry, cry ...//... and I couldn’t stop. And I was not crying over [ex-husband], I was not crying over [husband’s ex-wife], I wasn’t crying over the procedure. I wasn’t crying over anything. I was crying over nothing ...//... I was empty. It was that bit that they got out of me if you like! It was like I just felt, I felt invaded! ...//... That’s how I felt. I just felt invaded. I felt like, I felt like there was a great big hole. And it was gone ...//... See I don’t think I needed to see [biopsy specimen]. If I hadn’t seen that, I don’t think I would have had that feeling ...//... vague and empty ...//... showing you the bit, is that really necessary? ...//... Do you really need to see it? (Terry)

For some of the women, like Terry in this study, the iatrogenic effects from the cervical investigations were immediate but, for others, like Jayne and Margaret, the cervical
investigations and treatment set off a chain of events that were to have long-term implications.

**Cascade of problems**

*Because I had the cone biopsy … (Margaret)*

Margaret, when she shared her story of having a cone biopsy to treat adenocarcinoma in situ and then giving birth to two premature babies and the sequelae of developing a recto-vaginal fistula that required a colostomy for treatment, was in no doubt that the cascade of problems started with the cone biopsy:

*Because I had the cone biopsy um. I had, then had two premature children. One, one at 30 weeks and um, the other at 35 ...//... My first one was a Caesar. She was an emergency Caesar ...//... and my second one was a forceps delivery with a pudendal block and I ended up having um, an undiagnosed third degree tear, so I then a few days after she was born had a colostomy! Because I developed a fistula ...//... colostomy for nine months because I had fistula surgery about 3 months after [baby] was born and it closed up most of it but not all. I had a really bad obstetric time, really and for no particular reason other than for ... as I say, I am in none of the risk groups for anything. But I just had a really bad time ...//... some of the previous surgery had had an effect that perhaps might have made a difference to what happened with the tear and all that sort of stuff.* (Margaret)

Margaret expressed concern in regard to the long-term consequences of the cone biopsy, third degree tear, recto-vaginal fistula and subsequent repair operations:

*God knows what my pelvic floor is like though! ...//... I actually know pretty well, what it’s like – pretty well shot to pieces! ...//... I certainly well, have some stress incontinence, not huge but some ...//... I probably should do more than I am in terms of exercising. But you think well, it’s all bloody scar tissue, so what’s the point anyway? After ...//... the cone biopsy and the episiotomy and the fistula and the fistula surgery, there’s a fair bit of scarring there I think. So I do sometimes wonder what the long-term consequences are going to be.* (Margaret)

In sharing her story, Jayne had no doubt that her sexual difficulties – the vaginismus she experienced together with the protracted vulvodynia – were directly related to the laser treatment to her vulva:

*He just burnt it to a crisp! I looked like a sundried tomato that was burnt! ...//... The response to the operation ...//... the vaginismus, but also the burning ...//... I tried to explain it like it’s like trying to put something round in something square and you’ve got to jam it in because it doesn’t fit ...//... I was actually trying to explain two things ...//... [Husband] and I, it’s funny we talk about happy times before the*
operation and then we talk about the operation and then we talk about after. So we identify the operation as when it caused problems and it did and obviously after the operation it was painful and that’s what we brought it down to and obviously, we, the involuntary reactions of my body’s which I can’t control is saying the same thing. ‘Once upon a time you put something close there’ .../... I can’t control it. Like [husband] and I will, you know, [husband] is so good. He’ll say, ‘We’ll just muck around and we don’t have to have intercourse .../...’ And that’s great and then I get to the point and I say, ‘Go on, let’s try!’ Because you want it! And we had fantastic sex prior to the operation and I’ll say, come on, let’s try and it’s just so painful ... it’s not like we don’t try and I get aroused and I guess, I can still have the pleasures of sex ... um... but, it’s just the intercourse .../... I feel like a part of me has died .../... the fact that the external laser treatment is seen as quite cruel and it was! .../... Yes it was cruel! .../... I hope to God that they don’t do external lasers anymore and I sometimes think of that doctor in Sydney and think of how bad or how wrong he was to do what he did. Because I would have to say that from that point on in my life – dramatic changes! Dramatic changes ... (Jayne)

The stories shared by Margaret and Jayne are valued for their affirmation of a woman’s subjective experience and the challenge they put out to cause the listener/reader to reconsider dominant health care ideologies. Sakalys (2000) argued that illness narratives function to make both power and weakness visible. The health system devalues psychosocial concern for the recipient by overvaluing so-called ‘hard’ scientific data and the technical quest for medical diagnoses and control. Kleinman (1988) believed that this devaluing and overvaluing process is a failing of medicine that disables the professional and disempowers the client. Critics of narrative type research, including Atkinson (1997) and Paley (1998), argued that studies that value personal narrative over the authority of medical meta-narratives are illegitimate as they reverse the credibility that normally distinguishes lay from professional knowledge. What is particularly confronting for Atkinson and Paley, is that the ‘medical gaze’ is turned from the usual professional, assumed to be objective, gazing of the person to the person gazing at the professional. Hunter (1991) and Kleinman (1988) argued that there should be greater reciprocity, in both gaze and dialogue, between health caregivers and receivers in order to relocate recipient subjectivity, meaning and culture as a significant component in the healing/medical process. On occasions the women in this study turned their observing gaze to the health professionals around them and noted incompetence.
Annabelle described being in a small, crowded room with four medical practitioners and/or students. Already feeling overwhelmed and embarrassed, her confidence in them was destroyed when she realised they did not know how to work the basic equipment:

*It was very, very cluttered and I was in something like a dentist’s chair ...//... I had to put my feet in the calipers! And they didn’t know how to work it very well to start off with; they had to get [staff specialist] to show them how to put it up. It was quite embarrassing. I’m lying there bright red in the face ...//... they did eventually [work the examination chair] but then they had problems with the duckbills ...//... one pair they managed to get in and they realised they couldn’t open them up, so they had to pull them out again ...//... the second pair they pulled out, they were like that [Annabelle uses her hands to show that the speculum slides were perpendicular to each other] ...//... all crooked. And they said, ‘Oh, we’ve got to get this fixed otherwise we can’t do the colposcopy’. So they eventually bend them forward. Because I was really starting to get worried ...//... they fixed them ...//... and then they didn’t warm them, so they were freezing when they put them in ...//... and they had problems with the second set again, trying to get them to stay open. And I was sitting there thinking, ‘God, oh no ...//... is this a waste of time?’* (Annabelle)

Annabelle was told that there were four areas requiring biopsy, but only three biopsies were taken. She wondered why only three biopsies were taken:

*It showed up four, four abnormal spots ...//... they took three of them, don’t ask me why they didn’t take the whole four, they only took three ...//... they took one and they dropped it oh, OK, and then the second attempt they didn’t quite get, so they had the third attempt at getting. And so they got the three and the last attempt, the last one they didn’t get properly to start off with, so they had two shots at it and then they said, ‘Oh we’ll have to take the blood out’ ...//... that freaked me out! ...//... Then they had troubles stopping the bleeding afterwards.* (Annabelle)

Julie described her experience of her abnormal Pap test results being lost, which led to a four-month delay in receiving further investigations. She was angry because she had rung the doctor’s receptionist and was told that ‘doctor would have rung if there was anything wrong’. The doctor hadn’t rung and, when the results were eventually found, no apologies or explanations were offered. Julie said:

*A period of four months had lapsed since between the time when I had the abnormal smear come back and the time I actually got to have the colposcopy done. Because the results had gotten lost in between time, apparently. Because I remember ringing [doctor’s receptionist] and saying, ‘What were the results of my test?’ And she said, ‘Doctor would*
have rung you if there was anything wrong’. And this is later on when she rang me to come back in and I sort of thought, ‘Hang on, you told me there wasn’t anything wrong and now there is something wrong’. And that sort of upset me as well! .../... When I had the smear test done to start with, it was only first stage, CIN 1 .../... and in four months it had changed from 1 to 3. So when I actually got there it was rather serious, and that sort of upset me more .../... I think the main thing was when they didn’t sort of give the results of the test to start with. And they didn’t give me any explanation why they got mislaid. And I sort of thought to myself, ‘How can you mislay things, you know’. You have the test, they send it away, it comes back. You know you should put it somewhere and, and obviously, somewhere in the handling it got lost. So I think that upset me a great deal. (Julie)

The Nocebo Effect is induced iatrogenically and is exacerbated by professional incompetence and dominance that value its own empirical knowledge over any other knowing. Medicine maintains its monopoly by labelling any non-medical views of health as ‘intuitive’, ‘alternative’ or ‘complementary’ with less power and status than the medical model (Illich 1976a; Milligan 1998). To reduce the incidence and impact of iatrogenic factors in women with an abnormal Pap test result, it is imperative that practitioners listen to and value women’s own expert ‘knowing’.

A synopsis of Jayne’s story follows and is used as a paradigm story to illustrate the Nocebo Effect that occurred when a woman presented to the gynaecologist having had a Pap test result that detected changes in the cells suggestive of HPV infection. Cervical screening is a tool used by the health system that is meant to prevent serious illness. No woman ever expects to be harmed by the system that is built on a framework deemed to heal and do good. Jayne’s story, however, encapsulates what is meant by the Nocebo Effect with ongoing and tragic sequelae.

**Jayne’s paradigm story**

Jayne was a 21-year-old university graduate at the time she had the abnormal Pap test result. At her preliminary interview, six years later, she described the difficulty she had in understanding why she never questioned the gynaecologist who performed what she was later to discover from another specialist was experimental treatment.

Jayne shared how the HPV detected at the time of cervical screening was largely ignored and the gynaecologist’s focus of attention became the subclinical wart virus
detected colposcopically on her vulva. Jayne gave her uninformed consent to laser treatment to her vulva, which she described as ‘being burnt to a crisp’.

Jayne’s responses to the gynaecological treatment bore similarities to the responses of people suffering from post-traumatic stress disorder (Taubman-Ben-Ari et al. 2001). Jayne described intrusive recollections, especially whenever vaginal-penile penetration was attempted:

So we identify the operation as when it caused problems and it did and obviously after the operation it was painful and that’s what we brought it down to and obviously, we, the involuntary reaction of my body’s which I can’t control is saying the same thing, ‘Once upon a time you put something close there …’. (Jayne)

Jayne attempted to detach herself from the experience. Near the end of the primary interview, she described how she managed to share her painful story. Jayne saw her ability to become detached as a self-protective strategy:

Over time, I’ve spoken about it so many times that I can say it, I can talk about it now with a smile. Because if you don’t you’d probably cry. But I wouldn’t now, because I’ve detached it. I’ve just detached it. (Jayne)

The laser treatment was on Jayne’s vulva, rather than her cervix. She had consented to the treatment but the consent was never informed. When Jayne told the specialist that she was not given information about the procedure, the specialist verbally abused the nurse who had very briefly spoken to Jayne about what to expect.

During the interview, Jayne described how she continued to experience secondary vaginismus and vulvodynia. Describing the changes to her enjoyment of sexual contact she said, ‘I feel like a part of me has died’. Jayne believed that the vulval treatment she received following her referral to a gynaecologist, for investigation of her screening detected cervical abnormality, was a major and dramatic life catalyst that permanently and adversely affected her life. She blamed herself:

The person that I was then – new graduate, fantastic job, fantastic opportunities, life at their feet ... And yet someone who allowed someone to invade you privately ... I didn’t allow it, but it happened and I never questioned it! (Jayne)

Jayne described herself in two time periods ‘the person I was then’ at the time of the laser procedure to her vulva and the person she had become, six years later and at the time of her interview, ‘So I guess I’m now a stronger person’. Personal transformation
and changes were a common theme dispersed through many of the informants’ stories. This transformation is explored in the chapter to follow.
Chapter 7
Transformations

One thing that comes out in myths, for example, is that from the bottom of the abyss comes the voice of salvation. The black moment is the moment when the real message of transformation is going to come ...//... It is suffering that evokes the humanity of the human heart. The happy ending of the myth is a transcendence of the universal tragedy. The objective world remains what is, but because of a shift in emphasis within the subject, it is beheld as though transformed.

Campbell 1949 cited in Younger 1995

What the informants in this study shared was no myth! In the three previous interpretive/discussion chapters, the women mirrored the observations of Freire (1972) and Street (1989) and saw themselves as subjects not in their own social drama, but as objects participating in a drama directed by others. Around the time of their abnormal Pap test result, the informants in this study had directors who oppressed them. These directors included people in their intimate relationships, identified in the first interpretive chapter, and health professionals, identified in the third chapter on the Nocebo Effect. Rita, for example, said:

[Dr] was also learning acupuncture and wanted an opportunity to practise it. I told him I didn’t want acupuncture ...//... He insisted and put a needle in. (Rita)

However, this final interpretive chapter demonstrates that the women did not remain as passive and static players in another’s drama. The participants in this study moved on and redefined themselves, not as victims but rather as women taking a change in direction. At the time of the preliminary interview, they saw themselves directing and participating in their own life drama and no longer dependent on their prior oppressor. Janette, for example said of her violent husband:

I could never go back, I couldn’t go back to the ‘yes’ person I was. And I couldn’t go back to all the difficulties that life would bring with [husband]. But I still care what happens to him. (Janette)

Many participants, like Janette, had taken their life experiences, including that of having had a cervical screening detected abnormality, and chosen to remould their self-definition in a transformative way.
A different time

_In making the above statement, Janette contrasted the woman she was once, prior to and around the time of the abnormal Pap test result, with the woman she had become and created a bridge between the two experiences. Janette’s experience was not atypical. The participants frequently spoke of themselves as the woman they were prior to and around the time of the abnormal Pap test result and the woman they were at the time of the interview. Frequently, during the interviews, when referring to themselves in the present, they described a woman who had changed, who was different to the woman they once were. It is not being suggested that the experience of the abnormal Pap test result is the direct cause of this transformative process. The participants only rarely suggested that they had changed because of the abnormal Pap test result. The abnormal Pap test result experience is not portrayed as a rebirthing or conversion type phenomenon for the majority of informants. The experience was more akin to a curve, or sometimes a hairpin bend on the life road they were travelling._

‘Becoming’

_By integrating their life stories and the experience of having an abnormal Pap test result, the informants verbally alluded to the Simone de Beauvoir’s concept of ‘becoming’ and, importantly, took it one step further. Simone de Beauvoir (1953) theorised that a woman’s body and her experience of that body are fundamental to the lifelong process of her ‘becoming’ a person. The women interviewed in this study agreed only in part with de Beauvoir’s concept that they would not be the person they were without their specific life and bodily experience. De Beauvoir theorised that human beings do not exist without backgrounds, they are limited to their bodily experience and they are therefore incapable of creating themselves (de Beauvoir 1953; Lundgren-Gothlin 1994). However, in this final interpretive chapter the informants moved on from ‘becoming’ in the ways theorised by de Beauvoir. The informants were no longer victims of any bodily experience. They were in the process of ‘becoming’ the women they were deliberately and consciously choosing to be and their stories illustrate how they had begun to see themselves as directors and subjects in their own life experience. The_
participants had begun to create and describe themselves as women who were strong, angry and assertive and with a future that was at least, in part, of their own making.

Having even the briefest reminder of their mortality, seeing themselves as they really are, not the immortal beings they wished themselves to be, shocked participants to rethink their reality and enjoyment of life. Without exception, informants found having an abnormal Pap test result a negative experience. The experience of having the abnormal Pap test result had broken down the pretences that allowed them not to think about what their lives meant. The participants were now closer to what Younger (1995) described as their own existence and such awareness had transformative effects. The informants mirrored Younger’s theory in their stories. They all suffered a sense of separation and alienation from others, feelings of shame and/or stigma and these feelings have been described in the preceding interpretive chapters. However, in keeping with Younger (1995), the informants described an evolving process where the feelings of alienation were reversed and a sense of connectedness, especially in relation to themselves and their own needs and personhood, developed. Life was richer, more appreciated since having had an abnormal Pap test result.

**Enjoying life**

*I enjoy most days (Janette)*

The participants shared stories of personal growth and enhanced quality of life since having an abnormal Pap test result. On multiple occasions they expressed an enjoyment of the ‘everyday’. Although the literature is skewed toward a preoccupation with researching negative emotions, when positive effects and personal growth are explored, they are linked to people’s preparedness to be open to experience (Schmutte & Ryff 1997; Penninx 2000). By being prepared to share their stories for this project, each of the women had been open to the experience of having an abnormal Pap test result.

Having an abnormal Pap test result was perceived as life threatening. The participants’ experience of having an abnormal Pap test result was similar to the women who had survived breast cancer in the Cordova et al. (2001) study and women who had experienced multiple stressors in the Fay and Sonnetag (2002) study. The fear of, or the experience of, cancer was a transitional time with potential for both positive and negative outcomes. Emotional growth and feelings of well being, particularly when
relating to others and appreciation of life, are positively associated with perceived life threat (Cordova et al. 2001; Fay & Sonnetag 2002).

Ann, in expressing enjoyment of the ordinary, spontaneously shared the pleasure she had in her relationship with her husband and in her identity as an Aboriginal woman:

*I’m married to one of the most wonderful men on this earth! Um, he is incredible and because of the way he feels about me and I feel about him, we just sort of bounce off each other and it makes me into a much better person ...//... my Aboriginality has a big bearing on it.* (Ann)

Janette described herself as a woman who enjoyed most days and gained a lot of personal satisfaction from the immense amount of voluntary work she did. Janette said:

*I enjoy most days. Most days are pretty special to me ...//... I volunteer as you know in various places ...//... So most days are pretty good in that light and I have two sons and two grandchildren. A pretty ordinary sort of life really. Well I see it as ordinary. Apart from being a paraplegic for nearly fifty years now ...//... But that really doesn’t have much of a bearing in my life ...//... it really doesn’t stop me from being who I am ...//... I’d love to write. I do write poetry and I love writing. Um, I am fascinated about history and everything I can learn about history. Just sort of general things in the world. I love to hear about problems and think about possible solutions.* (Janette)

Having survived a horrific war and the belief that she was going to die because of her abnormal Pap test result, Melanie described the changes in her life at the time of the preliminary interview:

*But you know with this job I am doing now. It is good. Everything is coming to its place ...//... It is good. I find myself more relaxed.* (Melanie)

To give the impression that Melanie (or any other woman in this study) lived happily ever after would not be true; she continued to experience isolation. Melanie loved to socialise but felt that discussing issues such as Pap testing was too personal to share with her friends. Her inability to share her concerns exacerbated her feelings of loneliness:

*I’m friendly, I like company. I like talking. I like being in company and you know, but this is not the thing that you can talk to them or to someone, this is personal, this is talked to really close friends and family ...//... Very lonely ...//... You know so alone.* (Melanie)

Julie described how the memory of having the abnormal Pap test result was getting easier to bear and she expressed enjoyment of life. Nevertheless, an abnormal Pap test result in Julie’s story was a lifelong reminder of mortality:
I think it is getting easier. I sort of try not to think about it ...//... Think about life now. That’s how it is because life is good now ...//...

[Abnormal Pap test result] tells you that you are not invincible. (Julie)

Verplanken and Holland (2002) argued that enhanced self-focus is associated with an increased sense of altruism. Having had time to focus on their own needs and having been reminded of their mortality, many participants described feeling more connected to others and they had a greater sense of altruism since the abnormal Pap test experience.

**More altruistic**

*I’d do something to ensure that at least some other girls didn’t come up with those sorts of problems* (Jayne)

The word, altruism is derived from the Latin words, *alteri huic* and means to express a regard for others as a principle for action (Gormley 1996). Stories of altruism related to the personal lives and incidents relating directly to having had an abnormal Pap test result. Janette, Marie and Terry expressed how they now felt more compassionate toward ex-husbands or others who had hurt them in the past but they were also aware of the need to protect themselves in these previously destructive relationships:

*I’ve tried to be compassionate with him and maybe he is better. Maybe, you know, he’s one [paedophile] in a million that has reformed himself ...//... And I understand his situation and I do feel sorry for him.* (Terry)

*I could never go back, I couldn’t go back to the ‘yes’ person I was ... and I couldn’t go back to all the difficulties that life would bring with [estranged husband] – but I still care what happens to him.* (Janette)

*I’m bringing those boundaries back in again because you have to protect yourself to some degree.* (Marie)

The term altruism has been used to describe selfless caring for others (Smith 1995) and on occasions has been confused with self-neglect (Reed & Leonard 1989). Janette and Terry were both demonstrating feelings of altruism toward their ex-husbands but it was an altruism that allowed them to create self-protective boundaries and to ensure that they would not neglect their own needs in intimate relationships.

Janette served as a volunteer, tirelessly working to improve access to services for people considered disadvantaged or stigmatised in her rural community. Although she gained personal satisfaction from this work, she also experienced frustration when working with a health care system that obstructed access to people when they were at their most
vulnerable. This frustration made Janette more determined to work and fight for the rights of people in greatest need of health care services. Janette was determined to use her own difficulties to ensure that other people did not suffer the same disadvantage.

Jayne expressed altruism, hope, sadness, regret and anger, a gamut of emotions when she remembered the treatment she had on her vulva and said:

*I just hope ...///... to God that they don't do external lasers any more and I sometimes think of the doctor in Sydney and think of how bad or how wrong he was to do what he did. Because I would have to say from that point on in my life – dramatic changes! Dramatic changes and you know I'd love to sue the pants off him! But that won't end my problems. It won't make it how it was before. But I often think if I did sue him and I got heaps of money, I'd set up something. I'd do something to ensure that at least some other young girls didn't come up with those sorts of problems and I think, I think he was very wrong for what he did – very wrong!* (Jayne)

Altruistic feelings were often overridden by anger. Many informants were angry at something or someone who had threatened their personal well being.

**Anger**

*Why shouldn’t I be angry about it and why should I be accepting?* (Margaret)

Many participants continued to feel anger when they recalled their experiences with health professionals. They often spoke in the present tense, suggesting that their anger had not abated with time. Janette described the mistake the first gynaecologist made when he took a biopsy from her cervix. She expressed her anger:

*I'm very, very angry with Dr [Gynaecologist]. I can no longer recommend him to women ...///... Cause I just don’t believe he cares that much.* (Janette)

Janette and Margaret were angry at the gynaecologists for making a mistake and the focus of their anger was on both their medical incompetence and their perceived lack of caring. Margaret wanted an apology and said:

*I blame [Gynaecologist] for what happened ...///... the fistula should not have happened and I do blame him for it ...///... no one ever took responsibility for it ...///... there was no ‘sorry!’ It’s silly isn’t it. There was no, ‘I think maybe I could have done something more’, something like that. There was nothing like that ...///... But I still think it was his fault.* (Margaret)
Margaret needed a person, a health professional to apologise to her for not listening, for not taking the care that may have prevented months of suffering and a lifetime legacy of pelvic floor problems. Drew (1986) argued that, in spite of all the technological advances, health care is still something that happens between human beings. She argued that the humanitarian nature of this relationship must be nurtured if the giver and receiver of health care are to benefit and not be harmed by the encounter. Margaret did not experience a humanitarian encounter and she was angry at the harm that resulted.

Marie believed that the fact that she was a health professional herself actually worked against her when she consulted other health professionals:

*Because I was a health professional, people also knew about me and that came before me as a human being.* (Marie)

Some women, having expressed their anger, demonstrated an outlet for it through a newfound assertiveness.

**Assertiveness**

*I couldn’t go back to the ‘yes’ person I was* (Janette)

This assertiveness was evidenced in the informants’ personal relationships and their relationships with health professionals. It stood in stark contrast to the stories of vulnerability shared by the same women in the chapter on abjection. Assertiveness was the lesson learnt from the experience of being vulnerable. Margaret had a strong, assertive image of herself and said:

*I’m fairly pragmatic and fairly straightforward and I tend not to pull too many punches I think. And I actually let people know what I think.*

(Margaret)

A sense of assertiveness was implied when Janette contrasted the compliant, ‘yes’ person she was to the woman she had become:

*I could never go back, I couldn’t go back to the ‘yes’ person I was.*

(Janette)

In contrast to the self that Janette described around the time of the abnormal Pap test result, at the time of the preliminary interview she felt autonomous and chose to direct herself in assertive new ways.
Terry once felt that she had to pretend that everything was perfect in her life, even when it was far from it. She felt responsible for the well being of others and was dependent on their approval. She no longer felt this way and said:

*Outwardly everything was perfect, because that’s how I was raised to be! ...//... You just keep fixing it you see ...//... Well, I’ve learnt you don’t have to fix it! ...//... And I’ve learnt that you can be yourself and if people don’t like it then they should move on and find someone else ...//... Because I’m always the compliant one. I’m always the one to brush everything over and make everything nice. But when it came to coming here and starting a new life – No! If you don’t like me the way I am ...//... then find somebody else ...//... Because I’m not going to change for you.* (Terry)

At the time of her abnormal Pap test result and colposcopy, Marie was more concerned about her husband’s needs than she was about her own. She described how she had changed:

*All I could think of was getting home to the babysitters and getting tea on and what time [husband] would be home and that all of that everyday life stuff got in the road. And because the babies were small and dependent upon predominantly me as their carer um ... [husband]’s running his own business and he needs to have his head focused on that so therefore take as much away from him to allow him to do whatever he wants to do. And I’ve got to deal with all this ... That’s my role, that’s my responsibility. I wouldn’t say that that would be the same now. If I was to have a baby now ... ‘Fuck you mate, you’re part of the picture!’ And that’s what I do now! You know, if I, if I ... I’m much more assertive now than I was then.* (Marie)

Having described their past compliance with medical practitioners, Janette and Jayne contrasted their experience with a more recent time when they felt assertive enough to ensure their needs were met in the medical encounter:

*I don’t always consider how I’m going, but I did that day ...//... Yeah, I felt great! It was good.* (Janette)

*[The Gynaecologist] said, ‘Well, if you’re having trouble with penetration, you can cut this way and stitch that way and make it better!’ And I just went, ‘See you later!’* (Jayne)

Jayne drew the comparison of her naive self at the time of treatment and the stronger, more empowered young woman she was at the time of interview. She believed her treatment from the gynaecologist would now be very different:

*[Gynaecologist’s] attitudes – probably his attitude was very young girl, doesn’t really have a clue about human papillomavirus. You know, very*
naive and I was and he knew that! He would have had to have known that ...///... But where if I went in now, it would be completely different.

(Jayne)

I have a vision of [gynaecologist] being tall and he probably wasn’t at all, and it was his way. I guess you could say he had a very good way of intimidating people ...///... God I wish I could go and see him now! ...///... I’d say, ‘One, let me read my file’, and then I’d say, ‘What reasons did you have for doing experimental laser treatment on a young girl, when it really wasn’t necessary and it was experimental?’ And I would explain what he has done since, the effects of it. And you know what? I still don’t think he would care. I really don’t. ...///... But you know, I just kick myself for not saying, ‘Why?’ ...///... I don’t think I blame myself, um, but I think that’s why I question things more now and I think that’s why I put so much effort into what I do. Because you learn from your mistakes.

(Jayne)

The lesson Jayne had learnt from the experience of feeling vulnerable, was the need to protect herself, to be assertive and harder:

I guess you harden to it ...///... So I guess I’m now a stronger person but at the same time not so sensitive, a bit harder, a lot harder. (Jayne)

Terry also believed that if she had to have repeat treatment for abnormal cells on her cervix, she would be forthcoming with expressing her needs:

God, I hope we don’t have to go through it again but if we do, for me personally, I mean I’m going to have something to say ...///... I’d be a bit reticent to go in again and do it like I did last time, and do it all the same way. (Terry)

Marie described being ignored and verbally abused by health professionals working inflexibly. The experience had made her angry and more assertive:

I would hate to not be assertive and this has made me more assertive.

(Marie)

As well as being more assertive with health professionals, the women described many and various ways they were taking responsibility for their own health and well being. They were making conscious decisions to become directors in their own life experiences and to ensure they wrote their own life scripts.
The road to self-healing

I’m bringing those boundaries back in again because you have to protect yourself to some degree (Marie)

Megan and Marie both described how they had become more likely to consider their own needs. Marie’s husband had recently suggested that she return to night duty so she could earn more income but she refused. Marie said:

*For me to look after myself and over the years it’s been getting better and better .../... And I do the meditations stuff .../... so that’s really important to me for my own well being .../... And also boundaries, like for me, I’ve had very loose boundaries in knowing that I am actually able to say no. I’m very open – my boundaries are very broad. And I’m bringing those boundaries back in again because you have to protect yourself to some degree .../... I also feel that I’ve been doing things to take care of myself. I’m very conscientious about my diet, I’m not conscientious about exercise .../... but I’m very conscientious about my spiritual needs. And so I meditate regardless.* (Marie)

Megan was also more caring of herself. She had learnt to recognise the physical signs that suggested her immune system was under stress and she took action:

*I think when I get run down it just gets worse .../... And if I get cold sores, I know when I’m getting low .../... so I slow up a bit .../... I take a day off work and do nothing or go shopping with my little kids .../... I give them the day off from school and I take the day off and we spend the day together.* (Megan)

By becoming more knowledgeable about their bodies and in particular their cervical health, some women were able to resolve the feelings that the abnormal Pap test result was a punishment or something that they needed to feel embarrassed or guilty about. Contrasting her knowledge base at the time she experienced the abnormal Pap test result with the present, Janette said:

*I wondered how it all occurred. How it happened to my body. Because I didn’t know much about it at that stage, I didn’t know much about my body. I probably don’t know as much now as I should, but I know more now than I did then, certainly I know a lot more now.* (Janette)

Marie described how she was so much more knowledgeable about HPV than at the time of her colposcopy:

*I mean I understand that so much more now but I didn’t understand it then.* (Marie)
Julie described how knowledge could reduce embarrassment:

> I think as you get older you get less embarrassed .../... I think you get to learn more and you know more about it. I think maybe if we know more about things that maybe we wouldn’t be so embarrassed and so hush hush about all these little things. (Julie)

Joyce had a hysterectomy to treat adenocarcinoma of the cervix and had a post-operative wound breakdown. She was told that the wound breakdown happened because she was a diabetic. Joyce did not accept this information and offered her own explanation:

> But I don’t think it had a lot to do with my sugar, I don’t think so! .../... I think it was just an infection! Because when they sent it away, they said something about a golden staph grew. (Joyce)

Janette described an embodied knowledge, an intuition about her own state of health:

> I know when I’m recovering! .../... I’ve got a pretty fair idea of what is happening. (Janette)

Naming, that is by being able to give their experience a name, was empowering and healing for both Jayne and Rita. Jayne described the relief she experienced when a sexual therapist named the two problems she was experiencing (burning vulva syndrome or vulvodynia and vaginismus). For Jayne, the naming meant knowledge:

> We worked out it was two problems. Which, you know, in effect that was fantastic to know that I actually .../... Burning vulva syndrome, so I was actually explaining two things, but prior to that no one was explaining, ‘Oh Jayne, you have burning vulva syndrome and you have vaginismus’. No one had clarified that I actually had a problem .../... The book about vaginismus and the other things, there was light at the end of the tunnel. It was like, you know, like I’d come home and I’d say, ‘I know what I’ve got! I know what I’ve got!’ And [husband] would say, ‘Well how do you fix it?’ And I’d say, ‘It doesn’t matter how you fix it, I know what I have!’ And that was fantastic! (Jayne)

Naming allowed a woman to have some power over what had previously been amorphous. As Posner (1991) metaphorically argued, only when the devil can be named is it able to be cast out.

Jayne described her thirst for information:

> I learn by reading. I want information, I want facts. I want research; I want other people’s situations, um, that’s how I learn. (Jayne)

At the time of her preliminary interview, Jayne was aware that it was very common for young women to have HPV detected. Lacey and Fairley (1995), for example, concluded...
that approximately 15–30% of women could have HPV detected within ten years of starting heterosexual coitus. This knowledge helped Jayne see the HPV in perspective and she said:

_I mean for God’s sake, all it was was human papillomavirus, that’s all it was and I look at it like that .../... looking at it now with your CIN ones and your leading up to you know, cancerous levels and understanding those levels now .../... how silly was I then .../... I think I’m more knowledgeable now._ (Jayne)

As well as finding courage and strength in gaining knowledge about their health, many participants described their endeavours to think positively about their future. Terry’s way of dealing with thoughts that the abnormal cells on her cervix might return, was to try to think positively or not at all about this possibility. However, her strategies to try to rid her mind of such thoughts were rarely successful:

_I try to keep my mind blank about it actually. I, I’ve had half my family die from cancer. Um, if I get told I have cancer, then I’ll start to think about cancer .../... I’d prefer to be a bit positive. I know it’s there. I know that it is in the family._ (Terry)

Like Terry, Margaret was aware of the ever-present possibility that the adenocarcinoma could recur but decided to get on with life:

_No guarantee that it wouldn’t recur .../.... After having that explained, um, I think I was fairly positive. Once we’d had the surgery done and the first few results had come back clear. Basically I made the assumption then that everything was going to be OK. And so I could continue on with um, the sort of semi-plans where I planned to do with my life._ (Margaret)

Annabelle shared what she has learnt from having had the abnormal Pap test result:

_I’ve learnt a lot! .../... Never put things off for too long. If there’s something to be done, then do it! Um, some things in life isn’t as bad as what they seem .../... Always think positive and never negative, because usually it is the positive that happens. Very rarely, the negative happens. So yeah, I have plenty of support._ (Annabelle)

Marie was driven to find positive outcomes, to give some reason and purpose to explain what had happened in her life, including the experience of having an abnormal Pap test result:

_And now it’s, it’s good that it happened in another. I have to find positives in the reasons why these things happen._ (Marie)

Having shared a story of cataclysmic events that Jayne said had led to the death of herself as a woman who once enjoyed sexual intercourse, she unexpectedly added:
Like there’s been so many, you know what? There have been so many positives that have come out of it. That there’s more positives than negatives! ...//... The positives are that I don’t have an abnormal Pap test in my life now. The last one was normal. I know what I have and that’s a positive thing. I know about vaginismus and I know about burning vulva syndrome and I know that there are alternative ways of making love. (Jayne)

Jayne believed that her positive attitude and healthy lifestyle were responsible for her cervical healing and the fact that her last Pap test result detected no effects of human papillomavirus:

*I felt healthy enough. I felt happy enough. And obviously that was fixing my problems because then my last test came through and there was nothing there.* (Jayne)

Marie shared Jayne’s belief that the body could be self-healing. Jayne relied on a positive attitude and a healthy lifestyle. Although Marie continued to have cervical screening, she relied more on a healthy lifestyle and spiritual visualisations to help her remain well:

*And I really believe I can visualise even as I’m sitting here now. I can visualise my cervix and direct universal energy and golden light to that area to heal it. And that’s powerful for me and that’s more powerful than any bloody colposcope or laser treatment or anything like that. And that belief in my own self-responsibility helps me to heal myself.* (Marie)

In contrast, Margaret and Julie described how their healthy lifestyle had offered them no protection from cervical pathology:

*I am in absolutely none of the risk groups – non-smoker, had the same partner for years and years, never had any, sexually transmitted diseases ...//... even on the result there was no detection of HPV or anything like that ...//... I have done all the right things. I’ve done everything that you have to, or I haven’t done all the things that you need to do to stay healthy and not get cervical cancer. It shouldn’t be me!* (Margaret)

*Because I mean, I didn’t do anything that sort of caused it or made it to happen! ...//... I wasn’t sort of somebody that sort of went out and got with anybody that I felt like. I wasn’t a very promiscuous person. I probably haven’t had very many relationships ...//... Like what have I done to cause this? ...//... I mean I ate sensibly ...//... I played sport. I still play sport. And ...//... I looked after myself ...//... So therefore you sort of think in the future, well, it could happen again.* (Julie)

Contrasts in the informants’ beliefs about the value of a healthy lifestyle in promoting health are also present in the stories the women shared about their individual spiritual expression. There is a growing body of evidence demonstrating that spirituality
enhances well being and healing (Goddard 1995; Fehring, Miller & Shaw 1997; Burton 1998; Mathews et al. 1998; Baldacchino & Draper 2001; Coyle 2002). However expressed, spiritual beliefs were seen as a comfort to women in this study.

**Spiritual comfort**

I think God has everywhere fingers (Melanie)

Spirituality defies a clear definition because of its elusiveness, conceptual confusion, ambiguity and scientific scepticism (Goddard 1995; Coyle 2002). The word, spirituality is derived from the Latin work *spiritus* and denotes the essential part of the person, incorporating but not limited to a person’s religious practice (Baldacchino & Draper 2001). Goddard (1995) whose work was informed by Van Kaam (1976) argued that a person’s spirituality is the force that causes growth and change and imbues life with meaning and a sense of purpose for existence.

A few participants shared how they expressed their spirituality, and the role they believed spirituality had in promoting their health. This spiritual expression was both in traditional Christian form and in non-traditional ways. Melanie was grateful that her friend came to visit her in the interim period between having the abnormal Pap test result and the colposcopy and she believed that this visit was due to God’s intervention. Melanie said:

And she came. Someone sent her – I think God really! She came to my place the same day ...///... she didn’t come and see me for four, five months and then suddenly she turned up and it was I think, about nine o’clock and I was shocked! You know, surprised and anyway, I was happy to see her but I had my mind somewhere else. And then she said, ‘Is everything all right?’ and then I started talking. That’s why I think, I think God has everywhere fingers ...///... I think it is nice when someone is listening. To listen while I am talking. (Melanie)

Melanie’s friend had arrived unexpectedly. During their conversation Melanie discovered that this friend had also had an abnormal Pap test result. Melanie was reassured by her friend’s disclosure and encouragement that abnormal Pap test results were rarely life threatening and she was so comforted by her friend’s presence and story that she believed the visit was due to God’s intervention. The metaphor Melanie used, ‘God has everywhere fingers’ demonstrates her need to make a connection between her old home, family and friends in Europe and her new, frightening and lonely Australian home. God, or at least His fingers, had become that connection for Melanie. When she
had the abnormal Pap test result it caused Melanie to again realise the lack of control she had over her life and health. However, if ‘God had everywhere fingers’ and could control or influence the surprise visit of a friend then, by implication, He could also affect her cervical health. Melanie’s use of spiritual strategies involving her relationship with her friend and her God helped her to cope and make meaning of her life, including the abnormal Pap test result.

The nature of God can take many forms for different people. For Melanie, God was perceived as deity who was personally interested in her and who played a role in her well being. Dyson, Cobb and Forman (1997) proposed that God took the form of whatever a person valued highest in their lives. Melanie took comfort in the Christian doctrine of God.

Rita and Marie expressed their spirituality in alternative belief systems to Melanie. Rita described her complex belief system:

So I am not a Catholic but there are elements of Catholicism and there are elements of Christianity that I believe and embrace ...//... there are elements of Buddhism, quite a lot of Buddhism that I would embrace. Quite a lot of Wicca that I would embrace ...//... I live as a vegetarian, not because of Buddhism but because it resonates quite comfortably with me because of that. As does the Wicca. (Rita)

Marie said:

My spirituality is another part of me who, that I feel is very, very important. My ... and that part of my personal and my professional inspiration from now on in. (Marie)

Although similar in their belief systems, Rita and Marie’s focus of spiritual expression differed in that Rita described a sense of connectedness that she had to a higher power, which was Mother Earth or Nature. Coyle (2002) described this connection as transpersonal transcendence and argued that it is the form of transcendence most frequently referred to by those who belonged to any particular religious community. Wicca was the community of faith to which Rita belonged. Marie’s spiritual expression was more akin to what Coyle (2002) referred to as an intrapersonal transcendence. Marie described contemplating her inner self and own resources and focusing on her self-potential. This provided her with a source of inner knowing and strength that was always present. Marie’s concept of spirituality was congruent with that espoused by Goddard (1995), that spirituality is a pervasive force that unites and directs all
dimensions of human life and is therefore the internal locus of health. For Marie, spiritual expression was essential for her health and well being.

Marie, Rita and Melanie all gained physical and emotional strength from their spirituality but to imply that it was a panacea for their problems or that they could cope with all of life’s adversities following their experience of having an abnormal Pap test result was untrue. Their spirituality did allow them to feel stronger and better able to cope with life’s traumas.

**Stronger**

*You get stronger, you know (Julie)*

Julie expressed her belief that if the abnormal cervical cells did return to her cervix, she would be better able to handle it and described the lesson she had learnt from having the abnormal Pap test result:

_I get stronger each hurdle I have to get over .../... but yeah, you become strong as a person .../... I think each battle you have to face, you sort of put up another brick wall .../... You get stronger, you know, you just build yourself up .../... I’m top of it I think! .../... But I think you just get, as you have to tackle something else. You put some more bricks on it and you just tackle it .../... So I see myself climbing._ (Julie)

Marie perceived vulnerability as a weakness and she never wanted to be seen as weak again. She felt the need to be strong so that she was able to have more control over her life. Marie described herself as a strong woman, who was frightened when she was not in control:

_I think I’m a strong character, a strong person .../... I’m not allowing myself to be weak or to be vulnerable .../... vulnerability is seen as weakness. And particularly as a female you are seen as weak if you need to be dependent on somebody else. And I guess I don’t want to be seen as weak because I have seen what happens in that weakness .../... ultimately you are not in control of anything .../... every human being wants to be in control of things. And, I guess that, that does scare me._ (Marie)

Jayne also described herself as being both stronger and harder since her experience of having the human papillomavirus treated. Like Marie, having a sense of control was very important to Jayne:

_I guess you harden to it. Like any pain that you’ve been through, whether it’s the loss of a family member or any pain, it’s a similar thing. It’s been_
an internal pain that has happened to me that you build your strength from it. Because there’s nothing else you can do. Obviously, initially, you wouldn’t think of anything else but then you get to a point and you have to accept it, because it happened ...//... I try to compare it like to someone who has died ...//... I look at the situation, and I think of what has happened and I can’t change that but I can change from now. (Jayne)

Jayne summed up her transformation from the time that she had the abnormal Pap test result to the time of the preliminary interview, when she said:

The person that I was then – new graduate, fantastic job, fantastic opportunities, life at their feet. And yet, someone who allowed someone to invade you privately. I allowed that to happen! I didn’t allow it, but it happened and I never questioned it. So I guess I’m now a stronger person but at the same time not so sensitive, a bit harder, a lot harder. (Jayne)

Without any professional intervention or specific information in regard to personality traits that mediate stress reactions, the participants had chosen to take on traits identified in the literature as enhancing their immune responses and reducing the likelihood of having another abnormal Pap test result (Kenney & Bhattacharjee 2000). Specific immune enhancing personality traits described by the women in this chapter and in the literature included Jayne expressing that she now felt harder (Kobasa 1979; Quellette 1993; Lambert & Lambert 1999; Dolbier et al. 2001; Pollachek 2001); Melanie confided in others (Pennebaker 1990); Marie and Rita recognised and were better able to express their feelings (Pert, Dreher & Ruff 1998); Janette, Margaret, Terry, Marie and Jayne had all become more assertive (Solomon 1981); Janette and Ann felt more able to love and trust others (McClelland 1986; McKay 1992); Terry, Jayne and Janette had become more altruistic (Davidson 2002); and Terry, Ann and Janette found themselves with complex and multiple roles (Linville 1987). Kenney and Bhattacharjee (2000) argued that these specific personality traits allow women to handle stressful events in a way that minimises harm to them and enhances their immune response. At the time of the interviews, it was highly unlikely the participants were aware of these theories, they had nevertheless transformed their lives to incorporate the proposed immune response enhancing traits into their persona. Janette’s story is used as a paradigm to illustrate this transformation.
Janette’s paradigm story

Janette, who had paraplegia, had lived with her husband who suffered from alcohol and gambling addictions, for 25 years before leaving this often-violent relationship. She shared:

When he was drinking, he was quite a violent person. And one drink was just too many. Because he never stopped with one ...//... [Estranged husband] was very violent both to the children and myself. (Janette)

A woman with very strong traditional Catholic values, Janette continued to care for her ex-husband by bringing him meals and helping to allay his feelings of loneliness. She was, however, also mindful of her own needs and the transformations that had happened in her life and reported:

I could never go back, I couldn’t go back to the ‘yes’ person I was ... and I couldn’t go back to all the difficulties that life would bring with [estranged husband] – but I still care what happens to him. (Janette)

She continued to refer to this man as her husband. The man with whom she now shared a living and sexual relationship, she referred to as her partner. Janette had two sons, who she loved unconditionally. One son had followed a traditional lifestyle; the younger son had made life choices including illegal drug use that caused Janette much concern and anxiety.

On occasions Janette had feared for her life in her troubled marital relationship, she spoke of finally finding the strength to leave after two and a half decades. Janette left her marriage and went to live in a caravan park for a number of years with her new partner. It was around this phase of her life, that Janette had the experience of her first abnormal Pap test result. Having been referred to one gynaecologist and having a cone biopsy, Janette described how she continued to feel very unwell many months after the treatment but was reassured by the gynaecologist that what she was experiencing was normal. Janette’s own intuition blended with some ‘out of character’ advice from the women’s health nurse who urged Janette to seek an opinion from a second gynaecologist. The second gynaecologist exposed the treatment mistakes made by the first gynaecologist and Janette has not experienced any further cervical screening detected abnormalities since that time.

Janette described herself as a woman who enjoyed most days. She was energetic and altruistic, she tirelessly devoted herself to voluntary work, and loving and trusting the
disadvantaged people with whom she worked and for whom she tried to increase access to health services. Having experienced disadvantage and discrimination all her life, Janette’s goal was now to improve access and opportunities for others who are considered disadvantaged and discriminated against in her rural community. Janette had a connectedness with her community and worked to enhance understanding of misunderstood issues and people.

Janette’s story was interlaced with evidence of strategies that had helped her to survive violence and hardship in her personal life and potentially life-threatening iatrogenic effects from treatment for the cervical abnormalities detected on a routine Pap test. She looked at the past and said:

That was a different time, a totally different time. (Janette)

Janette positively looked to the future and said:

There’s lots in my life that I haven’t touched yet ... //... there is still a lot of things I would like to do! (Janette)

There is also much that needs to be done to enhance nursing (as well as medical) practice if women who experience an abnormal Pap test result are not to be further traumatised by the event. The chapter to follow will use the participants’ narratives as the springboard to make recommendations for transformations to be made to clinical nursing practice so that both the incidence and the impact of an abnormal Pap test result might be reduced.
Chapter 8

Recommendations

We may be justified in concluding that there is something intrinsically valid about personal experience and that, in coming clean about their own perspectives on health and illness, women may actually bring about the beginning of a change in those who hold powerful alternative views.

Oakley 1993, p. 8

The preceding four interpretive/discussion chapters examined the informants’ contextualised experiences of having an abnormal Pap test result. This experience was described according to the four overriding themes drawn from the women’s stories. First, in terms of the ways women defined themselves according to the stresses they experienced prior to and around the time of the abnormal result. Second, the feelings of abjection, abhorrence and self-loathing they had when they realised their Pap test result was abnormal and which were exacerbated by the treatment they received at follow-up. Third, the harm that was done by health professionals during the cervical screening, results giving, further investigations and treatment process for their screening detected abnormality. Fourth, the personal transformations participants reported from the time of the abnormal Pap test result to the time of the preliminary interview.

In this chapter, recommendations drawn from the participants’ narratives are made to enhance clinical practice so the negative impact of an abnormal Pap test result might be reduced. The intention is to learn from the women who have shared their stories for this project. When the women shared their stories, they did so knowing it was a nurse who was interviewing them and the overall aim of the study was to learn from them so nursing practice could be improved. For this reason, although most of the recommendations made could apply to any health or medical professional, the inferences in this chapter apply specifically to nursing practice. The recommendations discussed are not exhaustive or complete. They represent an overriding concept or exemplar discussed by the women from each of the preceding chapters. Supplementing the informants’ narratives and derived recommendations are best practice models sourced from the literature.
When asked to share something about themselves as women, the informants discussed stressful incidents in their lives prior to and around the time of the abnormal Pap test result. The experience of sexual and physical violence was the most prevalent stressor discussed. This chapter will open with an exploration of how women’s health clinical practice can best serve the needs of women who have survived physical and/or sexual violence.

The women in the second interpretive chapter described a sense of abjection. Abjection was embodied in the participants’ rejection of self that led to an intense aloneness when they had an abnormal Pap test result. The concept is revisited and strategies suggested that nurses might use to reduce women’s feelings of isolation and loneliness.

Two women, Margaret and Jayne, shared horrific examples of the Nocebo Effect and their belief that the recto-vaginal fistula and the secondary vaginismus they experienced were directly related to the abnormal Pap test result they had had. These devastating instances are not explored further except to say that both catastrophes might have been avoided if caregivers had listened and taken time to value Margaret and Jayne’s knowledge and skill to be able to contribute to the clinical decision-making process. More universal Nocebo Effects relating to clinical and health promotion practice associated with cervical screening are explored in this section. The importance of promoting cervical health from a social perspective rather than just cervical screening is discussed.

The final component of this chapter will address how nursing practice, like the lives of women who had had a cervical screening detected abnormality, can be transformed. The value of having female specialist nurses attend to their gynaecological health care was continually reiterated by the informants. These nurses were usually specialist women’s health nurses educated from a feminist perspective and practising autonomously in a community health setting. Recommendations are made to increase the number and breadth of practice of nurses in women’s health in Australia. Lessons learnt from overseas on the value of including nurses as colposcopists are discussed. Finally the importance of creating an atmosphere of mutual respect and equality between health caregiver and recipient is described.
Working with women who have survived violence

It is estimated that at least one in four Australian women experience sexual assault before their 18th birthday (Mazza, Dennerstein & Ryan 1996). Many adult survivors of child sexual assault experience overwhelming emotions, intrusive or unwanted thoughts, body memories and feelings of detachment in their bodies during cervical screening (Robohm & Buttenheim 1996). Their gynaecological care provider had never asked 82% of the survivors in the Robohm and Buttenheim (1996) study about a history of sexual abuse or assault. Routine but sensitive history taking may help to destigmatise the experience and reduce women’s feelings that they are to blame for the assault. If the woman chooses to, being asked about a history of assault legitimises her desire to debrief both the violent event(s) and the cervical screening experience and provides an opportunity for her to be referred for ongoing counselling. Asking about the possibility of sexual violence can also increase the nurse’s awareness of the need to consider the possibility of traumatic reactivation of sensations, thoughts and memories during the cervical screening process.

Gynaecological screening procedures are degrading and distressing, painful, embarrassing and unpleasant for many women (Barling & Moore 1996). Increasing practitioners’ awareness and preparedness to respond gently to women’s distress and fears has the potential to reduce negative sequelae for those that present for Pap tests and to increase the number of women prepared to participate in cervical screening.

Some women, especially early in the clinical relationship, may choose not to disclose a history of sexual violation – that is clearly their choice and right. Clinicians have the responsibility to present non-disclosure as a viable and acceptable option for all women during history taking and consultations. Practitioners should therefore practise ‘Universal Precautions’ in an additional context to the usual infection control, and consider the possibility of a history of sexual assault for all women undergoing any pelvic examination.

In the cervical screening setting, it is the clinician’s responsibility to make the consultation and procedure the antithesis of any abusive relationship. At a very minimum, the woman needs to be involved in the consultation and history-taking
process while she is fully clothed and sitting comfortably in a comparable chair to the practitioner’s before any examination takes place. Adequate time and a conducive environment need to be created that will encourage the woman, with the support of the practitioner, to explore any anxieties she may have and to receive a full explanation of any procedures to follow. Permission to have any student or other personnel in the room must be given by the woman, while the other person is not present and in a manner that ensures the woman’s right to refuse another person’s presence is respected and valued. There must never be more than one additional person observing a procedure. The woman needs to be given a private place to remove any clothes and only the minimal amount of clothing needs to be removed. Appropriate replacement covering such as a gown needs to be large enough to fit any and all women. The room needs to be an appropriate temperature and all invasive equipment warmed. The practitioner needs to be aware of their postural stance and avoid ‘standing over’ the woman during the procedure. The woman’s comfort on the examination couch needs to be carefully considered. Following the procedure, after the woman is dressed and sitting in a normal chair, any concerns or anxieties she may have need to be readdressed. Counselling and information giving need to be amended to suit the needs of individual women. Written information needs to be available and offered to the woman to take home and read. The information leaflet should contain the names and telephone numbers of professionals and support groups the woman may choose to contact if she has any further questions or concerns.

Sexual assault and intimate partner violence (IPV) are interrelated and often occur concomitantly (Chambliss, Bay & Jones 1995). When asked, almost one in three women attending a ‘well-baby clinic’ reported that they had survived IPV at some time in their lives (Weir 2000). One in six pregnant women (Parker 1995) and nearly a quarter of all women attending a family planning clinic (Chambliss, Bay & Jones 1995) disclosed at least one episode of IPV in the preceding year.

Women are rarely asked by any health professional about the possibility of violence occurring in their lives (Mazza, Dennerstein & Ryan 1996). However, the majority of victims/survivors in the Eisenstat and Bancroft (1999) study reported that they hoped they would be asked if they had been abused, and if asked in a caring, sensitive manner they would be prepared to discuss the issue of violence with the health care professional.
Women attending for a Pap test or any health matter need to be given the opportunity to disclose IPV. Visual cues such as posters on the walls can alert women to the fact that violence takes many forms and is not a rare event in intimate relationships. Two simple screening questions are suggested by Weir (2000), ‘Do you ever feel unsafe at home?’ and ‘Has anyone at home tried to injure you in any way?’ These questions have a reported sensitivity of 71% and specificity of 85% (Eisenstat & Bancroft 1999). Ashur (1993) argued that by asking these and similar questions relating to the woman’s sense of safety, degree of social isolation and plans for an emergency, she is validated as a person and her sense of alienation can be reduced. The goal of universal screening needs to be redefined from identification and detection to sensitive and compassionate asking; that is in itself the first step for helping women who have suffered violence in their intimate relationship(s) (Gerbert et al. 1999).

Universal screening for IPV must be attended carefully and sensitively if it is to be of more benefit than harm. It is essential that the possibility of violence is never raised in the presence of another person known to the woman or her partner. To ask questions about violence in the presence of another person is unlikely to elicit an honest response and may place the woman at greater risk as perpetrators often escalate the violence when their partners seek help or separation (Parker 1995; Gerbert et al. 2000). Some women may be prohibited from attending health care if their violent partner suspects their crime might be detected (Hyman, Schillinger & Lo 1995).

Universal screening will detect more women who are in violent relationships (McFarlane et al. 1995) but that should not be the primary goal. Providing support and assistance to women who have suffered violence perpetrated by their partners is more important than asking about it (Plichta & Abraham 1996). Nurses will need to simultaneously lobby for greater legal and community resources including refuges for women at risk and who seek a safe separation from their violent partner. Availability of places in women’s refuges continues to be severely limited, and rurally isolated, indigenous and non-English speaking women, women with low independent income and lesbians face the greatest difficulty in accessing social and legal services (Hyman, Schillinger & Lo 1995). As part of the process of screening for IPV, nurses need to offer sensitive support, address the woman’s safety, document the abuse, provide information about options and resources and offer referrals (Gerbert et al. 2000).
woman’s safety is of paramount importance and the nurse must assess if the woman is in immediate danger (Eisenstat & Bancroft 1999).

Health professionals report a reluctance to introduce the subject of IPV, furthering the silent nature of the problem (Weir 2000). The literature (Parker 1995; Mazza, Dennerstein & Ryan 1996; Eisenstat & Bancroft 1999; Weir 2000) described the epidemic proportions of IPV. Yet a third of obstetric and gynaecological residents surveyed by Chambliss, Bay and Jones (1995) estimated the prevalence of IPV to be less than one per cent. Six per cent of the residents surveyed estimated the incidence to be less than 1:1000. Such low estimates are not congruent with the health professional’s personal experience (deLahunta & Tulsky 1996). In their anonymous survey of medical faculty staff and students, deLahunta and Tulsky (1996) found that almost one quarter of all respondents had personal experience with family violence in the form of either physical, sexual abuse or both. Apart from underestimating the prevalence of IPV, other reasons have been given for not discussing the possibility of violence in the health care setting. These include the professional’s discomfort, fear of offending clients, powerlessness to ‘fix the problem’, time constraints, fear of opening ‘Pandora’s box’ and/or the belief that it is a ‘private matter’ that should not be discussed (Sugg & Innui 1992; Alpert 1995; deLahunta & Tulsky 1996; Gerbert et al. 1999). Warshaw (1993) offered a feminist interpretation for the reason why a physician might be reluctant to identify with a woman who has been victimised. She hypothesised that their own medical training required them to be in control and to identify with those in positions of power, rather than with the victim of violence. Whatever the reason for the clinician’s reluctance to discuss IPV with women, it is clear that professional education programs need to address the issue of violence against women from a sociological perspective (Chambliss, Bay & Jones 1995).

Chambliss, Bay and Jones (1995) argued for a more intensive education program for medical students/obstetric and gynaecology residents. The need for IPV to be included in all nursing, midwifery, medical and allied health professional undergraduate, graduate and continuing education programs is ratified by the prevalence of the problem and the shared stories of the women in this study. Professional education must incorporate an analysis of why practitioners are reluctant or unable to identify and/or work with women who suffer IPV. Professional education and awareness raising can refute myths and provide evidence to show that the fear of offending clients is not
evidence based (Freidman et al. 1992; Eisenstat & Bancroft 1999). Although health professionals may feel powerless, they underestimate their influence and the positive impact a multidisciplinary health care team can have (Alpert 1995).

**Addressing feelings of loneliness**

> It was a pretty terrible feeling. It was pretty much like I was all alone again. Alone like I was when I had the miscarriages … I felt so alone (Janette)

Feelings of abjection, abhorrence and self-loathing were described by many of the informants and feeling alone extenuated these feelings. Loneliness has been described as a discrepancy between a person’s social and/or emotional needs and wants and their social reality (Killeen 1998). Many of the informants in this study described a feeling of intense loneliness, sometimes an exacerbation of a pre-existing loneliness, when they experienced the abnormal Pap test result. In Marie’s description, the loneliness was attributed to an emotionally distant partner. Emotionally she felt the need for social support from her partner, but the reality was that he was unable or unwilling to provide the level of intimate support she desired. Janette described an incredible loneliness around the time of being told of her abnormal Pap test result that she likened to her earlier experiences of miscarriages and the feeling that no one cared for her emotional needs, in either situation.

Killeen (1998) reported that loneliness was at an epidemic level in Western society, brought about in part because there is no imperative to speak with another human being on a personal level. The nurse is not in a position to alleviate loneliness but Strandberg, Norberg and Jansson (2001) argued that the nurse could play a role in reducing the intensity and pain of loneliness.

Nurses can reduce the loneliness experienced by women experiencing an abnormal Pap test result. Encouraging and supporting women to establish telephone or other forms of peer support groups is one strategy that could be used. Self-help or support groups do not absolve professional responsibility or input. There are many benefits to a support group approach but there are some women for whom a group would be undesirable or even counter-therapeutic and, for these women, face-to-face professional counselling should always be an option (Gutteridge 2002). The majority of participants in groups request professional involvement. Nurses can serve either as instigators and core
members or as consultants on the peripheral. Support groups function best when they are a supplement to the existing health care system (Adamsen & Rasmussen 2001).

Support groups both pre- and/or post-colposcopy could be organised (and evaluated) for groups of women and facilitated by a nurse. Kavanagh and Broom (1997) argued that structural impediments to women asking questions and getting information would be reduced because the group could be organised around the needs of women rather than the needs of colposcopists to ask questions and examine women. Pre-colposcopy, the focus could be on explanations about medical terms, details of the procedure, treatment options and the after effects women might experience as well as encouraging questions and exploration of issues women think important. The session could involve a video of the procedure. The women could then make an informed choice as to whether they wanted to view their own cervix colposcopically. Post-colposcopically, women could again ask questions and obtain/provide emotional support. In geographical areas where the small number of women may make a support group unfeasible, a similar service could be offered both pre- and post-colposcopically by volunteers who have had an abnormal Pap test result and are trained in telephone support (Dietsch 1999).

A characteristic of initiators and participants within support groups is the perception that their needs are not being met by existing professional institutions and social/interpersonal networks (Katz & Bender 1976), a perception reflected in many of the participants’ stories. Support groups, an ever-increasing phenomenon in Western societies, have been found to strengthen participants’ self-perception and sense of belonging (Adamsen & Rasmussen 2001; Wolf 2001; Gutteridge 2002). These two effects have the potential to reduce the sense of abjection experienced by women with an abnormal Pap test result. Tangible benefits for women participating in a support group may include contact with other people, reducing loneliness, forming friendships and new behaviour patterns, increased self-confidence and acquisition of new knowledge. Smith (1980) reported that women in support groups share and compare their experiences and often come to the realisation that previous adversities are not self-induced but are in fact societal failings. This has the potential to empower women by lessening any Nocebo Effect and reducing the shame associated with the traumatic life stressors experienced by many of the informants. Progressing within this feminist framework, some groups might choose to question social structures and existing medical/nursing and health system practices and lobby for better services for women in
relation to violence prevention, cervical screening and treatment for screening detected abnormalities. Adamsen and Rasmussen (2001) proposed that in the next 10–20 years self-help (support) groups might become the therapeutic model of choice for many ‘life predicaments’.

**Reducing fear**

*I thought I was going to die … But I wasn’t ready, I’m not ready to die. I was scared, that was my thought (Melanie)*

There is a relationship between cervical cancer and cervical screening in both professional and health promotion literature. As a consequence, many women in this study believed that even the slightest abnormality on their Pap test result indicated that they had cervical cancer and were going to die from it. The participants often described a desperate desire for reassurance that was not forthcoming from nursing or medical professionals about the implications of their abnormal Pap test result.

Fear of cancer and death were common to all of the informants and yet these fears were rarely acknowledged or explored at the time they were told their Pap test result was abnormal. Because of the association between abnormal Pap test result and the life-threatening nature of cervical cancer, many women described how they were able to absorb only the minimum of information given to them at the time of being informed of their abnormal Pap test result. Written backup material and follow-up contact with women in the days and weeks between notification of the abnormal Pap test result and colposcopy are therefore essential.

Recruitment strategies to encourage women to attend for cervical screening by emphasising the Pap test’s role in detecting cancer, results in exaggerated fear for women when their Pap test is found to be abnormal. There is no argument that, on very rare occasions, an abnormal Pap test result may predict a cervical malignancy and that effective cervical screening programs have saved the lives of countless women. The argument is with the need to shift away from recruiting women to cervical screening through subtle (or not so subtle) fear tactics. Cervical screening recruitment strategies that focus on cervical health rather than cervical cancer are urgently needed in women’s health promotion.
Lupton (1995a) reported that in Britain, North America and Australia, health promotion is a middle class movement dominated by professionals from English speaking backgrounds and, as Eva Cox argued, ‘Works best for those who need it least!’ (Eva Cox, personal communication 2002). Health promotion, including cervical screening campaigns, especially those using the mass media, are politically conservative and paternalistic (Lupton 1995a). Lupton argued that their ‘top-down’ communication methods uncritically accept their own objectives and are directed towards infusing women, who are perceived as being empty vessels, with a message or knowledge. Health promotion programs make no attempt to encourage critical thinking or challenging of the status quo. The aim of health promotion is to disseminate the ‘right’ message to as many women as possible for their own good (Lupton 1995a).

Cervical health promotion, like health promotion in general, has focused on discussing individual risk factors but not on determining and then managing the social causes of CIN. Social factors related to health and ill health are not easy to research as there are too many variables to modify and it is considered too political (Peters 1998). It is argued that traditional, positivist approaches to research concentrate on individual rather than social risk factors in relation to disease and serve to maintain and protect medical dominance and health care institutions:

> [It] produces a lifestyle approach to social policy, decontextualises risk behaviours, seldom assesses the relative contribution of nonmodifiable genetic factors and modifiable social and behavioural factors; and produces interventions that may be harmful (Pearce 1996, p. 679).

An ideology of choice is created where individuals are responsible for their own health or illness and the impact of social factors that may negate individual choice is ignored (Peters 1998).

In Western nations health care policies, financing, resourcing and regulation of health professionals are all focused on disease. Cervical health promotion is no exception and cervical screening is the only strategy given serious consideration to protect cervical health and then it is defined within the clinical context as the absence of disease (Peters 1998). A woman has a negative Pap test result because no abnormal cells are detected, and this is a positive outcome for her. When a woman has a positive Pap test result, abnormal cells are predicted and this is a negative outcome.
Health promotion campaigns designed to encourage as many women as possible to attend for Pap tests have attempted to use emotional manipulation by drawing on women’s guilt, anxiety and fear of cancer (Lupton 1995a; Somerset & Peters 1998). To attract women who experience no symptoms to cervical screening depends on raising anxiety levels around death and disease high enough to cause women to question their own health assessment and rely upon technology assisted, medical intervention to detect the invisible signs of potential disease (Lupton 1994). The consequences of the New South Wales Cancer Council campaigns such as ‘Cancer of the cervix. It can’t happen to me. I have a regular Pap test’ and ‘No excuses’ led women like Marie to interpret:

*The only understanding that I had about Pap smears was that they looked for cancer cells. That was my only knowledge of what Pap smears were all about.* (Marie)

Another consequence of health promotion campaigns to encourage cervical screening was that many women in this study believed that they had brought the cervical abnormality upon themselves. This was especially evident for Faye and Marie who had ‘failed’ to have regular Pap tests prior to the screening detected cervical abnormality. They felt they had no excuse for not having a Pap test and were reaping the consequences for their self-neglect. They believed that others, especially health professionals, would consider them irresponsible and poor stewards of their health. Lupton (1995a) argued that focusing on healthy lifestyle choices and regular screening such as Pap testing are seen as an alternative to prayer and religiosity as a means to make sense of life and death in Australia. The emphasis in health promotion campaigns is upon lifestyle choices and the individual’s responsibility for preserving health and avoiding risk (Lupton 1994). Health professionals and the general public have used health promotion discourses to make sense of ill health in ways that cast moral judgments upon those who are ill or perceived to be at risk of becoming ill, including the woman who has an abnormal Pap test result (Lupton 1995a). As a consequence, fear of other’s judgment and self-blame were frequently reiterated in the stories shared by the informants.

Strategies to promote cervical health can operate from both the self-responsibility model and a social model that work towards creating a healthier and safer social environment, especially for women. Self-responsibility to maintain cervical health includes eating a healthy diet, practising safe sex and having regular Pap tests. Health
education strategies aimed at recruiting women to cervical screening need to emphasise cervical health rather than cervical cancer.

However, health promotion strategies must involve more than educating women about the importance of having regular Pap tests and adopting a healthy lifestyle if cervical health is to be optimised. Nurses working within policy-making branches and in the clinical and health promoting setting, need to work on developing strategies that make the social environment in which women live more conducive to cervical health.

Social strategies within cervical health promotion must, as a matter of priority, include those that aim to reduce the incidence and impact of violence towards women. They need to provide relevant and accessible education opportunities for women and address issues relating to body image and societal/self acceptance of women, regardless of the woman’s body shape. A woman being safe in her own body and home has the potential to improve cervical health. So too does access to education for females. In this project, Annabelle and Janette lamented the lack of educational opportunities available to them. Increasing education opportunities for young women will improve cervical health, as there is a direct correlation between early school leaving, early coitarche and CIN (Grunseit & Richters 2000). In NSW, it is young rural women who are most at risk of developing CIN and who are least likely to complete year 12 education (Lewis et al. 1999; Public Health Division 2002). Policy development and strategies that make school education available, desirable, esteemed and relevant for young rural women will improve cervical health. Tertiary education opportunities that are ruralised and promote equity of access to post-school education for all students have the potential to reduce the incidence of CIN.

Until such time that health promoting social strategies become effective and the Pap test is seen as a tool to promote cervical health rather than detect cervical cancer, the emphasis must be on reassuring women when their test predicts an abnormality. As the abnormal Pap test result only extremely rarely predicts a potentially life-threatening pathology, reassurance has the intent to communicate with women who are anxious, worried and distressed that they are safer than they believe or fear (Teasdale 1995).

Teasdale (1995) argued that reassurance is sometimes used to reassure the health professional and silence the client. There is an art to providing reassurance that is
accurate but not placating, and encourages the client to seek more information without adding to their anxiety, worry or distress. Significantly lower levels of anxiety are experienced by women when they receive written information describing the nature of their abnormal Pap test result or verbal explanation of cervical screening procedures (Wilkinson, Jones & McBride 1990; Foxwell & Alder 1993). However, not all studies have been so favourable. Reassurance and information giving are not necessarily synonymous. Miller and Mangan (1983) report higher levels of anxiety and discomfort in women undergoing colposcopy who had been given a combination of procedural, sensory and behavioural information compared to women given the usual levels (presumably less) of information prior to colposcopy. In this study some women, including Julie and Megan, were neutral or reassured by being able to watch the colposcopy procedure on the monitor or being shown the biopsy specimens. Other women, including Terry and Jayne, found these sightings to be particularly distressing. Information giving per se may be harmful if it is directed by the health professional’s need to educate women rather than being guided by the individual woman’s needs and desire for information. Reassurance and information giving must therefore be personalised to meet the needs, communication and learning styles of the individual woman. Such strategies are time consuming and health professionals must consider the provision of informational, tangible and emotional support at the core of the cervical screening/reporting process.

Transforming nursing practice

And [women’s health nurse] were really, really caring and understanding. It was really good of [her] to ring me in the evening. And to let me know. And [she] was concerned about was I OK? (Terry)

The participants in this study demonstrated their innate ability to transform their lives. No longer victims of oppression, they became strong women who sought the means to optimise their own health. The well being of women and the progress of nurses have always been interlinked (Street 1989). As nurses, we can use the role modelling of the participants to transform practice for the benefit of women and the profession of nursing. Bearing in mind the Foucauldian concept that power requires people in order to be perpetuated (Foucault 1980), nurses need to strive towards ensuring that women who have an abnormal Pap test result receive a better deal than that described by the participants in this study.
All of the informants expressed their unsolicited support and appreciation of the role women’s health nurses played in their health care. The only negative comment was that of Janette’s, when she described how she had had contact with five women’s health nurses and all but one had been extremely caring. Janette described the fifth nurse as having ‘a coolness about her’ that was in contrast to the warmth of the other four nurses.

Experience in Britain and America demonstrates the cost-effectiveness, community acceptability and positive health outcomes for clients utilising nurse-led primary health care practice including nurse colposcopists and sexual assault nurse examiners (O’Brien 1996; Edwards et al. 1998). The invaluable role nurses in Australia play in cervical screening programs has been acknowledged in the literature (Reynolds & Foote 1990; Coxhead et al. 1992; Barclay et al. 1993; Leach 1998; Anti-Cancer Council of Victoria 2000) and by the participants in this research project. PapScreen Victoria is particularly proactive in its commitment to supporting this nursing role and outlines a number of supportive strategies in its ‘2000–2005 Communications and Recruitment Strategy’ (PapScreen Victoria 2000). Nurses are especially successful in attracting women least likely to use existing medical services for cervical screening and who are at greatest risk of developing a cervical pathology – women who are disadvantaged by age, geography, culture and disability (Leach 1998). In view of the reported positive nature of the role of nurses in cervical screening, it is recommended that this role be expanded. The training and employment of more specialist women’s nurses by area health services would increase the development of social and cervical health promoting strategies and the number of women at greatest risk of cervical pathology having Pap tests.

The advantages of having nurses attend cervical screening have the potential to be mirrored and accentuated for women if nurses are also trained in colposcopy. Nurse colposcopists have been practising in the USA for many years but are a newer identity in the United Kingdom where, like Australia, colposcopy was the exclusive practice of the medical profession. An illustration of successful questioning of medical domination is the UK nurses’ struggle to extend their role from cervical screeners to become accredited nurse colposcopists. Prior to the British Society of Colposcopy and Cervical Pathology developing a national training program for colposcopists, colposcopy in the UK mirrored the Australian situation and remained the jurisdiction of the medical officer. Medical hegemony, relating to colposcopy, was maintained through elite
education, legal sanctions and political economic, social/traditional and cultural practices. Medical dominance had been legalised and the roles, relationships and access to resources of other health professionals, including nurses, had been extremely limited (Street 1989). However, with the introduction of the British National Training Program in Colposcopy, nurses attained the same standards of practice as medical officers and therefore became colposcopists in their own right (Smith 2000).

Having nurse as well as medical colposcopists has advantages, including greater continuity of care, improved contact, greater choice, improved flexibility of clinic times, decreased waiting times and greater involvement and job satisfaction for nurses (Smith 2000). Smith (2000) argued that all colposcopists need to maintain a caseload of at least 50 colposcopies per year and participate in regular local, regional and national clinical audits to ensure an adequate skills base. It is recommended that a model of colposcopy training in Australia be developed to include nurses as well as medical practitioners.

**Mutual respect**

> I think it all has to do with character – one who understands a person’s situation ... very sensitive and understanding ... and I think that only comes with someone’s character .../... You can teach someone [communication skills] but it’s their character .../... I guess it’s just the way you do your job and your character and how sensitive you are. Never assuming that people know what you’re talking about. Keeping it in lay terms (Jayne)

In the above quotation, Jayne was describing the essence of what she believed made a good nurse or medical officer. Nurses attending Pap tests and/or colposcopy will do very little for transforming the health system unless their technical expertise and knowledge base is combined with absolute respect and empathy for the woman receiving the service, the ‘character’ that Jayne is trying so hard to put into words. As nurses we need to combine clinical competency and relationship equity when we work with women. The image of a powerful, all-knowing professional is antithetical to establishing positive rapport with women. The relationship between health caregiver and recipient needs to be one of equality with the woman being considered the expert on herself (Orr 1986).

Women will benefit the most when nurses combine the science of their technical skills with the art of their nursing knowledge. Masson (1996, p. 203) defines art as ‘a specific
skill in adept performance, conceived as requiring the exercise of intuitive faculties that cannot be solely learned by study’. It is a nursing art to convey the news of an abnormal Pap test result to a woman in a way that realistically portrays the nature of the result while at the same time listening and responding to the inevitable concerns the woman will have. The nurse’s tone of voice, speed of delivery, calmness, eye contact, body language, consciousness of the woman’s verbal and non-verbal cues, demonstration of warmth and caring and their willingness to listen are equally if not more important than any technical skill. It is a nursing art to measure the amount and type of information and counselling an individual woman requires. It is a nursing art to understand the subtle needs of women and reduce their vulnerability at the time of having a pelvic examination, Pap test, colposcopy or treatment. Nursing care, the very core of nursing art, has the potential to heal and empower women. And ‘Caring is the most basic way of being in the world’ (Heidegger 1962 in Benner & Wrubel 1989, p. 368).
Chapter 9
Conclusion

This thesis explored women’s contextualised experience of having an abnormal Pap test result. The concluding chapter briefly examines and articulates the major outcomes of the literature review with key findings from the study. The review of the literature both preceded the study and was integrated with each step of the research pathway (see Appendices 3 & 4). The strengths and limitations of the study are outlined, and avenues for further research proposed.

Major outcomes from the review of the literature and key findings from the study

From the copious amounts of literature available on the biomedical aspects of abnormal Pap test results, it was concluded that the Pap test is an extremely useful screening tool in the prevention of cervical cancer (Koss 1989; Sevin 1999). The literature also established that, although HPV has been identified as the central causal factor in CIN and cervical cancer, the causes of HPV that are usually (but not universally) considered to be by sexual transmission have not been clearly isolated (Cothran 1996). HPV alone is not considered sufficient to cause cervical cancer (Haverkos, Rohrer & Pickworth 2000). The majority of Pap test results predicting CIN and changes suggestive of HPV will spontaneously regress to normal (Holowaty et al. 1999). Nevertheless, the dilemma remains that it is impossible to know which individual women with CIN will develop cervical cancer and which will persist as CIN or spontaneously regress to normal (Kavanagh, Santow & Mitchell 1996). However, as the majority of conditions detected at cervical screening would have regressed or remained asymptomatic throughout life, any emotional trauma that arises from having an abnormal Pap test result must be regarded as a side effect of screening.

An abnormal Pap test result is very common for women involved in cervical screening. In 1996, Kavanagh, Santow and Mitchell estimated that a 15-year-old girl living in Australia has a 76.8% lifetime chance of requiring further investigations for an abnormal Pap test result before she is 75 years old. In contrast to the commonness of

The above studies noted that fear is the primary response for women with an abnormal Pap test result. This fear has multiple facets – fear of cancer and death, fear for fertility and sexuality, fear of being labelled promiscuous, fear of pain and of further investigations. The thirteen participants in this study, without exception, experienced incredible fear when they were notified of their abnormal Pap test result. This was fear that threatened their sense of who they were as women and culminated in what Kristeva (1982) defined as abjection.

The level of anxiety induced in some women by the initial notification of an abnormal Pap test result is similar to that experienced when a parent dies (Palmer et al. 1993) and women with an abnormal Pap test result are twice as likely as women with a normal result to have anxiety levels high enough to indicate a probable psychiatric disorder (Wardle, Pernet & Stephens 1995). For many of the participants in this study, including Jayne, Julie and Megan, high levels of anxiety continued to be experienced many years following their experience of having an abnormal Pap test result.

Having an abnormal Pap test result has long-term adverse effects on a woman’s self-concept. This negative sequelae is directly related to the widely promoted association between HPV and sexual expression. A common theme in the literature related to women’s expressions of feeling unclean, contaminated, defiled and dirty (Posner & Vessey 1988; Quilliam 1989; Gregory & McKie 1991). For the participants in this study, their feelings of defilement and contamination were exacerbated by a sense of guilt and self-blame for making what they or the health professional considered were unwise choices in their past or present sexual relationships.
Sexual dysfunction affecting all phases of a woman’s responsiveness was commonly reported in the literature when a woman had an abnormal Pap test result (Campion et al. 1988; Anderson, Anderson & de Prosse 1989; Cull, Cowie & Farquharson 1993). Jayne shared the most poignant experience of sexual dysfunction in this study. She developed vulvodynia and secondary vaginismus shortly after treatment for HPV and it had not resolved eight years later at the time of the preliminary interview.

The studies by Schover, Fife and Gershenon (1989), Plichta and Abraham (1996) and Geyer (2000) suggested that women who suffer traumatic life events such as sexual assault and IPV are at greater risk of developing CIN/cervical cancer. Informed by Gadamerian hermeneutic phenomenology, this study did not ask women if they had a history of traumatic events. Rather it asked women to respond to two prompts, the first of which was, ‘Please tell me about yourself as a woman’. The participants in this study, with only one exception, Margaret, chose to respond to that prompt by sharing stories of significant trauma. The women had chosen to define themselves according to the traumas they had experienced. These traumas were usually related to sexual assault and/or physical violence but also included stories of profound grief and loss. It was as if the sharing of their experience about having an abnormal Pap test result caused a history of pain and violation to surface. In the words of Julia Kristeva, ‘The disenchantment that I experience here and now, cruel as it may be, appears, under scrutiny, to awaken echoes of old traumas’ (Kristeva 1999, p. 1486).

With the exception of Quilliam (1989) and Price et al. (1996) who identified the needs of lesbians, all of the reviewed literature presumed women to be able-bodied and heterosexual. There was no literature describing the experience from the woman’s perspective of an abnormal Pap test result for women who had a disability, or were obese, Aboriginal, of a non-English speaking background, socio-economically and/or geographically disadvantaged or aged at either end of the recommended cervical screening spectrum (18–70 years). Deeply rooted Western stigma around disability, poverty, homosexuality, indigeneity, ethnicity, obesity and ageing devalues the personhood and worth of these women. Even in feminist literature, which can also be blinded by cultural norms (Olesen 1994), the experiences of women who are not able-bodied, middle class, well-educated, within a specified age and weight range (usually young and slim) are rendered invisible.
The research question, ‘What is the “lived experience” of women with a screening detected cervical abnormality?’ was addressed in this study. The women invited to answer that question were from groups considered at greatest risk of developing CIN/cervical cancer and whose voices were least likely to be considered in the existing literature. It was the contextualised experience of these women and the meanings they ascribed to having an abnormal Pap test result that have been described.

**Strengths of the study**

The strength of this study is primarily the depth of honesty and openness that the thirteen participants had when they shared their stories. The narratives of pain and trauma shared by the women are the stories they selected and wanted to share. They are the stories of women from groups whose voices are silent in the existing literature.

The two predetermined interview prompts used were deliberately very broad and served to contextualise the experience of having an abnormal Pap test result for the participants. The first prompt that asked women to describe themselves as women had the purpose of replacing a reductionist approach that centred on their cervix to a holistic approach that looked at their lives and the experience of having an abnormal Pap test result (the second prompt) in context.

My role was to listen to the women and be enabled by them to see the experience through their eyes. In the Gadamerian tradition, researcher and participant horizons became fused, allowing for meanings to be established and described. Selection of a research design that was informed by Gadamerian hermeneutic phenomenology allowed for a critical approach to be taken when the participants shared instances of suppression and oppression.

A secondary gain and strength of the study was the therapeutic benefits reported by the women who participated in the project. All the women shared, during subsequent interviews, how they had benefited from their participation. Very recently, I received a phone call from the daughter of Joyce, one of the participants. This woman contacted me to tell me the sad news that her mother had died from a condition not related to cervical adenocarcinoma. This daughter spontaneously shared how much her mother had enjoyed and gained from her participation in our project and how proud she would be to know that it was nearly finished and that her willingness to participate may assist
other women who experience an abnormal Pap test result. This research project is indebted to Joyce and the other twelve participants; these strong women are this project’s greatest strength.

**Limitations of the study**

*Whenever a phenomenological concept is drawn from primordial sources, there is a possibility that it may degenerate if communicated in the form of an assertion.*

Heidegger 1962, p. 60

The findings from this research are unable to be generalised. Generalisation is not the aim of a phenomenological study based on Gadamerian principles. As Koch (1998, p. 8) argued, ‘generalisation is not the aim of such work, reaching a new or better understanding is’. A person using a different perspective could possibly challenge my interpretations.

Bernstein (1988, p. 155) pointed to the Gadamerian dilemma when Gadamer spoke against ‘the peculiar falsehood of modern consciousness[,] the idolatry of scientific method[,] and the anonymous authority of the sciences’. He was appealing to critical standards and norms that demanded rational justification and argumentation. Paradoxically, Gadamer frequently presented his own thinking as a corrective to the onesidedness and excesses of the scientism that dominated scholarship and which he traced back to Cartesian and Enlightenment concepts. Bernstein (1988, p. 155) asked, ‘Isn’t there also a claim to truth in the Enlightenment tradition that needs to be recovered and honoured?’ This paradox is acknowledged and a disclaimer added that, in keeping with traditional phenomenological philosophy, positivistic methodology is also seen as a valuable tool in increasing knowledge and enhancing nursing practice. It is not, however, seen as the only legitimate scientific method or as an appropriate methodology for this study.

Gadamer (1975a) stated that he never offered a theory of interpretation and he has been criticised for not establishing a principle of validity for investigations (Weinsheimer 1991). Establishing validity was, however, an integral component in this study and strategies to ensure validity were discussed in detail in the chapter on ‘Method’.
Weaknesses attributed to phenomenology can contradictorily also be the methodology’s strengths. Barritt et al. (1983 cited in Lynch-Sauer 1985) argued that phenomenology could be criticised because: it was difficult to replicate a descriptive study of experience, it was too subjective, researcher bias interfered with pure results, phenomenological language was too vague and ephemeral, there were no procedural guidelines and it was frequently based on the memory of informants. Lynch-Sauer (1985) argued that these limitations were the great strengths of phenomenology and the attributes that distinguished phenomenology from the traditional and prevailing quantitative methods. Qualitative research methods serve different purposes and should not be measured by criteria of quantitative research methods. Hesse (1980, p. 247) argued, ‘The attempt to produce value-neutral social science is increasingly being abandoned as at best unrealisable, and at worst self-deceptive, and is being replaced by social sciences based on explicit ideologies’. Reinharz (1985, p. 17) concurred and added, ‘Since interest-free knowledge is logically impossible, we should feel free to substitute explicit interests for implicit ones’.

Qualitative nursing research, including phenomenology, has been criticised on the grounds that it lacks specific methodology (Baker, Wuest & Stern 1992). It has also been criticised as being an ‘orgy of subjectivism’ (Turner 1986, p. 475), and the hermeneutic circle is critiqued as a vicious cycle if we validate interpretations by appealing to other interpretations (Kaelin 1988; Bernstein 1988). In response to these criticisms, every effort has been made to include the original data provided by the participants, so that the reader can form their own opinion as to whether the interpretations and recommendations drawn from the data are valid.

Critical hermeneutic phenomenology seeks to influence nursing practice and empower people, in this instance, women, indirectly and overtly through enhanced understanding of the phenomenon under review. As we enter the 21st century, women continue to be oppressed, violated and have their needs negated. Women are dominated and oppressed by masculine structures and processes and so the potential for emancipation features strongly in this research.

Gadamer spoke of the dangerous role of experts and technicians in society when they are invested with ‘exaggerated authority’ but he did not describe how to account for this phenomenon and determine its social consequences (Bernstein 1988). He was silent on
issues relating to domination and power and which formed an integral part of this study. It is for this reason that hermeneutic phenomenology was blended with critical and feminist methods. The study also borrowed heavily on Foucault’s admonition that ‘no intellectual orientation that seeks to illuminate concrete praxis in the contemporary world can be judged adequate if it fails to confront questions concerning the character, dynamics and tactics of power and domination’ (Foucault 1984 cited in Bernstein 1988, p. 156).

Power imbalance between myself and informants

In spite of every motivation and endeavour, a power gap still occasionally appeared in the interviews. Women wanted to please me, and some said at the beginning of their interview:

*I just hope it’s really going to work out to be what you want, that’s all.*
(Janette)

*Is that what you want to hear?* (Jayne)

*I can’t think of what I am going to say to you. I mean, what do you want me to say?* (Joyce)

Fortunately, this desire to share information that I wanted to hear was soon negated. Once women were assured that I wanted to hear their stories, that I wanted to hear the information they chose to tell me, the desire to please me was abated. This was evidenced by their honesty, openness and depth of sharing.

Drew (1986) argued that when there is an imbalance of authority and power, the person without the power is vulnerable to the message of the other. This power imbalance had devastating consequences when Janette was describing how she had left her very violent first marriage of 25 years to live with her partner. As a clarification I had asked Janette whether this was before or after her abnormal Pap test result. Janette answered:

*You’ve related the abnormal Pap smear to me, as being directly concerned with when I left [first husband] ...//... we are both brought up in the Catholic faith. Which meant, as far as I’m concerned, faithful to one another. And I would say that of [first husband] as well. Because that seems to be the kind of person he was. And still is. Whereas with myself, I’ve gone to live with [new partner] ...//... I know [he] has had many relationships with other women in the past and at least one other relationship that I’m aware of since [we’ve] been together ...//... so if it’s related, if the abnormal Pap smear is related to the change in sexual partners, which it could be, couldn’t it?* (Janette)
Because of an unintended power imbalance, Janette was very vulnerable to my question and misinterpreted my rationale for asking her.

At the time of the interview, all informants were aware that it was a women’s health nurse who was interviewing them. This may have inhibited them from sharing negative experiences involving nurses in general and women’s health nurses in particular. Although negative experiences involving nurses are described, these are rare. It cannot be known whether that is because the women’s experience of being with nurses was predominantly positive or whether it was because of a reluctance to share negative instances with an interviewer who identified as a nurse.

**A retrospective study**

This study collected retrospective accounts of women’s experience when they had an abnormal Pap test result and consequently it is acknowledged that recall bias may affect the accuracy of some of the concrete details reported. Women’s feelings about their experience have possibly been clarified or even accentuated with time. The impact of their experience of having an abnormal Pap test result is better known many months or years after the incident than if the women were interviewed at the time of having the abnormal Pap test result and/or further investigations and treatment.

**Avenues for further research**

A possible relationship between stressors such as sexual and physical violence and cervical cell changes needs to be explored in longitudinal, triangulated, qualitative and quantitative type studies. These studies, conducted under strict ethical parameters, could be used to determine any possible causal effect as well as the short- and long-term consequences of IPV and sexual violence against women and children.

The women in this study continued to redefine and make meaning from the traumatic events in their lives, some of which had happened decades earlier and some of which were more recent. It is possible that a significant trauma or stressor, once experienced, continues to redefine women, predisposing them to vulnerability and to pathological cellular changes to the cells on their cervix. This study does not and cannot answer that question but instead alerts the reader to a possibility and urges further research in this area.
A significant factor in the harm caused to women when they had an abnormal Pap test result was the time they spent waiting for appointments, professional attention and results. A multidisciplinary action research project that uses a business management type framework could be used to determine strategies that would reduce waiting time for women.

The thirteen women in this study adopted personality traits that have been identified in the psychoneuroimmunology literature as protective to their immune system (Kobasa 1979; Solomon 1981; McClelland 1986; Linville 1987; Pennebaker 1990; McKay 1992; Quellette 1993; Pert, Dreher & Ruff 1998; Lambert & Lambert 1999; Kenney & Bhattacharjee 2000; Dolbier et al. 2001; Pollachek 2001; Davidson 2002). Not one participant reported remaining in an abusive relationship at the time of their interviews. It cannot be known whether this self-protective adaptation phenomenon is widespread for women who have an abnormal Pap test result or if it is peculiar to the thirteen participants who had already worked through many issues related to the experience and felt strong enough to share their stories for this project. Further qualitative type research, especially if it were informed by a critical feminist perspective, could be used to explore this concept.

Suggestions have been made in this study that could enhance women’s health care when women experience an abnormal Pap test result. Suggestions included nurse colposcopist clinics, peer (including telephone support) support groups and information evenings conducted by specialist nurses pre- and post-colposcopy for women with an abnormal Pap test result. Such strategies would require careful evaluation and reporting to ensure they are of optimum benefit to women.

**A few final words**

The shared stories of the thirteen participants indicate that, when a woman recalls her experiences of an abnormal Pap test result, her past becomes her present. Old traumas such as intimate partner violence, child and adult sexual assault, betrayal and profound grief are awakened and serve as vehicles by which the woman defines herself. Her present, affected by the past, threatens her sense of self and her future as the abnormal Pap test result is perceived to be life threatening, no matter how minor the abnormality. However, for the thirteen women in this study, this threatened future was not where they stayed. The participants, each in their own transforming way, took on those traits...
that are reported to be immunoprotective, reducing their risk of future abnormal cervical changes. These traits included heightened ability to express feelings, confiding in another, to love and trust others, altruism and assertiveness. These thirteen strong and resilient women shared their stories in the hope that health professionals may hear them and transform their clinical practice into one that is mutually respectful, sensitive, gentle and attentive, providing the optimum therapeutic outcome for all women.
List of References


Moscicki, A., Hills, N., Shiboski, S., Powell, K., Jay, N., Hanson, E., Miller, S., Clayton, L.,


Munoz, N., Bosch, F., Desanjose, S., Tafur, L., Izarzugaza, I., Gili, M., Viladiu, P., Navarro, C.,

Munoz, N., Kato, I., Bosch, F., Eluf-Neto, J., de Sanjose, S., Ascunce, N., Gili, M., Izarzugaza,


Appendix 1: Ethical clearance

This research project received ethics clearance from the Institutional Ethics Committees (IEC) of the two participating institutions, The Greater Murray Area Health Service and Charles Sturt University. When I, the researcher, relocated to Charles Sturt University, Wagga Wagga to take on an academic position in 2001, all participants were notified of the change of contact details in a letter that discussed the progress of the project to date and inviting them to contact me at any time. Charles Sturt University IEC and The Greater Murray Area Health Service IEC were also notified of the move and the transfer of tapes and documents. All documents and tapes that had previously been locked in a filing cabinet in my Community Health Centre office were securely transferred to a locked filing cabinet where they remain in my University Office.

Copies of three documents follow:

- The invitation forwarded to potential participants after they had been introduced to the study by the women’s/sexual health nurse.
- Plain language statement briefly describing the project for potential participants to read.
- Consent form for women to sign if they chose to participate in the study (reformatted for the purpose of the thesis presentation).
1: Invitation to participate in the study

Elaine Dietsch
Clinical Nurse Consultant: Women’s Health
PO Box 841
Leeton 2705

Telephone: 02 69 531221
Fax: 02 69 531214

Date

Information for women considering participation in the Research Project:

‘What is the lived experience of women with a screening detected cervical abnormality (abnormal Pap test result)?’

Dear

Thank you for considering participating in this research project which will be listening to a woman’s experience of having received an abnormal Pap test result. During this project, it is the depth of your experience and your willingness to share that will be highly valued.

The enclosed information will hopefully answer many of your questions and give you some more detailed information about the project. If you have any questions or concerns then please contact me on 69 531 221.

If, after reading the information sheets, you would like to participate in the study, would you be kind enough to complete the consent form enclosed and return it in the stamped, self-addressed envelope. I will then contact you to arrange a time and place that suit you for the taped interview.

Thank you for considering this invitation to participate.

Yours sincerely,

Elaine Dietsch
2. Plain language statement

The study is about your experience when you had an abnormal Pap test result.

My name is Elaine Dietsch. I work as a Clinical Nurse Consultant in Women’s Health and am employed by the Greater Murray Area Health Service. I am also a Doctor of Philosophy Candidate with the Charles Sturt University.

Women, like you, who have had an abnormal Pap test will be asked to participate in an in-depth interview. The initial interview will last 1–2 hours. Two to three other interviews will be required to ensure that the information you have shared and the way I have interpreted your story is accurate and true. The first interview will be audiotaped and then written out word for word. These taped and written interviews will then be studied extremely closely. The knowledge gained from you during the interview will then be used to increase understanding and positively influence nursing practice.

Each interview will be different, because the researcher will follow your lead – it is your story that is important! During the interview you will be asked to describe, in as much depth as possible, your experience when you received the abnormal Pap test result(s) and went for further investigations and possible treatment with the gynaecologist. You may also like to share any other aspect of your life story that you believe is significant or may have some relevance.

Should you have any questions or concerns before, during or after the interview, then please free to express them at any time I will do my best to answer them. You may choose to turn the tape recorder on or off at any time.

Some women may find sharing during the interview a distressing experience. The recalling of traumatic and/or distressing events can be an extremely difficult for some women. Throughout the interview and following it, you will be offered time to ask questions and seek further information. A referral to a specialist counsellor can be given if you desire.

Your interview will be audiotaped, written out and then studied very carefully. You will be able to choose another name for the written transcript and all identifying information will be changed to protect your anonymity. The audiotapes and a copy of the typed interview will be stored in a locked filing cabinet in my office until the conclusion of the study. Five years later they will be destroyed.

Please know that you are under no pressure to participate. Your decision to choose to participate or not will be known by no other person except you and I, unless you choose to tell someone. Your decision to choose to participate or not, is respected by both the nurse who introduced you to the project and myself and will in no way affect the care you receive at the women’s or sexual health clinic.

You may withdraw from the study at any time. Should you withdraw from the study, all tapes and transcripts will be immediately destroyed and not used as part of the research. Again, the decision to withdraw will not affect the care you receive from the women’s or sexual health nurse.
Please know that you have the following rights:

- Absolute confidentiality
- You are under no pressure to participate and may withdraw at any time.
- If you choose to withdraw from the study, all tapes and typed transcripts of your interview will, with your permission be destroyed.
- To choose your own identifying information (false names etc).
- Should you share any information that shows a child is at risk of physical, emotional or sexual abuse, then please know that the interviewer has the moral and legal obligation to notify the Department of Community Services who will help ensure that child is protected.
- To have the interview at your choice of venue and at a time that is convenient for you.
- To share as much or as little information as you would like and you may always refuse to answer a question or discuss an issue.
- To turn the audiotape on or off at any time.
- To complain, if ever you feel the researcher may be acting unethically.

You may exercise any of the above rights without interfering in any way with your consultations at the Women’s Health or Sexual Health Clinic.

The story you share and the information you provide during the interview will be studied very carefully. The findings will then be used and presented in a way, which protects your confidentiality and anonymity, as part of the requirements for the degree of Doctor of Philosophy for Elaine Dietsch, the Researcher.

The results of this research project will probably also be published in a professional Nursing Journal and presented at Conferences. It is hoped that this research project will influence nursing practice and help other women who may have or be at risk of having abnormal Pap test result(s).

Charles Sturt University’s Ethics in Human Research Committee has approved this project. If you have any complaints or reservations about the ethical conduct of the project, you may contact the committee through the Executive Officer:

Executive Officer
Ethics in Human Research Committee
The Grange
Charles Sturt University
Bathurst NSW 2795

Phone: 02 6338 4628  Fax: 02 6338 4194

Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.

Greater Murray Area Health Service (GMAHS) Ethics Committee has also approved this project. If you have any complaints or reservations about the ethical conduct of the project, you may contact the committee through the Executive Officer:

Dr Paul Curtis, GMAHS Ethics Committee, Locked Mail Bag 10, Wagga Wagga 2650
Phone: 02 69215588
3. Consent form

Written Consent Form

Name of Research project:  
*The ‘lived experience’ of women with a cervical screening detected abnormality: A phenomenological study.*

Name, Address and Phone number of Principal investigator:  
Elaine Dietsch  
Leeton Community Health Centre  
PO Box 841, Leeton 2705  
Phone: 02 69531221

I, …………………………………………………………………………………………………. consent  
to my participation in the research project entitled, *‘The ‘lived experience’ of women with a cervical screening detected abnormality: A phenomenological study’.*

I understand that I am free to withdraw my participation in the research at any time and that if I do I will not be subjected to any penalty or discriminatory treatment.

The purpose of the research has been explained to me, including the potential risks and discomforts associated with the research. I have read and understood the written explanation given to me and I have been given the opportunity to ask questions about the research and received satisfactory answers.

I permit the investigator to tape record my interview as part of this project. I understand that any information or personal details gathered in the course of this research about me is confidential and that neither my name nor any other identifying information will be used or published.

Charles Sturt University’s Ethics in Human Research Committee and the Greater Murray Area Health Service Ethics Committee have approved this study. I understand that if I have any complaints or concerns about this research I can contact:

Executive Officer  
Ethics in Human Research Committee  
The Grange  
Charles Sturt University  
Bathurst NSW 2795  
Phone: 02 6338 4628  
Fax: 02 6338 4194

Signed by: ……………………………………………….. Date: …………………..
Appendix 2: Publications, conference presentations, seminars and workshops arising from the research project

Publications

2003  

2001  

Conference presentations

2003  

2002  

2002  

2001  

2001  

Seminars and workshops presented

2002  

2001  

2001  
Dietsch, E., Gibb, H., Francis, K. Gadamerian Hermeneutic Phenomenology, School of Clinical Sciences, Research Seminar for PhD candidates, Wagga Wagga.

2001  Dietsch, E., Gibb, H., Francis, K. The PhD process – time management and survival. School of Clinical Sciences, Research Seminar for PhD candidates, Wagga Wagga.


2000  Dietsch, E. Prioritising women’s health nurse services for those at greatest risk. Workshop for the GMAHS Cervical Screening Program committee, Lockhart.