INTRODUCTION

This paper reports on part of a larger phenomenological study that was purposed to explore women’s experiences when they had an abnormal Pap test result (Dietsch 2003). The larger study asked the research question, ‘What is the lived experience of women when they have a cervical screening detected abnormality?’ When women were invited to participate in the study they were advised that they would be asked to respond 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.’ The first request for information was made in an endeavour to encourage the woman to share her story in a manner that was contextualised, integrated and whole. The stories the women shared in response to that first prompt have been dialogued with the published literature in this paper to create shared meanings, but the primary voices always belong to the women.

BACKGROUND

A review of the literature attended prior to data collection for the overall study was deeply disturbing because it strongly focused on the woman’s cervix, causing her life context to be invisible and her story inaudible. The literature only occasionally contextualised the experience of having an abnormal Pap test result and even less often alluded to the observation that women

ABSTRACT

In this phenomenological study women who had experienced an abnormal Pap result in the past were asked to share something about themselves as women, prior to describing their experience of having an abnormal Pap result. From their responses, we hear stories of how their sense of self was intricately entwined with their experiences of physical, emotional or sexual violence and/or a profound sense of grief and loss. The stories of violence, trauma and loss alert the nurse and midwife to the possibility that giving a woman information, for example that her Pap test result is abnormal, may compound existing feelings of fear and create a new threat to the woman’s sense of ‘self’.

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Women defining themselves: Shared stories of private hell

Key Words
Pap test; sexual assault; domestic violence
who experience abnormal Pap results are more likely to have lived ‘troubled lives’ related to intimate partner violence, sexual trauma or their partner’s misuse of alcohol (Beresford & Gervaize 1986; Schover, Fife and Gershenson 1989; Quilliam 1990; Gregory & McKie 1991; Kellogg & Parra 1995; McKie 1995; Coker et al. 2000; Geyer 2000; Stevens-Simon et al. 2000). In the Schover et al. (1989) study as an example, almost half the women with early stage cervical cancer were victims of domestic violence and over a quarter of women reported sexual trauma. Stress, such as that associated with violence has been shown to correlate with the onset of cancer, and therefore by implication, cervical dysplasia (Kotsirilos 1998).

The literature, though scant, confirmed the author’s own clinical experience suggesting that many women who experienced an abnormal Pap result had lived very ‘troubled lives’. The balance of available material related to cervical screening is heavily slanted towards the microbiological and cytological perspective. The voices of women are both silent and silenced by the scientific literature. The woman’s experience of this very common phenomenon has been largely ignored. This ignorance has led to a tendency for women with an abnormal Pap 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 exacerbates the problem. The meaning(s) an abnormal Pap test result has for women are seldom taken into account in the literature (Posner 1991). Materials easily accessible to the general public reflect the same professional partiality. In analysing Australian health education information about Pap testing, Lane and Lawler (1997) found that the Pap test was contextualised as a procedure ‘done to’ women and their experiences of the encounter and any possible sequelae are not described. This paper seeks to start to redress the imbalance and swing the nurses and midwife’s attention back to the woman herself.

**METHOD**

The paper is informed by phenomenology. In fundamentalist and pure Husserlian phenomenology the researcher needs to ‘bracket out’ all preknowledge and preunderstanding (Husserl 1970; Wilding & Whiteford 2005). In this study, that would mean ‘bracketing out’ any thoughts of possible violence, abuse and exploitation experienced by women with an abnormal Pap result. From many years in clinical practice, listening to the horrifying stories of women, the author did not believe this possible or desirable. To attempt to ‘bracket out’ known collective stories would be an act of disloyalty to those women who had survived such horror.

Gadamerian phenomenology, however, can be used in congruence with a critical approach that seeks to uncover oppressive and suppressive influences that affect women and does not necessitate the practice of ‘bracketing’ (Annells 1999; Denzin & Lincoln 2003). In fact, Gadamer (1965/1975: 324) argues that to try to eliminate one’s concepts in interpretation is not only impossible, but absurd, ‘A person who imagines that he [sic] is free of prejudices, basing his [sic] knowledge on the objectivity of his [sic] procedures and denying that he is himself [sic] influenced by historical circumstances, experiences the power of the prejudices that unconsciously dominate him’ [sic]. In studies informed by Gadamerian hermeneutic phenomenology, it is however, essential that all prejudices are disclosed and they are never allowed to influence or contaminate the data collection or analysis processes.

In the interests of phenomenological inquiry, that ‘preunderstanding’ continues to be acknowledged and conscious efforts made to never allow it to influence the way data was collected, collated, analysed or reported. For this reason each in-depth interview with each of the thirteen participants was entered 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’.

Informants in phenomenological studies are selected because they have lived the experience being investigated (Holloway 2005). In this instance – their experience of having a screening detected cervical abnormality and being clients at a women’s health nurse clinic. Selection of participants was therefore purposive and in keeping with its aim of illuminating the richness of the individual experience, the number of participants was kept deliberately small at thirteen. The very nature of this research project was to ‘give women a voice’, especially those women who are considered disadvantaged and/or whose voices are usually unheard or at least, unpublished. These are women given priority of attendance at Women’s Health Nurse clinics, as they are least likely to access ‘mainstream’ gynaecological and sexual health screening services. They are also from groups identified as being at greatest risk of experiencing a cervical screening detected abnormality. Sprague (2005) supports this selection process when a feminist study requires inclusion of women from a variety of ethnic/racial backgrounds and sexual orientations, a range of socioeconomic circumstances, ages and physical abilities.

Sixteen women were invited to participate in the study and thirteen accepted. Of the women who declined, one was a sex industry worker with a newborn baby who felt that she was too busy to be involved and two were from non-English speaking South East Asian countries and did not feel confident enough with their spoken English. 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 (the level of this participant’s cognitive impairment did not preclude her from giving informed consent to a study she was very keen to inform). 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 and one was a refugee (both of these women communicated comfortably in English and did not require an interpreter during the interview process). One woman identified as lesbian and three of the women having heard of the research project through other women’s health nurse clients, contacted me and asked if they could also share their stories.

The initial in-depth interviews, each lasting between one and a half to four hours, were audiotaped and transcribed verbatim. All identifying details were changed to protect informant confidentiality. As stated, interview questions were non-specific, open-ended and designed to avoid influencing the informants’ answers in any way. A recursive model was used where the interview followed normal conversational flow. The transcripts were offered to the women to read and discuss with the researcher before and after interpretative and thematic analysis, which served to increase catalytic validity. Only one woman declined her transcript and she requested that she not participate in this aspect of the study, as she felt it might be too painful for her. This possibility had been considered and addressed in the ethics proposal preceding the data collection phase of the study. Therefore, validity was able to be maintained in this instance by seeking her informed consent to have the deidentified transcript and early interpretative analysis critiqued by select members of the authors’ women’s health nurse research support team.

The women invited to participate in the study were all clients from eight women’s health nurses practices in rural and remote New South
Wales, Australia. Women were not selected because of any known history of stressful life events. At the time of invitation this information was rarely known, only that they had had an abnormal Pap result(s) in the recent or more distant past. The time from the abnormal Pap result notification ranged from 8 weeks to 15 years. The women’s health nurse who they consulted informed women of the study. When the woman expressed an interest in participating, with her permission, the nurse contacted the researcher and a package was mailed to the women that contained information about the study, a consent form for them to sign if they wished to participate and a return envelope. The researcher did not inform the nurse whether the woman consented to participate or not. However, every woman spontaneously shared their decision with the women’s health nurse who had referred them.

Both the Charles Sturt University and Greater Murray Area Health Service Institutional Ethics Committees approved of this project. Informed consent to participate in the study was obtained from all participants. Most importantly, every participant has expressed the desire that their story be shared as widely as possible so that clinicians might learn from their experience. In the interests of participant confidentiality, all names and identifying data have been changed.

DATA ANALYSIS
The data analysis process used in this study draws upon the articulated strategies described by Benner (1985 & 1994) and Koch (1998). Interplay between the processes of intuiting, interpreting and describing took place in order to develop a framework for thematic analysis and identification of exemplars and paradigm cases. Interpretation, analysis and critique were the methodological vehicles used to ensure this study provided a descriptive report that is as true as possible to the stories told by the women interviewed. The issue in any qualitative study is not whether another investigator would discover the same findings, but rather if the findings of the research are worth paying attention to (Denzin & Lincoln 2003). The stories shared by the thirteen participants in this study demand careful attention.

FINDINGS
Of the thirteen women who participated in the study, 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 and their husbands had 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. When asked to ‘please tell me something about yourself as a woman’, all but one participant shared a story of trauma related to physical, sexual and/or emotional violence often compounded by experiences of profound grief and loss. Many but not all of the women in this study related the trauma they had experienced directly to their having an abnormal Pap result. However, with only one exception, their description of themselves as women could not be divorced from the their traumatic life experiences.

DISCUSSION
The stories of the twelve women who shared stories of violent and/or sexual trauma, by necessity cannot be recounted in full. However, snapshots are shared with the reader to illustrate how twelve of the thirteen participants in this study defined and continued to redefine themselves in relation to the following themes.
identified: militaristic violence, intimate partner and paternal violence and sexual trauma they had survived.

**Militaristic violence**

*It is painful, what the war did to us.* (Melanie)

Melanie, who had survived indescribable horror and violence during a war where her five-year-old son was defiled and her young husband was killed said:

I am originally from Yugoslavia … I was married and I lost my husband during the war … I escaped with son … and now I think every 7th woman in Bosnia is suffering from cervical cancer … 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)

Melanie’s anecdotal accounts from Bosnia are reflected in the NSW Chief Health Officers Report (Public Health Division 2000: 93). The report indicates that unlike the time prior to the escalation of conflict in the former Yugoslavia, women born in former Yugoslavia are now significantly more likely to be diagnosed with cervical cancer than Australian born women. It is estimated that 90% of war casualties in former Yugoslavia are women and children and that sexual assault used as a tool of ‘ethnic cleansing’ was carried out so systematically that it was a product of nationalistic and militaristic policy (Swiss & Giller 1993):

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 part and, there are periods, carrying with me, it’s not normal. (Melanie)

Melanie’s home country had once been a source of patriotic pride and allegiance. Now it had become the vehicle that had murdered her husband and transported her and her tiny son to a land where they were refugees and knew no one. Melanie’s sense of self, the ordinary and her normality had been irreparably shattered by war.

**Intimate partner and paternal violence**

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

Experiences of physical, sexual and emotional violence were common in the stories shared by Australian as well as overseas born women. Many women in this study described feelings of terror and life-threatening fear of their partners, fathers and stepfathers. Megan shared:

He was a wife abuser! … 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)

Janette, confined to a wheelchair, described fearing for her life when her husband was in a violent rage:

[He] was very violent both to the children and myself … I had been grabbed and pushed out of my [wheel]chair … terrifying! He threatened to throw me over the side of the um, Motel we were staying in. I think we were about four or five stories up. (Janette)

Some women specifically said that their husbands never ‘hit’ them. Nevertheless, a woman does not have to be ‘hit’ to experience violence as these stories of fear demonstrated:

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. (Terry)

I had bruises and I had to cover up to go to work … I mean he never sort of, as such really, hit me, but just used force to sort
of bruise me and make me scared . . . .
Shame! (Julie)

Julie, Ann, Megan and Rita all described feelings of shame when they suffered violence by a person who they love(d) and trust(ed). Shame has been defined as ‘the pain of feeling unloved and unlovable’ (Wurmser 1981: 97). For the women in this study, experiences of shame were isolating, highly personal and resulted in feelings of abjection where their sense of self as a human being of worth was threatened. Many years later, it was these experiences of violence, fear and shame that surfaced within minutes of being asked to share something of themselves as women.

Sexual violation and trauma

And then about eight years of age . . . . 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. (Marie)

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

Marie shared that her current aversion to oral sexual contact was as a consequence of forced oral sexual contact with a perpetrator as a child and later incestual abuse by her stepfather when she was a teenager:

Less of the penetrative intercourse [with my stepfather] but more of the oral stuff . . . . . there was some physical abuse in that space of time too . . . . . my Mum suspected that my Dad was sexually abusing me but she wasn’t sure. (Marie)

Although Rita had repressed the memories of her brother’s incestual abuse for many years, when the abuse came to her attention as an adult, she confronted her brother, the perpetrator of the incest and he confirmed the accuracy of her memories. Rita summarised her feelings:

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

Terry explained that both she and her ex-husband had survived child sexual assault, but she did not believe that this excused his criminal, paedophilic behaviour as an adult:

He had been molested as a child . . . . . 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. (Terry)

Annabelle had been homeless and was eighteen years old at the time of her preliminary interview. She was a survivor of child sexual assault and a number of vicious rapes during her adolescence. Annabelle described trying to cope by attempting to become detached and distant from her memories but her strategies were often unsuccessful:

I was raped quite a few times . . . . . 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. (Annabelle)

Sexual trauma includes but is 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. Jayne described feeling a sense of betrayal that had resurfaced when she was diagnosed with human papilloma virus (HPV):

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! (Jayne)
Megan, Marie and Faye all discovered that their husbands were having a sexual relationship with their close friend. Faye, as an example, had just given birth to twin boys, one of whom was still-born:

I came from hospital a day early …//… I went home and caught my husband and my best friend there …//… I was hurt, very hurt. (Faye)

A woman who I called a friend …//… [husband] had an affair with her. (Marie)

You’ve sort of got no one. (Megan)

These three women’s sense of betrayal and loss was exponentially exacerbated when they realised their husband was having a sexual relationship with a woman they considered a close friend. When Faye, Marie and Megan were exposed to their partner’s sexual infidelity, the experience was accompanied by intense grief for two of their most intimate relationships. Their primary sources of emotional support and comfort had not only been demolished, they had been the cause of indescribable shame and pain and they now had to suffer alone. For Megan, Marie and Faye their sense of self, previously connected to two intimate others had been totally destroyed.

With the exception of only one participant, every woman in this study told stories of multiple stressful life events when they were asked to share something about themselves as women. These vignettes illustrate that for these women, their sense and definition of self, was intimately entwined with the traumatic life events they had experienced.

**Limitations**

The nature of phenomenological research does not allow for generalisations to be made. Assumptions cannot be made as to any correlation between stressful life events, including those related to violence and loss and cervical dysplasia. 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 results may have also lived ‘troubled lives’. Another possibility is the stories that these participants have shared may be common to all women, who may or may not have had an abnormal Pap result.

**Recommendations for further research**

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 may 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 it alerts the nurse or midwife to the possibility and urges further research. Furthermore, the possibility of a relationship between sexual and physical violence and cervical health needs to be explored in longitudinal, triangulated qualitative and quantitative studies to determine any causal effect. The need to examine the short and long term consequences of interpersonal violence for women is urgently required and preventative strategies instigated globally to reduce the incidence and impact of violence on women and children.

**Conclusion**

The women in this study were not asked to recall or share traumatic experiences, but rather to share a little of themselves as women, prior to sharing their experience of having had an abnormal Pap result. Women spontaneously shared the stories that have been briefly alluded to in this paper and they welcomed the opportunity to do so. They experienced violence and loss as an integral chapter in their lives and it had become at least part of what being a woman meant for them. The stories that the informants
shared were in response to the simple prompt, ‘please tell me about yourself as a woman.’ Phenomenologically speaking, this ‘self’ that the women described could not be separated from the violence and trauma they had experienced. As long ago as 1953, Sullivan described ‘the self’ as a social construct developed from experience, culture, societal influence, gender issues, spiritual and psychic components. For almost all of the women in this study, the experiences of violence, trauma, grief and loss had bought them to their present understanding of ‘self’. This ‘self’ had been threatened on many occasions and had once again been threatened because of their experience of having an abnormal Pap test result.

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