

# Women's subjective experience of hysterectomy

PAOLA FERRONI AND JOHN DEEBLE

Paola Ferroni is a Senior Lecturer in the School of Social Work at Curtin University. John Deeble is a Health Service Fellow at the National Centre for Epidemiology and Population Health at the Australian National University.

## ABSTRACT

*This paper presents data on the experience of hysterectomy from a sample of 656 women aged between 30 and 50 years recruited from patients of a random sample of 50 general practices in Perth. Respondents were identified as women who:*

- *had undergone hysterectomy for reasons other than cancer*
- *were affected by gynaecological conditions*
- *had neither gynaecological problems nor had undergone hysterectomy.*

*Respondents voluntarily completed a self-administered questionnaire which covered demographic information, general health, gynaecological problems and hysterectomy, sexual activities and family relationships. Formal measures of depression and self-esteem were included.*

*The main concern was with the psychological and social outcomes of hysterectomy rather than its physical results. The findings showed that of 107 women who had undergone hysterectomy, only two had negative comments about the outcome. There were significant effects on both work and sexual relationships for women in the gynaecological condition group, with 52 per cent reporting adverse effects on work and 46 per cent believing that their sexuality was affected. Few women regarded the uterus as 'essential to femininity or womanhood' and very few saw it as affecting sexuality. Women in the hysterectomy group reported that their satisfaction with sexual activity had improved, whereas those with gynaecological conditions believed that it had deteriorated. Depression and self-esteem scores were significantly worse for women with gynaecological conditions.*

## Introduction

Hysterectomy is one of the most frequently performed surgical procedures. Santow and Bracher (1992) quote prevalence rates of 25 per cent for Australian women aged 50 or more in 1986. This figure is well below that of the United States in 1985 (Pokras & Georges Hufnagel 1988), but higher than the 20 per cent reported for Great Britain and a much higher rate than for Europe as a whole (van Keep, Wildermersch & Lehert 1983). A survey on the prevalence and characteristics of women who have had a hysterectomy showed that abdominal hysterectomy was the seventh most performed operation in Australian public hospitals and the third most common in private hospitals in 1985 (Schofield et al. 1991).

Hysterectomy is also one of the more controversial procedures. Pokras and Georges Hufnagel (1988) reported that in the United States one out of every three women will be affected by hysterectomy, making it by sheer magnitude a very important health issue. Some have claimed that a significant proportion of hysterectomies, predominantly those for non-cancer-related illness, are unnecessary and could be avoided (Opit & Gadiel 1982; Georges Hufnagel 1989). Farfalla (1992, p 1) also postulated that 'two out of every five women will undergo hysterectomy without knowing all the facts'. Feminist writing has been concerned about the power and gender relationships involved in gynaecological interventions as argued by Georges Hufnagel (1989), a gynaecologist who advocates a reduction in the number of hysterectomies performed and greater research on alternatives to the procedure. Domenighetti, Luraschi and Marazzi (1985) noted that, amongst Swiss gynaecologists, females performed about half as many hysterectomies as males.

This paper is more concerned with the psychosocial outcomes of hysterectomy than with its physical results. In this area, attention has generally been given to depressive reactions and to adverse effects on sexual health. The results are often contradictory. Bunker and Brown (1974) concluded that many women see the operation as signalling 'a loss of womanhood and attractiveness' and there are conflicting reports on its effects on sexuality. Raboch, Boudnik and Raboch Jr (1985) reported that, of 164 German women who had undergone hysterectomy, 47.5 per cent showed a deterioration of sexual activities and only 14 per cent an improvement. A Korean study with 230 subjects found a decline of around 20 per cent (Yun Soon Choi & Soon Bok Chang 1989). Richards (1974), in his general-practice setting, found that 49.5 per cent of 200 women who had undergone

hysterectomy manifested depression within three years. In the same period, Chynoweth (1973, p 102) observed that 'about one-third of women' presented with 'some evidence of psychological maladjustment', although much of this appeared to be related to pre-hysterectomy personality traits.

By contrast, Lalinec-Michaud, Engelsmann and Marino (1988, p 312) found a general reduction in depression scores following surgery and reported, for hysterectomy in particular, that 'far from causing depression, [it] brings a relief in the general health of the woman'. A prospective study by Carlson, Miller and Fowler (1994, pp 561-2) of 418 women who had undergone hysterectomy found a significant improvement in scores for indicators of mental and general health at a six-month follow-up. Ryan, Dennerstein and Pepperell (1989, p 522) conducted a prospective study with 60 women and found no evidence that hysterectomy itself 'precipitates adverse psychological sequelae'. A recent report from the National Health and Medical Research Council (1992) reached similar conclusions.

There has been little published research, however, on the *subjective* experience of women who have undergone hysterectomy. This paper presents data from a sample survey of Western Australian women which was undertaken as part of an investigation into the effects of gynaecological problems on physical, psychosexual and social health. They shed some light on both professional and popular attitudes to the indications and effects of hysterectomy. The emphasis is on psychological and social outcomes. Physical results are reported only in so far as the responding women perceived them.

## Methodology

A cross-sectional sample of 656 women aged between 30 and 50 years was recruited from those attending a random selection of 50 general medical practices in Perth, Western Australia. The women responded voluntarily to an anonymous pre-paid and self-administered questionnaire made available at the reception counter. According to their responses, the women were assigned to one of three groups:

- (i) those who had neither gynaecological problems nor had undergone a hysterectomy, and who considered themselves generally healthy (n = 358)
- (ii) those currently affected by gynaecological conditions (n = 191)
- (iii) those who had undergone hysterectomy for reasons other than cancer in the last five years (n = 107).

Women whose hysterectomy was cancer-related were excluded from the study because the ramifications of a potentially life-saving operation may overwhelm all other sequelae in the respondent's mind. The questionnaire covered demographic information, general health, gynaecological history and hysterectomy where relevant, sexuality, family relationships, belief systems and life events. It was developed from a pilot study of 106 women in 1991 and contained 55 questions plus a 23-item Beck Depression Inventory (BDI) (Burns 1980) and a 25-item self-esteem scale (ISE) (Hudson 1990). The main survey was conducted between July and September 1992 with varying periods of participation by individual practices.

**Table 1: Demographic features of study sample with comparable population**

	Study sample %	1990 Perth population %
<b>Age</b>		
30–34	27.0	27.5
35–39	27.2	26.4
40–44	23.3	24.7
45–50	22.5	21.4
<b>Country of birth</b>		
Australia/NZ	66.8	67.1
UK/Ireland	21.9	15.4
Europe	4.8	6.0
S. Africa/USA/Canada	2.6	1.5
Asia	2.2	5.3
Others	1.0	4.5
<b>Relationship status</b>		
Married or in a relationship	81.0	
Single, divorced, separated and not in a relationship	18.0	

Sample characteristics

In table 1, demographic characteristics of the sample are compared with data for the 1990 Perth population of women of comparable age. Note that women born in the United Kingdom, Ireland, Africa, the United States and Canada were over-represented in the sample and those from Asia and Europe were under-represented. Table 2 shows the characteristics of each group. Table 3 compares the characteristics of women in the hysterectomy sub-sample with those of all Western Australian women who had a hysterectomy over the five years to 1990. The smaller proportion of older women in the hysterectomy sub-sample (between 45 to 50 years old) is difficult to explain other than that there may have been some confusion at recruitment between the cut-off age of 50 years for inclusion in the survey and the condition that the hysterectomy be performed not more than five years ago. Some hysterectomies on women aged between 45 and 50 might have been excluded in this way.

For country of birth (tables 1 and 3), the smaller proportion of women in the study sample born in Asia and Europe may be partially attributed to language difficulties, or cultural attitudes which discouraged participation in a survey of this kind.

There were no statistically significant differences between the groups with respect to country of birth, relationship status, gross family income, satisfaction with partner or belief systems respectively ( $\chi^2$  1.9834 df 2  $\rho$  = .3709;  $\chi^2$  1.98701 df 2  $\rho$  = .37028;  $\chi^2$  1.2508 df 4  $\rho$  = .86966;  $\chi^2$  3.72168 df 4  $\rho$  = .44498). However, there was a significant difference in age and education levels, the hysterectomy group being older ( $\chi^2$  17.37487 df 4  $\rho$  = .0005) and having a lower educational attainment overall ( $\chi^2$  40.73969 df 6  $\rho$  = .00005).

Table 2: Characteristics of sub-samples

Mean average	Healthy group (n = 356)	Gynaecology group (n = 191)	Hysterectomy group (n = 107)
Age (yrs)	39	39	42
Relationship score*	2.02	2.07	2.07
Satisfaction with partnership score†	1.10	1.12	1.08

\* Relationship status: 1 = single, 2 = married or significant relationship, 3 = divorced or separated.

† Satisfaction with partner: 1 = happy, 2 = unhappy.

**Table 3: Characteristics of the hysterectomy subgroup**

	Study sample %	WA 1986–1990* %
<b>Age</b>		
30–34	15.0	17.6
35–39	33.6	28.4
40–44	37.4	30.5
45–50	14.0	23.5
<b>Country of birth</b>		
Australia, NZ	65.4	63.2
UK, Ireland	21.5	21.0
Europe	7.5	8.5
S. Africa, USA, Canada	4.6	3.0
Asia	1.0	3.8
Others	0.0	.8

\* All non-cancer hysterectomies performed in WA, 1986–1990. Source: Health Department of Western Australia hospital morbidity statistics.

**Table 4: Reasons for hysterectomy**

	Number of responses	% of women*
Menstrual disorders	87	81.3
Prolapse	17	15.9
Fibroids/cysts	36	33.6
Endometriosis	10	9.3
Bleeding on intercourse	13	12.1
Other	20	18.7

\* Percentages add to more than 100 because of multiple responses.

## Results

### Hysterectomy group

The mean age at hysterectomy was 39 years with a range from 29 to 49 years. One hundred and one women (94 per cent) had natural children, with an average parity of 2.3. The reasons for hysterectomy, as reported by the women, are shown in table 4. In this and in certain other tables, percentages add to more than 100 because of multiple causes or outcomes. The relevant tables are annotated accordingly.

Of the 107 hysterectomies, 75 were abdominal and 32 vaginal. Bilateral oophorectomy was reported by five women. The hysterectomy group had experienced more gynaecological surgery than the other two groups. Forty-one per cent had undergone tubal ligation and 18 per cent had undergone the excision of a leiomyoma, compared with 19.3 per cent and 0.5 per cent respectively for the 'healthy' women and 25 per cent and 3.6 per cent for the gynaecological condition group. The incidence of abortion was lower in the hysterectomy group – 15.8 per cent compared with 19.8 per cent of the healthy women and 22.0 per cent of those with gynaecological conditions. The incidence of tubal ligation in both the hysterectomy and gynaecological condition groups was apparently high but the figure for the healthy women in this study is consistent with that for a larger study of 1511 Perth women of reproductive age in 1988 in which 17.7 per cent of all women reported tubal ligation as a contraceptive measure (Waddell & Lee 1991, p 62).

Women were asked whether hysterectomy had been suggested to them by a doctor and, if so, whether they were satisfied with the explanation given. Those who had experienced hysterectomy were generally satisfied (94 per cent). Those in the gynaecological condition group were somewhat less satisfied. A hysterectomy had been suggested to 45 (27 per cent) women in that group. Twenty-five (60 per cent) expressed satisfaction with their doctor's explanation although they had not yet accepted the procedure. Sixteen (35 per cent) were not satisfied and two (5 per cent) were unsure. It may of course be that some of these women did ultimately undergo hysterectomy.

The reported outcomes of hysterectomy were overwhelmingly positive. Table 5 shows the women's responses. Of the 206 comments only eight were negative. Two women assessed themselves as generally worse. One of these felt emotionally worse because the loss of her uterus had affected her sense of womanhood, although she felt better physically. The

**Table 5: Outcomes of hysterectomy**

	No	%*
Generally better	83	77
Generally worse	2	2
Worse because of scar on my body	2	2
Worse because my partner makes negative comments about my body	2	2
Better because my partner makes positive comments about my body	7	6
Better because I no longer fear pregnancy	16	15
Worse because without my uterus I feel less than a woman	2	2
Better because I have been relieved of symptoms	92	86

\* Percentages add to more than 100 because of multiple outcomes.

satisfaction rating in this study was much higher than in some others (Chynoweth 1973; Lazarov et al. 1979). This may have been related to the length of time since the hysterectomy which was on average 2.8 years. Responses closer to the event might have been quite different.

## Gynaecological condition group

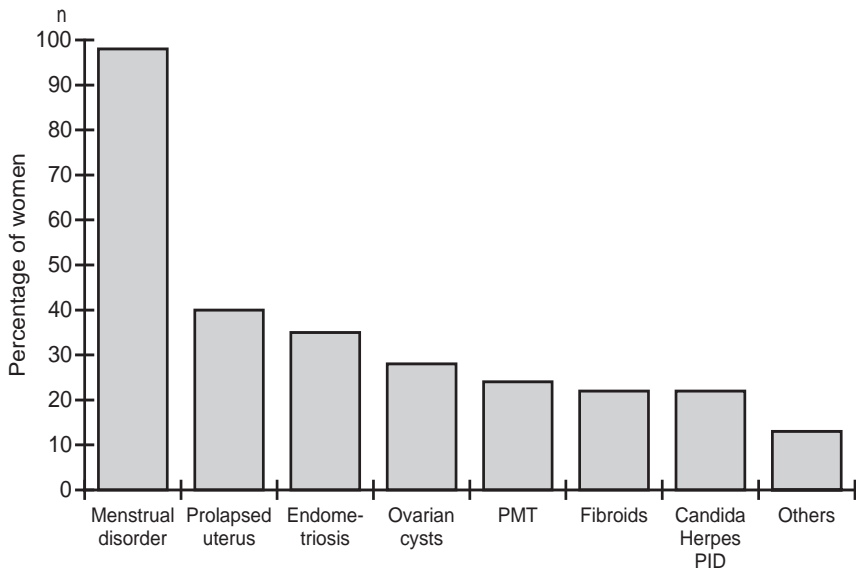
Ongoing gynaecological conditions in women who had not had a hysterectomy are shown in figure 1.

The most frequent conditions were menstrual disorders but endometriosis was reported as the most disabling condition and the one most associated with pain (figure 2). Although 39 per cent of conditions had been present for less than four years, the mean duration was nearly 7.5 years and 20 women reported them as being present for more than 20 years or since they started menstruating.

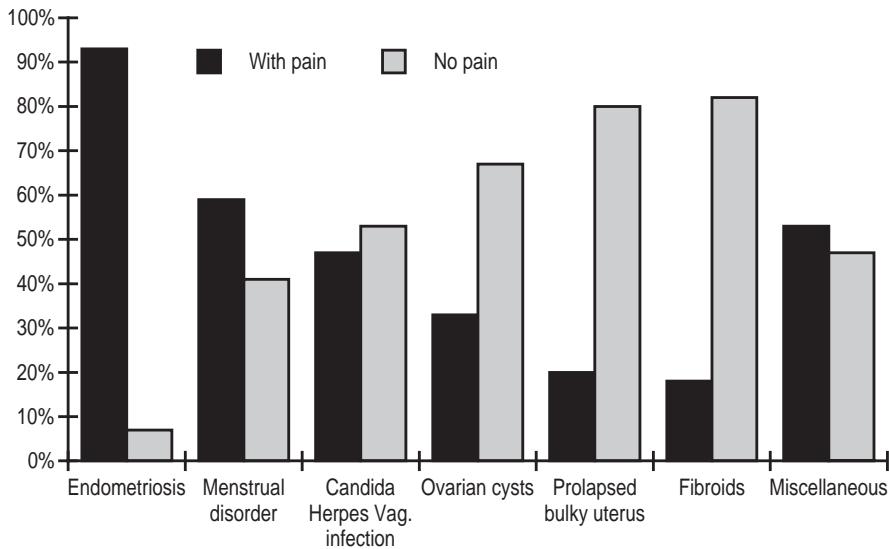
Fifty-two per cent of the women in the gynaecological condition group reported that their condition affected their work. Twenty-four per cent recorded time lost from work and 29 per cent assessed their work performance as reduced. Over one-third reported irritability and short temper. Forty-six per cent assessed their gynaecological conditions as adversely affecting their sexual life. Dyspareunia (26 per cent), loss of sexual desire (26 per cent) and feeling 'low' or 'depressed' (19 per cent) were the most commonly reported causes.



**Figure 1: Gynaecological conditions reported by the gynaecology group (n = 191)**



**Figure 2: Pain associated with gynaecological conditions\***



## Attitudes to hysterectomy

The women sampled were asked for their views on the relevance of the uterus to sexuality, femininity and womanhood and on its association with youthfulness. Another question explored attitudes to menstruation. Together they throw some light on the beliefs which might form women's perceptions of the procedure.

Few saw the uterus as having any function other than reproduction. Only 16 per cent saw it as 'essential to femininity and womanhood', and some of these qualified their responses to 'contributing' rather than 'essential'. Maintenance of one's youth was believed by only 2.8 per cent and very few saw it as having an effect on sexuality (4 per cent). Overall, 54 per cent of women in all groups felt 'good' or 'very good' about their menstrual periods, but amongst the hysterectomy group 92 per cent reported feeling 'relieved' or 'very relieved' about their cessation. As shown by the anecdotal accounts, the attitude towards hysterectomy was overwhelmingly positive, associated with beneficial outcomes: 'I'm sorry I've waited five years before deciding to have a hysterectomy...I've lost five years of good health.' In the words of another respondent: '... as far as I'm concerned, hysterectomy is the best thing since sliced bread.' This apparently utilitarian approach to the significance of the uterus might well be a relatively recent phenomenon.

## Emotional health

Depression and self-esteem were measured by the Beck Depression Inventory (BDI) and the Walmyr Assessment Scale (ISE) respectively. Their use has been validated in both clinical and non-clinical populations (Conoley 1991; Abell, Jones & Hudson 1984). The mean results for each group are shown in table 6. In both cases, higher scores imply less satisfactory outcomes; that is, greater depression levels on the BDI and lower self-esteem on the ISE. They were examined using analysis of variance to establish whether there were significant differences between groups and by the Sheffé procedure to establish whether one group differed from the others. The analysis of variance showed there were significant differences between them ( $F_2 = 11.24$ ,  $p = <.005$ ;  $F_2 = 6.481$ ,  $p = <.005$ ); the Sheffé test indicated that it was the gynaecological condition group which differed significantly from the others at the .05 level.

**Table 6: Measures of emotional health**

	Depression (BDI)	Self-esteem (ISE)
<b>Mean scores</b>		
Healthy group	5.735	29.234
Gynaecological group	8.241†	34.925†
Hysterectomy group	6.253	30.929
<b>Analysis of variance</b>		
F Value	11.244	6.481
F Probability	.0005	.0016

† significantly different at .05 level (Sheffé)

None of the depression measures approached clinical importance (a score over 10 denotes the possibility of clinical depression). However, the average self-esteem score for the gynaecological condition group suggests that at least some of them had clinically significant problems in this area.

**Sexual activity and satisfaction**

Women were asked about their participation in various sexual activities and about their levels of satisfaction. The hysterectomy and gynaecological condition groups were also asked whether satisfaction had increased, decreased or was unaltered since hysterectomy or the emergence of gynaecological symptoms.

Although problems of recall over time may reduce the reliability of some data, the majority of women who had undergone hysterectomy reported no change in satisfaction from all sexual activities. However, those who did identify a change were much more likely to report an increase in satisfaction than a decrease.

Similar proportions rated sex as ‘important’ or ‘very important’ for them (75 per cent, 83 per cent and 78 per cent for the healthy, gynaecological condition and hysterectomy groups respectively) and their levels of sexual activity were similar. Table 7 shows the average frequency of activities per month across the three groups. Only 3.4 per cent of women reported no activities at all. There were no statistically significant differences between the

**Table 7: Frequency of sexual activities per month**

	Healthy group	Gynaecological condition group	Hysterectomy group
Coitus	6.63	7.69	7.99
Other activities	5.43	5.74	4.46

groups. The results were somewhat surprising, considering the gynaecological condition group's clear identification of their conditions as subjectively affecting their relationship with partners and contributing to sexual avoidance. However, actual behaviour appears to have been unaffected. Their activity was, in fact, a little higher than the average.

## Discussion

Several remarks need to be made about this survey's design. Firstly, compared with other studies, the sample of 107 hysterectomy cases was not particularly large. Opit and Gadiel surveyed 826 women in 1982. Dennerstein, Wood and Burrows (1977) and Ryan, Dennerstein and Pepperell (1989) covered 89 cases in 1977 and 60 cases in 1989 respectively. In 1973, in the United Kingdom, Richards (1974) examined 200 women. However, none of these studies used an external control group to establish baseline data for emotional or sexual health amongst 'healthy women' and, more importantly, amongst those suffering from gynaecological conditions for which hysterectomy may be indicated. The three categories defined here are an imperfect representation of the states through which women may progress from health to gynaecological dysfunction to hysterectomy, but they are as close an approximation to them as a cross-sectional study allows. Surveys immediately before and after hysterectomy capture only the latter end of the process.

Secondly, the size of the survey and its nature imposed some limitations on its content. Because some very personal and sensitive information was sought, the women's participation had to be voluntary and their anonymity assured. Interview methods were therefore precluded as were any references to medical records or input by practitioners. The emphasis was on women's own experience and understanding, rather than on clinical documentation. The questionnaire aimed to elicit attitudes and feelings as accurately as possible but in familiar, non-technical terms.

Beyond the structured questions, respondents were invited to provide, in free form, any further information; about 70 per cent of women did so.

The results must be interpreted carefully, in particular, the women's very positive assessment of hysterectomy. Such high levels of approval could possibly be explained in conventional ways. The length of time since hysterectomy may have allowed side-effects or other adverse outcomes to either moderate or be accepted by the women. Most other studies have occurred at shorter intervals when long-term outcomes could not reasonably be assessed. Also, for their psychological well-being, some women may need to justify their acceptance of such a major and irreversible procedure by emphasising its positive aspects. However, their views were expressed in a comparative sense only. The relevant survey question (table 5) invited a choice between broad qualitative statements, not limited objective ones. In their supplementary responses, women with gynaecological conditions clearly identified the intensity of the symptoms from which they suffered and the impairments which these placed on both their private and public lives. The researcher was left with the strong impression that some conditions profoundly affect a woman's psyche. There is no reason to question the assessment of improvement after hysterectomy. However, this does not imply that all outcomes were favourable, only that they were better than the women's past experience. Some outcomes which have been posited as important by outside observers, such as bodily mutilation, appear to have ranked less highly in the respondents' minds.

Not all of the data were subjective. The measures of depression and self-esteem which have been widely validated showed significantly worse scores for women with current gynaecological conditions. It is a reasonable inference that hysterectomy improves them. Sexual satisfaction is clearly immeasurable objectively and activity levels are an unsatisfactory proxy. The difficulty of assessing such data is highlighted by the apparent contradiction between the clear perceptions of women in the gynaecological condition group that their sexual life had been adversely affected and the reported level of activities which showed them to be slightly above average. However, the causality is not always clear. Sexual frequency is not necessarily reflective of a woman's desire alone. For some, sex may be to please their partner or even, as is possibly the case of the gynaecological condition group studied here, a reassurance of their continuing capacity and attractiveness as a sexual partner. The reported levels of sexual activity provide no evidence of ill-effects from hysterectomy. These results are consistent with those of Ryan,

Dennerstein and Pepperell (1989) but not with all such studies and they are certainly not consistent with many popular beliefs.

In conclusion, this study showed that women who underwent hysterectomy were generally satisfied with the outcome. Most of them were also satisfied with their doctor's explanation of the procedure. About 21 per cent of the women with gynaecological problems had discussed possible hysterectomy with their doctors and three-quarters of those respondents were also satisfied with the information given. This does not necessarily mean that all relevant information was always available but it was sufficient for what most women believed to be an informed choice. By comparison, the women in the gynaecological condition group reported lower levels of well-being overall and their scores on the measures of depression and self-esteem were congruent with their subjective responses. Hysterectomy is, for many women, the end of a long, drawn-out and damaging experience and it is not surprising that a procedure which relieves symptoms so effectively is widely welcomed. The very positive response to it may be more a reflection of the alternative – a life of gynaecological problems – than a ringing endorsement of the procedure itself. Gynaecological illness has a special impact on sexuality and the sense of self. Its psychosocial and sexual dimensions deserve at least as much attention as its physical outcome.

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