RECOVERING FROM HYSTERECTOMY:

An exploratory study of how women manage following discharge from hospital

by

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Statement of Authentication

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in whole or in part, for a degree at this or any other institution.

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PLEASE NOTE

The greatest amount of care has been taken while scanning this thesis,

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DEDICATION

I dedicate this thesis to my family- husband Alan, two sons Marcus and Angus (16 and 19 years), who have suffered with me the agonies of developing research proposals and writing up data, who have missed many social outings because I was busy trying to put the ideas all together and who missed many hours of computer games because the thesis took priority over them. I love them all very much and am thankful they humored me in down times and rejoiced with me when things went well. I also dedicate this thesis to my mother, Lilian, who has had a long twenty two year battle with breast cancer and at the time of this writing has gracefully retired the field age 79, alert and still contributing to her social milieu with strength and spiritual support for others. Mum, I salute you.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES AND ILLUSTRATIONS

ABBREVIATIONS

Abbreviation	Expansion
ADL	Activities of Daily Living
ADLI	Activities of Daily Living Index
ACOG	American College of Obstetricians and Gynaecologists
ANZCOG	Australian and New Zealand College of Obstetricians and Gynaecologists
DDL	Demands of Daily Living
Gynae	Gynaecologist
HRT	Hormone Replacement Therapy
NSW	New South Wales
NUD*IST	Non-numerical Unstructured Data* Indexing, Searching and Theorising
Op	Operation
RCOG	Royal College of Obstetricians and Gynaecologists
SPSS	Statistical Package for Social Sciences
STAI	State Trait Anxiety Inventory
UK	United Kingdom
USA	United States of America

ABSTRACT

Ninety-six women, average age 47 years, who had a hysterectomy between October 1997 and June 1999 were initially interviewed in hospital and followed up for four months after discharge. The findings of the study indicate that adequate support was needed in the early recovery period and discharge programs should take into consideration the needs of women with small children and those who have no onsite home support. Women were discharged in a state of semi-dependency on others and had a higher level of pain affecting independence if they had an abdominal wound. Anxiety prior to discharge was higher in the under 50s age group and appeared to be related more to home conditions than the type of surgery. Women experienced complications more frequently in the first six weeks of convalescence, with urinary tract function and wound healing most likely to be affected. Strategies used by the women to assist convalescence included support from family and friends but little in the way of health professional or community support. The majority of women returned to normal activities by four months. Communication between women and health professionals was also considered by the women to be important following discharge, especially in terms of information and reassurance about their progress during recovery.

Chapter 1

INTRODUCTION

1.1 Hysterectomy: a life-change event

Hysterectomy is a commonly performed surgical procedure that impacts on many aspects of a woman's life. Removal of the uterus with or without conservation of the ovaries is often performed at a time when women may still be caring for children, be involved in paid employment outside the home and be required to care for ageing parents. In addition, women undergo hysterectomy because they are suffering from reproductive system dysfunction and, in many cases, unpleasant, sometimes debilitating symptoms for a lengthy period of time. Reasons women have the operation include symptoms caused by uterine fibroids, ovarian and uterine cancer, menorrhagia, endometrial hyperplasia and uterine prolapse.

Women's choice of treatment is influenced by the information provided by health professionals and sometimes by the stories from other women who have had a hysterectomy, or who have known someone who has experienced the outcomes of hysterectomy. While many women are happy with the results of the hysterectomy, some suffer adverse physical outcomes, such as sexual dysfunction, urinary and bowel continence problems or hormonal imbalances. These problems may be reported some years after the operation. Reproductive function is linked, in some societies, to the social definition of what it is to be a woman, and the removal of the uterus and ovaries may have an impact on a woman's self-image and understanding of her place in a particular society.

1.2 Changes in health care delivery

While recovering from hysterectomy women require specific attention at this particular time. Two factors contribute to this need. These are the current healthcare policy to decrease the length of time spent in an acute care setting following surgery, and the introduction of new surgical procedures that affect patient outcomes. As the Australian health system moves toward more acute care facilities, day stay surgical units and shorter hospital stays, the burden of caring for post-surgical and medically ill people falls more frequently on the family, and to a lesser extent, on community resources (Montalto 1996; Santamaria & McKenzie 2000). In New South Wales, transitional post-operative care is now being offered by health professionals in the person's home (Montalto and Dunt 1993). The person remains admitted as a patient by the hospital, but is cared for at home by nurses who visit on a regular basis.

The introduction of new technology that enhances the surgeon's skill and reduces the invasive nature of surgical procedures has been occurring since the 1970s. The use of the laparoscope to assist hysterectomy operations has resulted in an increase in laparoscopically assisted vaginal procedures and a decrease in the need for abdominal procedures (Lowell and Kessler 2000). The use of this technology is dependent on the medical diagnosis for surgery and it is now widely available in most metropolitan hospitals in New South Wales. When it is used the woman is usually permitted to go home within 72 hours of operation. In these instances, the recovery time at home is also shortened. Laparoscopically assisted vaginal hysterectomy is not always possible or appropriate, however.

Reduction in the length of stay in hospital has many positive benefits for lowering hospital costs, decreasing the incidence of iatrogenic complications and enabling women

to return to their normal environment more quickly. Resources required at home may include non-professional or professional help. However, if these are not available, or sufficient, to assist in managing normal responsibilities at home, earlier discharge may result in undue emotional stress and pressures to return to normal life before a woman is ready. Appropriate and relevant information to prepare women for surgery and convalescence is also needed so that anxiety about the surgery is minimised. The type of procedure, whether vaginal or abdominal, may also influence the level and type of support needed for successful recovery.

In the light of changes to health care delivery, it is important to explore the process of recovery for these women so that professionals within the health system are adequately informed regarding its processes. Data regarding the experiences of women following discharge may help to inform the discharge planning process for women while still in hospital and ensure that the support available to women following discharge is sufficient and appropriate. This knowledge is of interest to health professionals working in this area in implementing and evaluating current practices.

1.3 Recovering from Hysterectomy: an exploratory study in how women manage following discharge from hospital.

This study focuses on the progress of recovery for 96 women who have had a hysterectomy. The women were recruited from two major hospitals in the South Western Sydney Area Health Service, New South Wales: the Campbelltown Health Service and the Liverpool Health Service. The women were initially interviewed in hospital prior to discharge and followed up for a period of four months by telephone interviews. A final face-to-face interview was conducted at the end of four months.

The aims of this study are:

1. to determine the level of dependence of women on discharge from hospital following hysterectomy;
2. to describe the strategies and support structures (formal and informal) used by the women;
3. to discover whether or not these strategies and support structures have an impact on the women's health outcomes in terms of readmission to hospital, medical consultations, return to normal activities, and resumption of responsibilities e.g. childcare, home duties, employment;
4. to determine the women's satisfaction with the level of pre-and post-operative information and education; and
5. to explore the experiences of the women as they progress through convalescence.

For the purposes of the study 'support structures' refers to those physical and psychosocial human resources used by the women during recovery. These include physical and emotional care, preparation for discharge and access to professional advice. As the study was exploratory in nature, other relevant issues raised by the women are also reported.

The next chapter, Chapter Two, provides an overview of literature concerning hysterectomy procedures and the impact on women who have this surgery. Chapter Three deals with the research methods. In Chapter 4 differences between the women are analysed and comparisons are made between sub-groups such as: according to type of procedure; women with children under twelve; and women who live alone. In Chapter Five, the experiences of women, as reported in their diaries and open-ended questions section in the exit interview questionnaire, are analysed under specific themes. In Chapter Six, I attempt to draw the results together and present final conclusions.

Chapter 2

LITERATURE REVIEW

2.1 Introduction

This literature review focuses on the broad concepts in past research regarding the incidence of hysterectomy surgery in Western countries, the reasons why women have hysterectomies, the women's experiences and outcomes of surgery, and in particular how women view their experience. Many past studies have focussed on either the adverse psychological effects of hysterectomy, or the physiological benefits resulting from changes in surgical procedures that have occurred with technological change and an increase in scientific knowledge. Some recent researchers in the 1990s have attempted to identify the individual experiences of women who have hysterectomies and this has resulted in qualitative and phenomenological studies of specific groups of women. Prospective and retrospective studies of early discharge programs have also added to the amount of knowledge evaluating changes in treatment and care. In addition, some studies have identified the need for counselling and education of women prior to and following surgery. Very little has been done on the way women manage their hysterectomy experience while continuing to fulfil their social roles (e.g. as mothers, wives, employees).

For this review, quantitative and qualitative studies of women who had hysterectomy surgery for benign (non-malignant) reasons were obtained through electronic searches of MEDLINE 1966-2003, CINAHL 1998-2003, PsychINFO 1996-2003 and the Social Science Index, as well as through reference lists from research publications.

2.2 Incidence of hysterectomy

Since the 1980s hysterectomy has ranked as one of the most frequently performed surgical procedures in Western countries (Dicker *et al.* 1982; Kjerulff *et al.* 1992). A comparison of hysterectomies performed in Australia with those of the United States of America and the United Kingdom shows high prevalence rates in the former two countries. While it could be expected that rates would change over time, the literature suggests very little change in the rate has occurred over the last two plus decades.

Dicker *et al.* estimated in 1982 that over 33% of all women in the United States of America (USA) would have had a hysterectomy by the time they reach the age of 60 years. A study by Kjerulff *et al.* (1993), also in the USA, showed that the overall percentage of women with a history of hysterectomy differed from state to state, with a low of 14.2% in New York State to a high of 29% in Oklahoma. Kjerulff *et al.* (1992) also suggested that an overall incidence rate of over 30% would be reached if the current rate were to continue. More recently, another study estimated the prevalence rate for a hysterectomy in that country to be 25% (Reich 2001). Regional variations were also found in Canada between 1988 and 1991 with a rate of 6.25 per 1000 women overall (Hall and Cohen 1994).

Hysterectomy rates are reportedly lower in the United Kingdom (UK). In a longitudinal study of women in that country, Vessey *et al.* (1992) found an average rate of 11% between 1975 and 1989. This study is continuing and further reports may show change in this pattern over time. A study by Kennedy and Jones (2000) found a prevalence rate in the United Kingdom of 13.6%, and a further study by Marshall *et al.* (2000) showed that a hysterectomy rate of 10% in a cohort of women aged 43 years in the UK increased to 21% when the same cohort was followed up to the age of 52 years.

In New South Wales (NSW) a retrospective study, by Schofield *et al.* (1991), of 5 781 women aged 28-68 years, found a hysterectomy prevalence rate of 17% (n=976). In a national longitudinal study of 14 072 women across Australia, aged 45-50 years, a prevalence rate of 22% was reported by Byles and her colleagues (2000). The national survey figure does not reflect ages below 45 or over 50 years. It is possible that the actual rate is higher than 22% since women outside this age group were excluded. However the study does indicate a hysterectomy rate that is comparable with other Western countries, while not as high as the United States or as low as the United Kingdom.

In the past, observed differences in the rates of hysterectomy in different countries and regions have been related in part to the preference of individual medical practitioners (Roos 1984a; Kaspar 1985; Geller *et al.* 1996). Other factors affecting the rate for this surgical procedure have been suggested, such as low socio-economic circumstances, level of education and differences in health insurance provisions between countries (Roos 1984a; Markes & Shinberg 1997; Palmer *et al.* 1999; Harlow and Barbieri 1999). It could be assumed from the above rates reported that hysterectomies are performed less frequently in countries with universal public health schemes such as the UK and more frequently in the USA where there is a reliance on private health insurance schemes. However, even with a universal public health scheme in Australia, the incidence of hysterectomy remains high, so that other factors must be involved in the number of hysterectomies performed.

Alternative treatment options, such as hormone therapy and endometrial ablation for menorrhagia or dysfunctional bleeding (Grant and Hussein 1984; Bernhard 1994; Wren 1998; Lethaby *et al* 2001; Hurskainen *et al* 2001; League 2003) and uterine artery

embolization or myomectomy for uterine leiomyoma (Smith 2000), may also have resulted in a decrease in some countries. However it would appear that, despite these alternatives in treatment being available, the rate of hysterectomy procedures has not changed significantly in the past two decades (Cockey 2002).

2.3 Technological effects on the experience of hysterectomy

The most important change affecting the 'hysterectomy experience' for women in recent years may be the development of technology to assist the surgeon (Wattiez *et al.* 2002; Zupi *et al.* 2003). The use of the laparoscope, which makes it possible to perform a less invasive procedure than abdominal hysterectomy, reduces the overall physical trauma to a woman. Having a laparoscopically assisted vaginal hysterectomy or vaginal hysterectomy allows her to spend less time in hospital as an acute care patient. Generally this means 24-72 hours in hospital as opposed to 5-7 days (Reiner 1988; Browne and Frazer 1991; Boike *et al.* 1992; Stovall *et al.* 1992; Railton *et al.* 1994; Martin 1995; Wood and Maher 1995; Al-Fozan *et al.* 2002). Although not common practice, in some cases the laparoscopically assisted operation has been undertaken as an outpatient procedure (Moore 1988; Stovall *et al.* 1992; Bran *et al.* 1995) which avoids an admission to hospital altogether.

In addition, Helmkamp *et al* (1997) observed that a marked decrease in hospital stay from 12.8 days to 3.5 days was possible for women following radical hysterectomy with modification of surgical technique and the use of a critical care pathway. The reduction in length of hospital stay has been seen as a positive step in reducing the potential for post-operative complications such as deep vein thrombosis or pneumonia.

It also minimises contact with other patients, or hospital environment, both of which can be foci for cross infection, such as multi-resistant staphylococcus aureus (Youssif and Ledward 1993).

It can be argued that the cost to the health system for vaginal hysterectomy or laparoscopically assisted vaginal hysterectomy is somewhat greater due to the high medical technology involved (Browne and Frazer 1991; Minelli *et al.* 1991; Boike *et al.* 1992) and that some of the cost of care has moved to the family or community. A study by Van Den Eeden and associates (1998) found that costs were highest for abdominal hysterectomy and lowest in vaginal hysterectomy, however, outcomes for the women were best following a vaginal hysterectomy.

Having a vaginal hysterectomy through use of the laparoscope has had the effect of reduced time in recovering following discharge (Minelli *et al.* 1991; Boike *et al.* 1992; Clinch 1994; Railton *et al.* 1994; Wood and Maher 1995). Women who have had a vaginal hysterectomy reportedly have also been able to return to normal activities within 4-6 weeks rather than the usual 6-8 weeks following an abdominal procedure (Reiner 1988; Van Den Eeden *et al.* 1998).

2.4 Reasons for hysterectomy

In the 1970s, the American College of Obstetricians and Gynaecologists (ACOG), identified situations that determined the need for hysterectomy (Roeske 1978). These included:

> *emergency situations* e.g. intra-abdominal haemorrhage; *mandatory situations*, e.g. the presence of malignancy; *urgent situations*, e.g. abnormal uterine bleeding, which requires further diagnostic evaluation or definitive

> treatment; *advisable situations*, e.g. pelvic relaxation, as with stress urinary incontinence; and *elective situations*, e.g. surgical procedures... for family planning purposes. (Roeske 1978, page 484. Author's *italics*)

Today, professional criteria exist to make appropriate recommendations for surgical intervention although there is scope for an individual decision by the gynaecologist. The Royal College of Obstetricians and Gynaecologists (RCOG) in the United Kingdom and The Australian and New Zealand College of Obstetricians and Gynaecologists (ANZCOG) have guidelines to encourage best practice for the management of menorrhagia and endometriosis as well as other gynaecology conditions (Broder *et al.* 2000). These guidelines (RCOG 2002) advise the use of alternative means of management such as medical means and endometrial ablation for non-emergency conditions, with hysterectomy as a last option.

Treatment options are usually discussed between the gynaecologist and the woman prior to a decision for surgery being made. In some cases, women may see many different health professionals prior to having the hysterectomy (Dell and Papagiannidou 1999; Lees *et al.* 2001). In general, women expect improvements in health and well being from the particular treatment option they consent to. These expectations may affect the woman's level of satisfaction with the actual health outcomes following hysterectomy (Henderson 1995). In making the decision to have a hysterectomy a woman may take into account the experience and/or 'myths' gleaned from other women, as well as expert information provided by health professionals, usually doctors or nurses (Dell and Papagiannidou 1999; Groff *et al.* 2000; Wade *et al.* 2000). Neighbours, friends and relatives can provide information from personal experience and stories passed on from other women (Entwistle *et al.* 2001).

While these experiences and stories may colour a woman's ideas about having a hysterectomy, generally the main reason they seek medical advice is the often debilitating unwanted symptoms, for example, menorrhagia, pelvic pain, anaemia, tiredness and uterine prolapse (Treloar *et al.* 1999; Wade *et al.* 2000; Entwistle *et al.* 2001) that are frequently part of the gynaecology problems.

Treloar *et al.*'s (1999) study of 524 women found that persisting chronic pelvic pain and bleeding, or a combination of these, was the primary reason for deciding to have a hysterectomy (68%). Large uterine fibroids, prolapse, urinary dribbling or stress incontinence may also cause embarrassment or psychological distress in women (Treloar *et al.* 1999; Entwistle *et al.* 2001; Rannestad *et al.* 2001) and constitute reasons for surgery. Kjerrulf *et al.* (1992) cites a wide range of medical reasons for hysterectomy that includes emergencies such as uterine rupture during labour, and malignancy. However, 90% of hysterectomy operations are usually elective procedures. Clarke *et al.* (1995) found over half of 366 women in their study felt that they had a choice on whether or not to have the operation, even though less than a third had been offered alternative treatment. The decision to have the surgery in such cases is related to quality of life issues rather than an acute life-threatening condition (Clarke *et al.* 1995; Dell and Papagiannidou 1999).

For some women, hysterectomy may be the only considered option. Marchant-Haycox *et al.* (1998) found that expectations of an improvement in well being from having a hysterectomy caused some women to put pressure on their general medical practitioner for referral. This is also supported in a study by Salmon and Marchant-Haycox (2000) who found that women used manipulative strategies during consultations to effect an outcome they desired.

Entwistle *et al.* (2001) also found that often women considered hysterectomy fairly early in their experience of gynaecology problems. These women actively made an effort to persuade their general practitioner to refer them to a specialist and then to influence the outcome of consultations with the specialist (Entwistle *et al.* 2001).

Other factors identified in the literature suggest that the woman's access to private health insurance and her level of education may affect the decision she makes (Roos 1984b; Palmer *et al.* 1999; Harlow and Barbieri 1999). In an Australian study, Treloar *et al.* (1999) found that women who had a high level of education tended to choose alternative treatment instead of a hysterectomy in the first instance. Higher educated women also are more likely to be in higher socio-economic groups. Roos (1984b), Vessey *et al.* (1992), Kjerrulf *et al.* (1993) and Marks and Shinberg (1997) have reported that women who had a lower socio-economic status were more likely to have a hysterectomy than women in higher socio-economic groupings. This may be reflective of the poorer health status of the women, or the lack of access to medical treatment early in the illness, that results in the need for more substantive treatment. Alternatively, it may also reflect the women's desire for a more permanent form of treatment. However Treloar *et al.* (1999) found that social class on its own was not of statistical significance in women making this choice.

In Australia, medical care is influenced by the Medicare universal health insurance scheme and thus, socio-economic factors may not have as much of an impact on women's ability to access medical attention for gynaecology conditions as it does in some other countries.

2.5 Early discharge to home environment

Transitional care, earlier than usual discharge, and hospital at home programs have changed the hysterectomy experience for many women in recent times. In most studies reporting on these programs, the women show a high level of satisfaction with early discharge from hospital (Reiner 1988; Taylor *et al.* 1993; Hackman and Navaneethan 1993). The carer's satisfaction with early discharge is not always as high however, and this may be due to uncertainty regarding what to expect, and how to care for someone who is still partially dependent (Michels 1988). Other factors such as the shift of the physical and financial burden from the hospital to carers in the home may also affect this. In contrast, carers who feel adequately prepared for their role are often very satisfied with looking after acutely ill relatives, who required a range of medical treatments including intravenous antibiotics, in the home (Nixon 1991; Montalto 1996). Programs that include the support of medical and/or nursing staff for complex procedures and monitoring are more likely to obtain the support of non-professional carers (Nixon 1991; Montalto 1996).

In two studies, showing high level of satisfaction, women were selected for early discharge or transfer into a hospital at home program on the basis of good recovery while in the hospital, the presence of a support person fulltime in the home, at least for a short period of time, and adequate physical facilities (Taylor *et al.* 1993; Hackman & Navaneethan 1993). The exclusion of other women from these programs indicates the limitations of applying the results of such research to the general population of women having hysterectomy. It is important to develop appropriate selection criteria to identify those women who are likely to do well following a shorter hospital stay if these programs are to succeed.

Two studies of early discharge of women who had an abdominal hysterectomy and including a control group for comparison, were undertaken by Taylor *et al.* (1993) and Clarke *et al.* (1996) (See Table 2.1). The study by Taylor and colleagues (1993) identified outcomes over the two weeks following discharge. Women in the study group were discharged from hospital 3-4 days post-operatively, and those in the control group at the standard time of 5-7 days. A liaison registered nurse with expertise in gynaecology nursing was assigned to care for the women after discharge. This was in addition to normal community nursing assistance. Outcome variables included the onset of complications, referrals to medical officers or hospital, readmissions and number of contacts with the general practitioner and the liaison registered nurse. In comparison, the study by Clarke *et al.* (1996) compared outcomes over three months between women who were discharged at less than 5 days under normal discharge conditions, that is, no added support from nurses in the community, with those who remained in hospital for the standard length of time of more than 6 days. The findings of this study reported few differences between the number of consultations, readmissions and complications for the two groups of women and no differences that were statistically significant.

The success of the programs in terms of complication and readmission rates between the study group and control groups indicate that shortened hospital stay is acceptable to the women, and is possible for women who meet specific criteria regarding their well-being, post-operative recovery and home conditions. Taylor *et al.'s* (1993) study showed that, in spite of additional support provided at home by health professionals, the number of complications was greater in the study group. In Clarke *et al.'s* (1996) later study, despite no additional professional support being provided, the study group experienced fewer complications after discharge than the control group.

Table 2.1 Comparison of outcomes in two studies of women who had shortened length of stay after an abdominal hysterectomy.

Author	No. Women	Procedure	Professional follow-up	Complications
Taylor et al 1993 UK	50 (3-4 days)	Abdominal hysterectomy	Nurse visit: days 4,5,7,8,10,14	Study group: No. cases Abdominal pain (2); Vaginal bleeding (2); Wound haematoma (1); pelvic haematoma (1); urinary incontinence (1); bowel dysfunction, dysuria, offensive vag discharge, depression (8) Readmissions (2)
	22 (5-7 days)		Nurse visit: days 7,10 14	Control group: Urinary incontinence (1); Low abdominal pain (1); Dysuria, constipation, haemorrhoids Depression (1)
Clarke et al 1996 UK	112 (<5 days) 251 (>6 days)	Abdominal hysterectomy	Interviews: at 10 days; 6 weeks; 3 months	Slightly lower rate of urinary symptoms (32.3%), wound infection (14%), urinary infection (13.3%) and constipation than control group (figures not given)

In terms of satisfaction with the support following discharge, Taylor *et al.* (1993) found that this was high, in particular where women obtained support from health professionals during the two weeks of the study. In contrast, Clarke *et al.* (1996) found that, while most women were happy about the early discharge, 25% of women felt that insufficient professional advice and community support had been available during convalescence and this was more likely in those who were discharged less than five days after surgery. In addition, 25% of women felt at six weeks post-discharge that they had been sent home too early. Family support was at the same level for the normal discharge group (<50% had support at home) and this may have affected their feelings about being sent home early (Clarke *et al.* 1996). It would appear from these studies, that early discharge on its own does not necessarily lead to more complications, and the assistance of carers at home may be of greater importance than the health professional who visits infrequently.

Other studies have evaluated outcomes in early discharge following hysterectomy (Reiner 1988; Hancock &Scott 1993; Hackman & Navaneethan 1993, Ng & Hogston 1994) (See Table 2.2).

Table 2.2 Studies that included professional home support following hysterectomy

Author	No. of women	Type of procedure	Professional support	Complication incidence (no. of cases)
Reiner 1988 USA	40	Vaginal hysterectomy	Day 1: nurse for 5-12 hours	Nil related to surgery
Hancock & Scott 1993 UK	42	Vaginal hysterectomy	Day 1: visits x2 Nurse visits: daily for 7 days	Urinary Tract Infection (2); haemorrhage (1); abdominal pain (1); readmissions (2); mild depression (1)
Hackman & Navaneetha n 1993 UK	102	Major gynaecology surgery including hysterectomy	24 hour nursing care for 4 days; visit at 6 weeks	Readmissions (3): Vault haematoma, urinary retention
Ng & Hogston UK 1994	40	Major gynaecology surgery including hysterectomy	Day 2 or 3: district nurse; Day 3: telephone call; 2 weeks: visit	Minor phlebitis (2); dysuria (1); wound abscess (1); abdominal pain (1)

These programmes have included in their protocol the support of registered nurses, enrolled nurses or health visitors for a short period of time following discharge. Support amongst the women for these programs was high.

Most studies in the literature reviewed showed a high level of satisfaction with the early discharge program from the women and their carers. This was more evident in the studies where professional support, consisting of registered or enrolled nurses, health visitors and/or general practitioner, was available to the women in their own home (Reiner 1988; Taylor *et al.* 1993; Hackman and Navaneethan 1993; Hancock & Scott 1993), than in studies where it was not available (Clarke *et al.* 1996). It was noted that, in most of these studies, there were no control groups of women discharged early without

the additional support of health professionals in the first week in most cases. Only Clarke *et al. 's* (1996) study measured outcomes under usual discharge conditions of no formal support provided for women in the shorter length of stay group. Despite this, all studies showed a low level of complication rate and readmission to hospital, so it could be concluded that earlier than usual discharge from hospital is likely to be favourable for select patients.

2.6 Physical outcomes of hysterectomy

Recent studies report that most of the symptoms or problems women experience before the hysterectomy are resolved within a short time after surgery (Henderson 1995; Kjerulff *et al.* 2000b). In contrast to earlier studies, Carlson *et al.* (1994) reported that hysterectomy resulted in a marked improvement in a range of symptoms including pelvic pain, urinary symptoms, fatigue, psychological symptoms and sexual dysfunction in a group of 418 women. In addition to this, significant improvements in scores for indices of mental health, general health and activity were found during the first year following the operation (Carlson *et al.* 1994).

Linenberger (1996), in a phenomenological study of 65 women, found that physical symptoms and physical restrictions due to the operation were the main concerns for most women after discharge from hospital. These concerns were not in evidence six months after the hysterectomy. Many studies, however, follow the women's progress for only a few weeks or months. Several retrospective studies found that in the long-term women complained of other symptoms or problems they associated with the hysterectomy. The reporting of these symptoms may be as low as 15% of women (Carlson *et al.* 1994) or as high as 73% of women (Bernhard 1992).

The most common physical symptoms reported by women after surgery have been related to hormone function, bladder function and bowel disturbances (Gould 1986). Other physical symptoms reported by women included poor appetite, indigestion, constipation, tendency to gain weight, urinary frequency, infections, stress incontinence, hot flushes and dyspareunia, in addition to headaches, backache, dizziness, disturbed sleep patterns and tiredness (Richards 1973; Webb and Wilson-Barnett 1983a). For a small percent of women, post-discharge complications and readmissions to hospital may have affected satisfaction with the operation (Kjerulff *et al.* 2000a). It is suggested that education be provided regarding the transitory nature of many of these problems and what to expect in terms of recovery (Clarke *et al.* 1995).

A retrospective study of 236 women in New South Wales undertaken 2-10 years post-hysterectomy by Schofield *et al.* (1991) found that 59% of the women complained of continuing or new physical symptoms that they attributed to the operation. The most common of these were hot flushes, dry vagina and weight gain. This is supported by Henderson, (1995), who reported that over 50% of 370 women in a retrospective study complained about problems or symptoms they believed to be caused by the hysterectomy.

Bernhard (1992), reporting on a longitudinal study of 63 women who underwent hysterectomy, found that while short-term benefits to physical and emotional well-being were experienced by women following hysterectomy, by two years post-hysterectomy 73% of these women also reported unwanted symptoms that they related to the operation. These included emotional feelings of loneliness, depression, irritability, nervousness, or climacteric symptoms of 'hot flashes' and/or 'night sweats'.

However, many of these may also be related to the onset of menopause or symptoms related to ageing. In the longer term, links between the surgical removal of the uterus, or uterus and ovaries, with physiological problems including sexual dysfunction, continence problems and cardiovascular disease have been identified (e.g. Roos 1984b; Schofield *et al* 1991), however there is still some debate on the validity of this.

2.7 Psychological outcomes of hysterectomy

Hysterectomy in the past has been both blamed for, and used in, the treatment for psychological problems thought to relate to the uterus or menstruation (Raphael 1972; Roeske 1978). Psychological morbidity post-hysterectomy, such as diminished self-esteem and post-operative depression, have been identified by several researchers including Raphael (1972), Chynoweth (1973), Richards (1973), Stanfill (1982) and Lalinec-Michaud and Engelsmann (1984). Some thirty years ago for instance, Raphael (1972) found that women who have emotional problems prior to surgery did not show an improvement in these after the operation (Raphael 1972). However this may be due in part to the underlying problem, such as psychosis, rather than a depression induced by their gynaecological symptoms suffered before the hysterectomy (Jawor *et al.* 2002).

Some later studies differentiate between women with pathological depressive illness and those who are depressed because of gynaecology problems (Gath 1995). Pre-operative anxiety was found in a cohort study of 102 women referred to a gynaecology clinic for non-malignant problems (Salter 1985). Anxiety and depression levels in this group of women were significantly greater than in the general population sample of women of the same age. This study found that the depression measure correlated positively with complaints of heavy bleeding, whereas the anxiety measure correlated positively with long-standing painful menstruation. It would be expected that a cessation of debilitating

symptoms following hysterectomy would see an associated improvement in psychological state. This is supported by Ryan *et al.* (1989) in a prospective study of 60 women aged 30-55 years. The researchers found that for many women their mental status improved following the surgery with the improvement in physical condition and the cessation of embarrassing and unwanted symptoms (pre-operative psychological morbidity score = 55%; post-operative score = 31.7%). Clarke *et al.,* in 1995, found that depressive symptoms, in a group of 366 women, changed from 70% before the surgery to just over 15% three months after surgery. Gath *et al.* (1995) also found that psychiatric morbidity fell significantly after hysterectomy (58% before; 26% after).

Anxiety in some women may be related to misconceptions about difficulties in sexual functioning, loss of femininity or sexual attractiveness and loss of childbearing capability (Dennersten *et al* 1977; Warrington and Gottlieb 1987; Bernhard 1992; Rhodes *et al.* 1999; Dell and Papagiannidou 1999). Although other researchers (Elson 2000) have found that social factors were more important to older women, pre-menopausal women in her study expressed feelings that their loss of fertility did impair their gender identity. Women have also expressed fear that the operation will make them unattractive, fat and old (Webb and Wilson-Barnett 1983b). The link made by some women, between the uterus (the 'womb') with 'femaleness' in terms of fertility and ability to bear children, may contribute to their anxiety concerning outcomes (Bernhard 1992; Dell & Papagiannidou 1999). Anxiety levels can also be associated with the woman's family situation, which may include many responsibilities and in some cases not very much support. Hudson (1995), in a study of 100 women, found that satisfaction with support from family members and friends affected anxiety and depression scores, with low satisfaction related to high scores.

Psychological depression experienced by some may also be related to their medical condition and the diagnosis. It would be expected that women who have a diagnosis of cancer would be more likely suffer from depression than women who do not have a malignant condition. An extensive literature review of randomised control trials and prospective cohort studies by Carlson (1997) concluded that pre-operative symptoms of depression and anxiety improve for the majority of women in the year following hysterectomy, particularly when the operation is undertaken for benign reasons (e.g. endometriosis or fibroids).

The different findings in the literature in regard to psychological outcomes, have been explored in a review by Khastgir *et al.* (2000). The review indicated that retrospective studies consistently reported adverse psychological outcomes of hysterectomy, while prospective studies showed that for many women psychological symptoms actually improve. This was partly due to the relief of distressing symptoms and the correction of any ovarian hormone deficiency. Webb and Wilson-Barnett, (1983a), also found that the majority of women in their study were very happy with the results of the hysterectomy, and depression levels were reduced as a result of improvement in health. Prospective evidence is more likely to reflect an accurate record of events, and overall, these results suggest there is likely to be an improvement in health and well being for most women following surgery.

2.8 Dependence on others

While the level of dependency at which women are discharged from hospital following hysterectomy is not something that is usually formally measured, several studies in the United Kingdom included an assessment of some activities of daily living (Taylor *et al.* 1993; Clarke *et al.* 1996). By using an Activities of Daily Living Index (ADLI) for

assessing women prior to surgery, and at ten days, six weeks and three months post-operatively, Clarke *et al.* (1996) found a sharp increase in the ADLI measurement score at 10 days and 6 weeks indicating a voluntary restriction in activities. Formal measurements of ability to perform specific activities/demands of daily living (ADL/DDL) are more frequently found in assessment of the elderly (Seeman *et al.* 1994; Ashworth 1994; Ensrud 1994) or rehabilitating patients (Keith 1984; Binnie 1985). ADL rating scales are used in the assessment of the person's functional ability in responding to changing needs within the environment, as well as the ability to perform set tasks (Keith 1984). A study of stroke patients by Shiekh *et al.* 1979, showed that assessment of ADLs in the hospital and home settings were highly correlated (0.96)). This showed that an assessment of function within a hospital setting was an accurate way of determining whether a person would be able to self-care when discharged to the home.

In assessing a person's readiness for discharge following surgery it is more usual to emphasise assessment of physical function (mobility, bladder and bowel function, eating and drinking) than the patient's level of pain, strength and energy, mood states and knowledge level (Schaefer *et al.* 1990). The latter criteria are as important for the assessment of women who have had a hysterectomy as for other surgical conditions (Simpson *et a.l* 1977; Fleury 1993; Reiner 1988; Taylor *et al.* 1993; Hackman and Navaneethan 1993; Titler and Pettit 1995; Clarke *et al.* 1995). Many women leave acute care settings very soon after surgery, in some instances within 24 hours (Reiner 1988; Railton *et al.* 1994; Martin 1995; Wood and Maher 1995), and it is reasonable to suggest that a formal assessment be made of the woman's ability to self-care, and include the level and type of support that she may require in the early stages of convalescence. Webb (1986) expressed the view that women who did not work outside the home were more likely to need support from nurses after discharge due to relative isolation from

other sources of support, such as work colleagues. This may refer to reassurance rather than actual physical care.

Other research has focussed on assistance provided by family members, relatives and others, and this has shown that the frequency and level of care obtained from this source depends on the carer's knowledge of the woman's needs (Montalto 1996). Webb and Wilson-Barnett (1983b) and Lees *et al.* (2001) found that the level of social support from the woman's partner was very important to women recovering from hysterectomy. However, in over 50% of cases, the partner's communication concerning feelings about the operation was minimal (Webb and Wilson-Barnett 1983b). These authors found that positive support from the woman's partner was associated with better outcomes on interview items related to physical health, resumption of activities and self-expressed satisfaction with recovery. In addition, support from friends had a positive impact on the woman's feelings of health and well being compared to those who were not so well supported. In a study of 22 married couples, Bernhard *et al.* (1997) also found that frequent lack of, or poor interpersonal communication between the woman and her partner had an effect on the woman's experience following hysterectomy.

In a study of 17 focus groups with 83 women, Richter *et al.* (2000) found that the women felt that their partners lacked essential knowledge regarding what had been done in the operation and how she was feeling. Similarly, Williams and Clark's (2000) study of 38 women, found that many male relatives were non-supportive. They concluded that the women's families needed current and appropriate information about hysterectomy in order to care for them appropriately.

2.9 Preparation for surgery through education and information

Several researchers have noted that women and their families expect expert knowledge and understanding from health professionals working in the area of gynaecology (Raphael 1972; Webb and Wilson-Barnett 1983b; Bernhard 1992; Lipman 1996) and recommended that appropriate education be given prior to discharge. Patient education, as a means of preparing persons for treatment and discharge, has been widely implemented by health services and individual medical practitioners as a necessary part of pre-operative consent and discharge planning. This has been offered, in particular, to persons who have functional deficits, e.g. the need for assistance to bathe, dress, toilet or transfer (Bowman *et al.* 1994). It is also used to provide information regarding specialist follow-up visits and medication requirements. Specific target groups, such as cardiac patients (Fleury 1993) and the acutely ill aged (Haddock 1994; Bowman *et al* 1994) in particular, have been identified for educational preparation for discharge due to their need for compliance with medication and activity regimes.

Traditionally, education of patients about their condition has often been fragmented because it involved a range of professionals. Social workers were involved in providing information about post-hospitalisation services; nurses were involved in terms of what to expect during hospitalization; and doctors provided specific information regarding treatment and surgical procedures. Schuman *et al.* (1976) and Haddock (1994) have argued that such fragmentation of educational preparation for discharge often results in confusion, anxiety and non-compliance of the patient. Frequently, confusion also existed amongst health professionals about their role in providing information.

In the United Kingdom, continuing contact with registered nurses who have gynaecological expertise has been advocated to meet the needs of women following

discharge after hysterectomy (Hancock & Scott 1993; Taylor *et al.* 1993; Ng & Hogston 1994). In the United States, Brooten *et al.* (1996) advocated the use of Masters prepared specialist registered nurses in the after discharge care of women. The obvious advantages that have been identified relate to accessible health professional consultation, continuing education and counselling, and an easy access to hospital if readmission becomes necessary.

The use of educational programs prior to and following discharge has been recommended as a means of meeting the needs of these women (Dulaney *et al.* 1990). The knowledge women acquire about the operation and its effects can assist them to manage their convalescence in ways that benefit their recovery. As early as the 1970s, Schuman *et al.* (1976) noted that 80% of 60 patients required some teaching regarding their illness during hospitalization. Patient teaching included increased awareness of the diagnosis and/or the necessary precautions or warning signs related to the diagnosis or treatment, the person's knowledge of medication and when to take it, an understanding of dietary requirements and who to call if assistance was required after discharge. According to Schuman *et al.* (1976), knowledge deficits were found in one or more areas of patient education in 14% of the control group and 32% of the experimental group. In addition, 14% and 7% respectively were found to have incorrect knowledge in the areas covered.

In a prospective study of 40 women, Cosper *et al.* (1978) found that it was not uncommon for the woman's individual questions and concerns to be unmet due to lack of time for discussion during acute hospitalisation and lack of available expert advice post-hospitalisation. However, while over 75% of women in Cosper *et al.'s* (1978) study reported that they had adequate information concerning the hysterectomy; just over

30% suggested that additional written information to refer to at home was preferred. In another study Webb, in 1986, found in interviews of women undergoing hysterectomy that there was a need for basic information about the operation. It would appear from these studies that education of women undergoing a hysterectomy is not uniformly consistent and is still a current issue, and the individual needs of women should be addressed when initiating pre- and post-operative education.

The type of information needed, identified by patients such as post-cholecystectomy and post-herniorrhaphy, included what foods to eat, what activities they could do and how often, what measures to implement for discomfort, and what they should consider normal or abnormal in regard to physical changes post-surgery (Leyder and Pieper 1986). The most frequent concern was in relation to physical activity in what they could and could not do. As was the case with women who had a hysterectomy, these researchers concluded that written information that the patient could refer to at home should be made available to them prior to discharge.

The patient's ability to vocalise concerns and express anxiety to health professionals was found by Leyder and Pieper (1986) to be affected by prior education, as well as gender and age. In their study, the researchers found that patients who had a higher education level (college and above) expressed higher anxiety levels prior to discharge compared to others. They concluded that these patients were better able to articulate their concerns to the nurses and doctors, than those with a lower level of education. For many women, particular concerns about changes in physical functioning may be difficult to articulate (Bernhard 1992). These concerns may be factors that impact on the progress of recovery, and it is important that women be encouraged to voice these to professional staff while still in hospital.

In a study of 144 women from two hospitals, Webb and Wilson-Barnett (1983a) reported that approximately 15% of 102 women (hospital A) and 14% of 42 women (hospital B) said that no-one had explained the operation to them. Four months later, approximately 22% of 95 women from hospital A, and 15% of 33 women from hospital B, reported that they could not remember any advice on convalescence being given to them prior to discharge, although 49% of respondents from hospital A had been given an information leaflet. It is interesting to note that a later study by Scriven and Tucker (1997) found that many pamphlets given to patients were not informative about the later stages of recovery from hysterectomy, and the information was presented poorly. This suggests that written information may not always be understood by patients and, by itself, may not be sufficient to inform them.

It has been noted that patient education plays a part in relieving pre-and post-surgical stress and improving patient outcomes in terms of complications and consultations after going home (Young and Humphrey 1985; Scriven and Chesterton 1994). The use of pre- and post-surgical education programs for groups of women undergoing hysterectomy benefits them when they are informed about aspects of the surgical procedure, what to expect during hospitalisation and, if they are given the opportunity, to discuss their own concerns (Dulaney *et al.* 1990). This suggests that more time is needed for patients who have problems in articulating their concerns than is currently being made available for this purpose. A study by Graff (1995) found that follow-up during recovery by expert nurses allowed the education needs of women to be met in a timely and appropriate manner. Education needs most frequently sought by these women related to their surgical wound and to activity levels. It would appear that personal follow-up by health professionals, as well as written material to inform women, is needed in some cases following hysterectomy.

2.10 SUMMARY

Hysterectomy remains one of the most common surgical procedures performed in Western countries, including Australia. Development of new technologies and alternative treatments have changed the experience of many women, but have not significantly affected the number of operations performed. Ninety percent of hysterectomies are performed as elective procedures. Relief of unwanted symptoms such as menorrhagia, tiredness and pelvic pain is the most common reason for women seeking treatment. Some women actively seek the surgical option despite other available treatment. From a medical perspective, the most common diagnoses leading to hysterectomy are fibroids, endometriosis and uterine prolapse. Factors such as socio-economic status, level of education and access to health insurance have been found to affect the decisions women make.

Formal assessment of the level of dependence at discharge following hysterectomy is not standard practice, but has been included in several early discharge programs. Assessment prior to discharge is narrow and focuses on physical recovery, e.g. wound status, bladder and bowel function. Most studies have found that women are discharged from hospital in a semi-dependent state and that care will be provided for a short period of time by relatives or friends. Studies evaluating early discharge programs and hospital-in-the-home programs included follow-up by health professionals during the immediate post-discharge period in most cases. The findings show that satisfaction with these programs is high when they have professional support included.

Research findings show that lack of support from family impacts negatively on women's experience. This is often due to poor understanding on the part of the woman's partner, of the woman's needs and the effects of hysterectomy. Several studies found that

insufficient detailed information was provided to women, explaining the procedure and the potential outcomes. Studies also found that if carers are better prepared prior to early discharge, a higher level of support is reported.

While research shows that the majority of women find an improvement in their health and well-being as a result of hysterectomy, some studies have found that a small number of women express anxieties regarding physiological changes resulting from the operation. Early studies have identified adverse psychological effects of the operation, however more recent studies have shown this not to be so. For example, pre-operative depression and anxiety decreases post-operatively in most cases, with the cessation of symptoms. It is suggested in the literature that patient and family education has a vital role to play in relieving pre-and post-surgical stress and improving outcomes for women after discharge.

Chapter 3

MATERIALS AND METHODS

3.1 Introduction

The purpose of this chapter is to describe the study design, sample population, data collection and statistical methods used in analyzing and describing the data. This chapter also deals with ethical aspects of the study and the preparatory stage, and provides a comprehensive description of the tools used. Finally, an explanation is given of the organisation of the results and their presentation.

3.2 Study design

A prospective exploratory design was used for the study. Two major hospitals, Campbelltown and Liverpool Hospitals (Health Services) located in the South Western Sydney Area Health Service New South Wales, were chosen because of the number of hysterectomy operations performed annually, and the region's importance as a growth centre. Verbal information from the Director of Nursing at each hospital suggested that the numbers of hysterectomy cases totaled approximately 300 in any given year[1] (personal communication 10/5/96). The project was discussed with the two Directors of Nursing and the Medical Director of Women and Children's Health services for the South Western Sydney Area Health Service. Support for the project was received from the gynaecologists at the Campbelltown Health Service and the Liverpool Health Service. The study provided a means of assessing the needs of the women in their care.

[1] The majority of these were undertaken for benign (non-malignant) reasons.

3.3 Participants

Ninety-six women undergoing hysterectomy surgery at two major metropolitan hospitals in Sydney were enrolled in the study between October 1997 and June 1999 (Appendix 1). The majority, 68%, were from Campbelltown Health Service. The women were followed up for a period of four months. While the group of women constituted a 'convenience sample' of women drawn from the two hospitals, this number did not reflect the total number of women who had hysterectomy surgery during the life of the project. Approximately 25% of women who were approached regarding the project declined to participate. Women were excluded from the study if the initial diagnosis was of cancer of the reproductive organs as it was considered that the recovery process and level of intervention would be different from other women.

Initial contact with prospective participants was made through either the pre-admission clinic or the gynaecology units of the hospitals. The Campbelltown Health Service admitted all women via the pre-admission clinic. Identification of suitable participants was made with the assistance of the nurse unit manager in this location. In the case of Liverpool Health Service, the initial contact was made with women in the gynaecology unit following the operation and acute recovery phase. The 'Participant Information Sheet' was translated into the Chinese language as this group was more representative in greater numbers of women in the Liverpool area than other ethnic groups and it was thought could provide some comparisons in the study. A small number of women who did not speak English were approached with the assistance of an interpreter but declined to participate.

A number of factors influenced the enrolment of participants in the study sample. These included communication problems of when admissions to the hospital had occurred[2]. In addition, the large number of women who had laparoscopically assisted vaginal hysterectomies performed as day surgery procedures, and the short length of time (48-72 hours) spent in hospital meant that some potential participants were missed. Overall, this had the effect of increasing the time needed to obtain a sample size considered to be sufficient for statistical analysis. It also resulted in the initial interview for two women, whose hospital stay was less than 72 hours, being undertaken at their homes within 24 hours of discharge.

The difference in length of hospitalization between women who had a vaginal hysterectomy compared to women who had an abdominal hysterectomy provided an opportunity to compare the outcomes for these groups of women (vaginal hysterectomy n=49; abdominal hysterectomy n=47). In addition, women who had children under the age of 12 years and women who lived alone were considered to have different needs to other women. These groups were identified in the data and compared to other women in terms of age, anxiety levels, complications, and satisfaction with support provided.

3.4 Data Collection and Measurement Tools

Data were collected over the first four months of recovery for each woman. A research assistant, who was a registered nurse, with experience in gynaecology nursing, 1-2 days prior to the woman's discharge, administered the initial questionnaire (Appendix 2). This questionnaire included the state anxiety set of twenty questions from the State-Trait Anxiety Inventory (STAI) that was filled in by the participant (Appendix 3). Additional

[2] The protocol for advising of admissions failed in some instances.

information, including medical diagnosis, type of procedure, any additional procedures, complications and length of stay in hospital, was obtained from participants' medical records at the same time as the initial interview (Appendix 4).

Follow-up by telephone questionnaire was made at one week post-discharge and then at monthly intervals for four months (Appendix 5). A final questionnaire was administered in person at the end of four months (Appendix 6). In addition to the questionnaires, all women were invited to keep a diary of their experiences when they went home (Appendix 7). The diary pages were provided before discharge to those women who agreed to do so. Each month additional pages were mailed to them. They were asked to mail what they had written back to the University at the end of each month. A self-addressed pre-paid envelope was provided for this purpose.

3.4.1 Questionnaires

The initial questionnaire focused on collecting demographic, personal, medical and socio-economic data, in addition to an assessment of ability to perform selected activities of daily living. Organised follow-up appointments with specialist or hospital clinic were recorded.

In the telephone interviews the women were asked to:

- identify from a list of activities those they had been able to perform that week;
- select from a list of activities those for which they received assistance that week, and to indicate who provided the assistance;
- report on the degree of pain experienced using a visual analogue scale, and to identify what medication, if any, they had taken for the pain;

- select from a list of options that which best described their feelings and emotions on that day;
- indicate if they had consulted a health professional that week, and to provide some details about any such consultation;
- indicate whether there had been any unexpected negative or positive result that they attributed to their operation, since the last interview.

The final interview, four months after discharge from hospital, was conducted face to face at a location of the woman's choice, usually her home or another location such as a cafe. Apart from information regarding physical recovery, this interview provided the women with the opportunity to express their own thoughts regarding how their families had responded to their situation, and give advice for other women. Three open-ended questions were included in the exit interview. The questions were designed to elicit information regarding the woman's perception of family members' knowledge and understanding about the effects of hysterectomy and how the level of understanding affected their expectations of what the woman could and could not do. Other questions probed the women's level of satisfaction with information provided by health professionals in relation to diet, wound care, feelings and emotions, activities to avoid and when to return to work. The same measurement of dependence in specific activities of daily living was used in the initial and final questionnaires.

3.4.2 Measurement tools

Different tools were included in the questionnaires to measure pain, dependence and anxiety. These were:

1) A visual analogue scale using measurements from 1-10 (1=nil, 10=severe) to allow a self-reported level of pain to be recorded. The visual analogue scale is commonly used in health care practice, for example, palliative care and surgical units, to determine the subjective level of pain experienced by the patient at any given time. It has also been used in research on arthritis sufferers (Simeoni *et al* 1994);

2) A six-level response measurement, developed for this project, to identify the level of dependence in specified activities of daily living in the initial and subsequent interviews;

3) The State-Trait Anxiety Inventory (STAI) score to measure anxiety. This is a scoring system that provides objective self-reporting measures of both state and trait anxiety and was developed by Spielberger, Gorsuch & Lushene (1970). Low scores indicate a calm acceptance of the situation. Intermediate scores indicated moderate levels of tension and worry; High scores indicated intense fear (Speilberger and Krasner 1988). The state anxiety score was applied in the baseline interview and final follow-up interview to determine the level of anxiety experienced by the women at the time of the interview. The two state anxiety scores were compared and related to other aspects of the woman's situation in the final results. Trait anxiety was not examined, as the variable of interest was women's anxiety related to their immediate circumstances. The level of anxiety may be related to the support anticipated by the women and the actual support accessed. Other factors related to the individual woman's situation in regard to health outcomes, dependents, normal responsibilities and support available during the recovery period might also contribute to anxiety.

The State Anxiety questionnaire measures the woman's feelings at the time of interview. The Trait Anxiety questionnaire is related to a normal response, with respect to anxiety, that should not change according to circumstances. When used together, the responses are given a value and added to form a summative score for each part of the scale. Either score may be used alone if preferred, as in this study. According to Spielberger *et al.* (1970), studies of college freshmen and high school students indicated that the scales had content, concurrent and construct validity which compare favorably with other published measurements of anxiety.

The STAI anxiety scoring system was also used by Lalinec-Michaud and Engelsmann (1984), in a study of 53 women who had had hysterectomy for benign reasons, and by Warrington and Gottlieb (1987), in comparing the relationship between uncertainty and anxiety in a study of 20 women who had total hysterectomies. In the study by Warrington and colleagues (1987) the women completed the STAI on day one pre-operatively, and days 3 and 6 post-operatively. It was found that the state anxiety score decreased by day 6 following surgery, as would be expected with return to normal anxiety levels with time.

3.4.3 Personal Diaries

All women enrolled in the study were invited to maintain a personal diary of their experiences for the duration of the project. Ten women agreed to do so. However, one woman ceased writing after four weeks and two others were still recording at nineteen weeks. In order to maintain confidentially, pseudonyms were used for

reporting on the women's views and comments in chapter 5. The data beyond the four months was not included in the analysis of trends.

There were two aspects to the diary. Firstly, women were asked to write about their experiences and feelings, and about the quality of interactions with significant others during their convalescent period. Secondly, they were asked to respond to semi-structured questions that focused on particular aspects of their convalescence. These questions included:

- how do you feel today?
- have you sought medical help this week?
- have any of the following people given you assistance this week – spouse/partner; children; relative; friend; community help; other?
- have you had difficulty in performing the following activities of daily living – washing, cleaning, driving, childcare, gardening, shopping, cooking, other?

Participants were asked to write a minimum of one entry per week on pages provided for them and to post them back to the researcher once a month in a pre-paid addressed envelope. Each month, around the time of the next telephone interview, the women were sent more pages. They were invited to write as much as they wished and to add pages if needed.

Diaries have been used in research studies (Marino *et al.* 1999) as a means of obtaining rich qualitative data that is less influenced by the researcher than face to face questioning. Moreover, participants are able to reflect on feelings and events as they occur, which provides a more accurate record of their experiences than events remembered from a distance some time later (Marino *et al.* 1999).

3.5 Data Analysis

Statistical analysis of the quantitative data from the face-to face questionnaires and the telephone interviews was done using the SPSS program (Version 11). Analysis of the qualitative data, from the final questionnaires and the diaries, was done using the Non-Numerical Unstructured Data *Indexing Searching and Theorizing (NUD*IST) program (Richards 1998).

3.5.1 Quantitative data analysis

Demographic data was identified for all women, and means calculated for appropriate variables, otherwise proportions are reported. In order to compare differences, the data was grouped according to the type of procedure, i.e. vaginal or abdominal hysterectomy. Further sub-group comparisons were made, by grouping women who had young children living with them, and women who lived alone. Women with young children were compared with women who did not have young children. The women were compared, within the sub-group and as a sub-group with the rest of the wider group, using statistical analysis that calculated the mean difference for continuous variables, and differences between proportions for categorical variables. Statistical significance was assessed using two-sample t-tests for continuous variables, and chi-square tests for categorical variables. The level of statistical significance was set at the 5% level for these analyses.

3.5.2 Qualitative data analysis

The diary entries were grouped according to the week following discharge so that progression of trends could be readily observed as the women's health improved. Prior to analyzing and presenting the data, the information was grouped according to themes identified in the issues raised by the women. The NUD*IST program (Richards 1998) was used as the potential to code chunks of data made the grouping

of issues and concepts easier. Various ways of coding the data were considered. Initially concepts were identified without links to specific weeks of recovery, however this was found to be less helpful than at first anticipated. In managing the data an assumption was made that over time the women's needs, feelings and activities would change during recovery as a result of their improved health status. In view of this, the concepts and issues were linked to specific time frames following discharge. In this way differences in experiences between the women were more readily identified.

3.6 Ethical considerations

Ethics approval for the project was sought and obtained from the Ethics Committee, Research and Development Unit of the South Western Sydney Area Health Service and the Ethics Committee of the University of Western Sydney.

Prior to initial interview each woman was provided with information on the aims and objectives of the research project. A consent form indicating agreement to be interviewed, and an understanding that the participant could withdraw from the project at any time, was completed and signed (Appendix 8). Respondents were given a code number that was used as an identifier for the questionnaires and interviews, as well as for the diaries. At the initial interview a record was made of the name, address and phone number of the participant, with the corresponding code number, so that ongoing contact could be maintained. This identifying information was kept separate from the data set and was not recorded electronically. Participants were assured of the confidentiality of the information they provided, and that all data collected were kept in a locked cabinet at the University of Western Sydney, accessed only by the principal researchers.

3.7 Preparatory stage and training of research assistants

A protocol for identifying potential participants and notifying the researchers of admissions was developed in conjunction with the staff in the pre-admission clinics and gynaecology units of each hospital. (Appendix 9) The protocol included, where appropriate, the woman's expected admission date or actual admission date and the anticipated discharge date, as well as how the registered nurses in the unit could notify the interviewer. Three registered nurses, experienced in gynaecology nursing, were interviewed by myself (as an experienced interviewer) and oriented to the aims and objectives of the project, the protocols to follow at the relevant hospital, and the use of the questionnaires so that they could assist with the administration of the questionnaires. Issues of ethics, such as confidentiality and doing no harm, were discussed during these sessions. Additional instruction was also provided in handling situations where women identified problems during the interview that had the potential to impact on their physical or emotional wellbeing. It was considered that some women might experience problems, anticipated or not anticipated, or become distressed about the short-term outcomes of the hysterectomy and require referral back to their general practitioner or the hospital services. While it was important to maintain objectivity in data collection, it was also considered that the registered nurses interviewing the women had a duty of care to ensure that appropriate referral was initiated in these situations. In two cases, after discharge, the interviewer identified the need to suggest to the woman that she consult with a medical practitioner regarding her problem. In another instance, the woman had already sought counseling before revealing her problems to the interviewer.

The registered nurses assisted with data collection and interviews at different times during the course of the project. Potential participants were identified by registered nurses at the admission clinic and gynaecology units of the hospitals, and then visited by

the registered nurse who explained the study and invited the women to participate. The registered nurse also provided the consent form and explained this prior to the women signing. One other person assisted with data entry.

3.8 Organisation of Results

The results of the analyses are organised into two chapters. The results of the quantitative analysis are presented and discussed in Chapter 4. The results of the qualitative analysis are presented in Chapter 5. Tables and figures are used where necessary to illustrate comparisons between the groups and identify more clearly the results of the study. In the final chapter I present the discussion of the overall results with recommendations arising from the study.

3.9 SUMMARY

The design of this project included both quantitative and qualitative data. The inclusion of both these was felt to be essential to the purpose of providing a broad picture of the women's experiences. The use of demographic information and baseline information is easily compared using statistical methods. Less structured data from open-ended questions and diary entries permits consideration of the women's opinions, feelings, observations and experiences that enrich the data and facilitate understanding of the phenomenon of hysterectomy.

Chapter 4

RESULTS - QUANTITATIVE DATA: Women Participating in the Study

4.1 Introduction

In this chapter the results from the analysis of quantitative data from the initial interview, the telephone interviews and the exit interview are presented. The results include a description of the women according to their demographic and social characteristics, hysterectomy characteristics and post-discharge experiences. The demographic and social characteristics include the hospital at which the surgery was performed, age, pre-existing health problems, family composition and employment status. The hysterectomy characteristics include medical diagnosis, type of procedure and additional procedures undertaken at the same time, immediate post-operative complications, length of hospital stay, level of pain, and areas of difficulty in performing activities of daily living. In regard to women's post-discharge experience: the number of consultations, complications and readmissions over four months, the support accessed during convalescence, the women's satisfaction with information provided by health professionals, their state anxiety at initial and exit interview and their return to normal activities, are presented.

4.2 Demographic and Social Characteristics

4.2.1 *Study Population*

Ninety-six women from two hospitals were enrolled in the study following hysterectomy between October 1997 and June 1999. Sixty eight percent of the women were recruited at Campbelltown Hospital and 32% from Liverpool Hospital. The participant response rate varied during the four months follow up period with 70% (n=66) response within two

weeks of discharge and 77% (n=74) response at four months. The response rate at two and three months post discharge varied between 54% and 43%. Because of the varied response rate, some results are based on different study population numbers as indicated in the text.

4.2.2 *Cultural Diversity*

The majority of the women identified themselves as Australian with English as a first language. Thirteen percent identified English as a second language, which was expected given the multicultural nature of the South Western Area of Sydney. Cultural backgrounds were diverse with a small number of women identifying different ethnic or national groups such as Italian (4%), Chilean (3%), Indian (3%), Maori (2%), Danish (1%), Croatian (1%), Serbian (1%), Dutch (1%), South African (1%), Macedonian (1%), Maltese (1%), Vietnamese (1%) and Greek (1%). Analysis of trends according to cultural differences was not possible due to the small number of women in each group. Twenty three percent of the women from Liverpool Hospital identified English as a second language compared to only 8% of women from Campbelltown Hospital. This was expected given the high non-English speaking population in the Liverpool area.

4.2.3 *Social Situation*

Eight percent of women lived alone, 75% lived with a spouse or partner and 3% had a parent living with them. While 68% lived with children, over 63% of these had more than one child with ages ranging from one year to twenty-nine years. The average number of children living at home was 2.5 (SD 1.4, range 1-9 children), with 15.5% of the 68% of women having more than three children at home. Thirty-one percent of women had children less than twelve years of age (43% of women who had vaginal hysterectomy and 48% of women who had an abdominal hysterectomy). Less than 20% of the women held membership in a private health care fund.

4.2.4 *Age*

The women in the study ranged in age from 32 to 79 years, with a mean age of 47 years (SD 10.5 years). Of 94 women for whom both type of procedure and age was recorded, those who had vaginal hysterectomy were significantly older than those who had abdominal hysterectomy: 50 years, compared with 44 years. The mean age difference of 6 years was statistically significant at the five percent level (t=2.911 df=92 p=0.005). Women who had children of less than 12 years of age, ranged in age from 33 to 48 years, mean 39 years, SD 3.8; compared to other women mean 50.3 years, SD 10.6. The mean age difference of 11.5 years was significant at the 5% level (t=5.65, df=93, p=<0.05). Women who lived alone ranged in age from 42 to 79, with five of these women being over 70 years.

4.2.5 *Employment*

Fifty percent (n=48) of the women worked in paid employment outside the home. This included a variety of occupations (see Table 4.1).

Table 4.1. Main occupation of women in the study (n=96)

Occupation	%	n=
Home duties, unemployed, pensioner	50	48
Clerical	10.5	11
Administrative, Executive, Management	9	9
Health, Welfare	9	9
Trades-persons, Production	6	6
Sales	5	5
Professional, technical	5	5
Process Workers	2	2
Service, Sport & Recreation	1	1

(Occupational categories, modified from 'Women at Work, Facts and Figures' to exclude those not identified by the women, Women's Bureau, Department of Employment and Industrial Relations, Victoria, 1986)

Five percent of women had more than one occupation. The majority of women included activities such as hobbies, sport or other social and craft activities in their normal demands of daily living.

4.2.6 *Pre-existing Health Problems*

Twenty-nine percent (n=28) of women stated that they had pre-existing health problems (see Table 4.2). Fifteen (15.5%) had problems with mobility, for example walking. Health problems affecting mobility included arthritis (8%), back pain (6%), leg pain or swelling (2%) and repetitive strain injury (1%).

Table 4.2. Pre-existing health problems (n=96)

Problem	%	n=
Mobility	15.5	15
Cardiovascular	6	6
Asthma	5.7	5
Gastrointestinal	2	2
Diabetes, thyroid	2	2
Urinary – bladder	1	1
Multiple	2	2
Nil	71	68

Note: women may have had more than one pre-existing health problem.

Interestingly, pre-existing health problems were more likely to be experienced by the under 50s age group, with only five women over 50 having a pre-existing health problem. The mobility problems in the under 50s age group were the result of motor vehicle and other accidents, and repetitive strain injury.

4.3 Hysterectomy Characteristics

4.3.1 *Medical Diagnoses*

A range of medical diagnoses were identified, with the majority of women suffering from dysfunctional bleeding, fibroids or prolapse, some had multiple diagnoses (see Table 4.3).

Table 4.3 Initial medical diagnosis (n=96)

Diagnosis	%	n=
Dysfunctional bleeding	45	43
Fibroids	26	25
Prolapse	19	18
Endometriosis	7	7
Polyps	3	3
Ovarian cyst	3	3
Pelvic pain	2	2
Cystocele/enterocele	1	1

Note: Women may have had multiple diagnoses

4.3.2 *Surgical Procedure*

Fifty-one percent (n=49) of the women had a vaginal hysterectomy. Three of these were laparoscopically assisted hysterectomies. The remaining women had an abdominal hysterectomy. Forty-eight percent (n=46) had additional gynaecological procedures at the time of surgery, e.g. oophorectomy, colpo-suspension, or multiple procedures, such as Manchester repair (see Table 4.4).

Table 4.4 Additional gynaecological procedures undertaken at the time of hysterectomy (n=92)

Procedure	%	n=
Anterior/posterior vaginal repair	22	20
Salpingectomy & Oophorectomy	12	11
Oophorectomy	3.5	3
Colposuspension	3.5	3
Multiple procedures	2	2
Dilatation & curettage	2	2
Salpingectomy	1	1
Tubal ligation	1	1

Note: Some women may have more than one additional procedure.

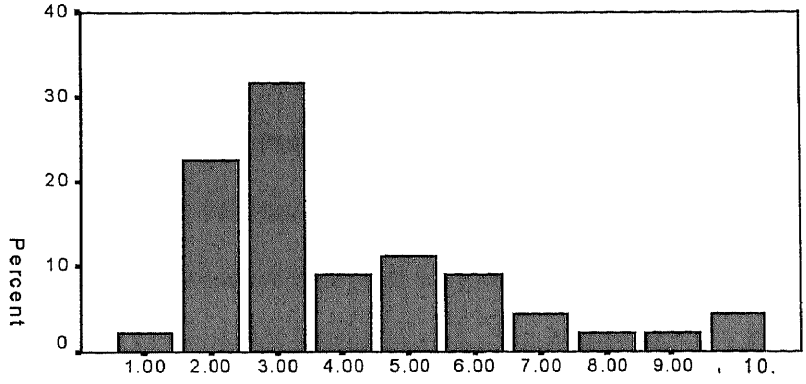
4.3.3 *Length of Hospital Stay*

Length of hospital stay was recorded for 83 women (44 who had vaginal hysterectomy and 39 who had abdominal hysterectomy). The mean length of stay for women who had vaginal hysterectomy was four days (range 1-10 days) and 4.5 days for those who had

abdominal hysterectomy (range 2-8 days) (see Figure 4.1a and 4.1b). The median differed for the two groups: 3 days following vaginal hysterectomy, and 4 days following abdominal hysterectomy. Given the skewed nature of the distributions, a non-parametric test, Mann-Whitney U was used to compare length of stay between the two groups. This finding was statistically significant (Z=-2.397, p=0.017).

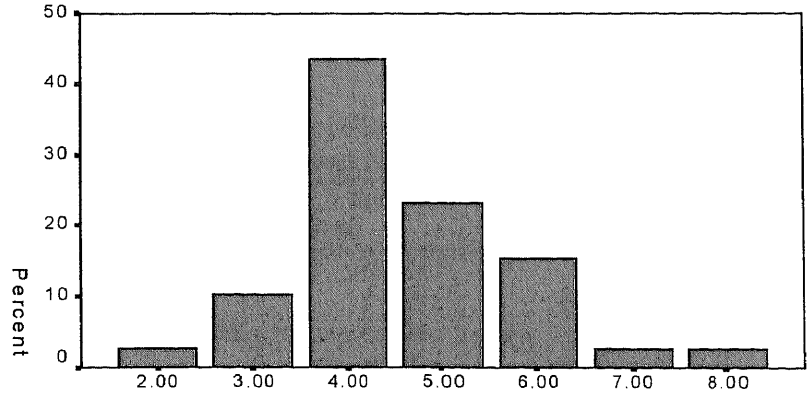
Figure 4.1 Length of hospital stay in days by procedure

4.1A VAGINAL HYSTERECTOMY n=44



length of hospital stay following surgery (in days)

4.1B ABDOMINAL HYSTERECTOMY n=39



length of hospital stay following surgery (in days)

4.3.4 *Assessment of Pain*

Women were more likely to experience moderate to high levels of pain or discomfort if they had had an abdominal hysterectomy. However this was not the case at 1-2 weeks and at 4 months. The mean score for pain at initial interview, reported by 95 women on a visual analogue scale of 1-10, was 4.1, standard deviation 2.6. At initial interview women who had an abdominal hysterectomy had significantly higher mean pain score (4.9; n=45) compared to those who had a vaginal hysterectomy (3.3, n=50). This was statistically significant at the 5% level (t=3.035 df 93 p=0.003). The 95% CI suggested this difference could be as high as 2.5 or as low as 0.5.

Sixty-nine percent (n=66) of women were using some form of pain relief on discharge. Forty-nine percent (n=47) were taking medication for pain three or more times daily. Pain or discomfort was still complained of at 1-2 weeks by the majority of women (76% vaginal hysterectomy and 72% abdominal hysterectomy) and also at 3-6 weeks (13% vaginal hysterectomy and 20% abdominal hysterectomy). At four months 14% of women who had a vaginal hysterectomy and 9% of women who had an abdominal hysterectomy reported that they were still experiencing pain or discomfort they associated with their operation (See Table 4.5).

Table 4.5 Percentage of women reporting pain related to the hysterectomy: initial interview to four months post-discharge.

Procedure	Initial n=94	1-2 Weeks n=62	3-6 weeks n=54	Four months n=74
Vaginal hysterectomy	66%	75.9% n=30	13.3% n=30	14% n=40
Abdominal hysterectomy	71.7%	71.9% n=32	20% n=24	9.4% n=34
X^2 test	X^2=0.367, df=1, p=0.544	X^2 = 0.125, df=1, p=0.724	X^2=0.465, df=1, p=0.495	X^2=3.22, df=1, p=0.073
Fishers Exact test	p=0.66	p=0.085	p=0.572	p=0.13

No statistically significant differences were found when comparing types of procedure in relation to complaints of pain over the four months.

4.4 Complications, Unexpected Symptoms and Readmissions

4.4.1 *Post-operative complications*

Thirty-one percent of women (n=30) experienced problems or complications associated with the hysterectomy while in hospital: 57% of these were following vaginal hysterectomy and 43% following abdominal hysterectomy. Minor problems included gastro-intestinal disturbances such as vomiting, diarrhoea and constipation. Others included bleeding, fever and urinary retention. Major complications such as wound infection, intra-operative bladder trauma and abdominal haematoma were experienced by a small percentage (3%) of women. Two women required a longer period of initial hospitalisation than was expected (due to intra-operative bladder trauma or abdominal haematoma). One went home on antibiotics.

4.4.2 *Post-discharge complications, other unexpected symptoms and readmissions*

Complications and unexpected symptoms were reported by less than 50% of women, however these were more frequently reported in the first six weeks following discharge from hospital than at any other time during convalescence (See Table 4.6 and 4.7). The rate of complications in the first two weeks was similar for both types of surgery: 8.5% following vaginal hysterectomy (n=30) and 8.5% following abdominal hysterectomy (n=32). The most common symptoms reported were severe pain (11%), bleeding (12%) and constipation (6%). More women complained of bleeding following a vaginal procedure (17%, n=5) than following abdominal procedure (10%, n=3) although this was not statistically significant. Three women had more than one problem.

Table 4.6 Complications and Unexpected Symptoms: Weeks 1-2 n=62

Unexpected Symptoms: Weeks 1 & 2		Complications: Weeks 1 & 2	
Bleeding	12.5% (n=7)	Haematoma	4.6% (n=3)
Severe pain	10.9% (n=6)	Infection	4.6% (n=3)
Constipation	6.2% (n=4)	Deep vein thrombosis	1.5% (n=1)
Dysuria	4.6 % (n=3)	Urinary tract infection	1.5% (n=1)
Scar numbness	3.1% (n=2)	Pneumonia	1.5% (n=1)
Dizziness	1.5% (n= 1)		
No complications or problems		51.5% (n=32)	

Three women reported both unexpected symptoms and complications.

Minor problems, such as dizziness, scar numbness and dysuria, were complained of by 9% (n= 6) of women (See Table 4.6). Two women reported readmissions within the first two weeks of discharge. This was due to haemorrhage and deep vein thrombosis. Women who had children under 12 reported a higher percentage of symptoms or complications (65.9%) at this time than other women (50%). This difference, however, was not statistically significant (X^2=1.363, df=1, p=0.243).

By weeks 3-6, when the majority of women had increased their physical activity, more women (17%) reported complications related to wound healing i.e. haematoma, oozing drain site, bleeding, wound infection, dehisced wound, than in the first two weeks (8%). During weeks 3-6 women also reported more urinary tract problems (14.5%) such as infection, incontinence and retention, compared to 1.5% in the first two weeks (See Table 4.6 and 4.7). One woman who complained of pain also reported symptoms of urinary retention. Three women who reported urinary incontinence or urinary tract infection continued to have these problems throughout their recovery.

Table 4.7 Complications and Unexpected Symptoms: Weeks 3-6 (n=55)

Unexpected Symptoms: Weeks 3-6		Complications: Weeks 3-6	
Constipation	5.45% (n= 3)	Urinary tract infection	10.90% (n=6)
Pain	5.45% (n= 3)	Bleeding	5.45% (n=3)
Nausea	1.8% (n= 1)	Wound infection	5.45% (n=3)
Pyrexia	1.8% (n= 1)	Urine incontinence	3.63% (n=2)
Hot flushes	1.8% (n= 1)	Urinary retention	1.8% (n=1)
		Scar haematoma	1.8% (n=1)
		Lung clot	1.8% (n=1)
		Anaemia	1.8% (n=1)
		Dehisced wound	1.8% (n=1)
		Oozing drain site	1.8% (n=1)
No complications or unexpected symptoms		61% (n= 34)	

Note: some women may have reported both unexpected symptoms and complications.

Complications reported by the women during weeks 3-6 included wound infection that required antibiotics (See Table 4.7). While one woman reported that her doctor had queried a lung clot, she did not report treatment for this or readmission to hospital. There were no significant differences in incidence of complications when comparing women who had a vaginal hysterectomy and those who had an abdominal hysterectomy. Some complications, such as dehisced wound or deep vein thrombosis, required medical intervention and may have affected the number of unplanned consultations reported. Other problems identified by the women, such as constipation or dizziness, were less severe and were more likely to be transient. These were described as unexpected and affected the woman's perception of their healing process.

Two women were readmitted to hospital during this period: one for suspected bowel adhesions, and one for back pain. One woman had treatment at the hospital clinic for wound breakdown (dehisced). While 50% of women with children under 12 years of age (n=18) reported symptoms or complications at this time, compared to 29.7% of other

women (n=37), this was not statistically significant (X^2=0.789, df=1, p=0.374). The majority of women (n=34) did not report any problems or complications.

Very few women reported unwanted symptoms or complications in the period after six weeks following discharge. From week seven to the final interview at four months (three telephone interviews) problems such as continuing urinary incontinence (3), urinary tract infection (1) and anaemia (1) were reported by a small number of women. Their general practitioner treated these women. One woman was still recovering from a deep vein thrombosis and another complained of unexpected dyspareunia following resumption of sexual activity.

4.4.3 Symptoms Requiring Hormone Replacement Therapy

Although no specific question on hormone replacement therapy was included in the questionnaires, seven women volunteered the information in the telephone follow-up or diary entries that they had commenced hormone replacement therapy (HRT) following the operation. This was usually on the advice of the medical practitioner or gynaecologist involved in their care. Five women reported that HRT was prescribed in response to early menopause symptoms, that is, hot flushes and palpitations. Two of these women indicated that they had been on hormone replacement therapy prior to the operation and had resumed taking it. Another woman stated that she preferred to eat foods with 'natural' phyto-oestrogens instead of taking hormone replacement therapy. Fifteen percent of women (n=96) had either a unilateral, or bilateral, oophorectomy in addition to the removal of the uterus, however all of these were not followed to the exit interview.

4.5 Return to Normal Activities

4.5.1 *Recovery expectations*

Seventy-eight women provided an opinion regarding how long it would take to recover. Their expectations varied. There was no statistically significant difference between the expectations of women who had vaginal hysterectomy and those who had abdominal hysterectomy in terms of how long it would take to recover from the operation (t=0.514 df=76 p=>0.05). The mean for the vaginal hysterectomy group was 5.4 weeks, SD 1.9, range 2-8 weeks; compared to 5.6 weeks, SD 2.1, range 2-10 weeks for the abdominal hysterectomy group. At final interview, 64% of the 74 women felt that they had recovered more quickly than expected, (72% of the vaginal hysterectomy group (n=49) compared to 56% of the abdominal hysterectomy group (n=47)); while 22% felt that recovery was slower than expected (18.5% of the vaginal hysterectomy group compared to 25% of the abdominal hysterectomy group).

4.5.2 *Primary support person*

Of the 96 women interviewed in hospital, the majority expected to convalesce in their own home, with a small percentage (9%) being cared for by a relative, friend or other person away from their own home. Over 75% of women had more than one person assisting them during the early recovery phase (first 2 weeks). The primary support person identified prior to discharge was a spouse or live-in partner (60%), child (18%), other relative (5%) or friend (2%) (see Table 4.8). A further 14% (n=13) expected to care for themselves or were unsure of support. Only 1% expected help from health professional and other agencies, for example, community nurse or meals on wheels. Fourteen women who had no live-in spouse or partner obtained support in the first few weeks from children.

Table 4.8 Expected Primary Support Person (n=96)

Primary Support person	%	n=
Live in spouse/partner	59.8	48
Child	17.6	16
Self / Unsure	14.4	13
Other relative	5.1	5
Friend	2.1	2
Community service	1	1

Assistance from family members in performing daily tasks for most women was greatest in the first two weeks following discharge with only 18.7% reporting no assistance for cooking, cleaning, shopping and home maintenance compared to 3-6 weeks where no assistance was given for cooking (72.7%), cleaning (50.9%), shopping (52.7%) and home maintenance (43.4%). By four months the majority of women (98%) had returned to normal activities.

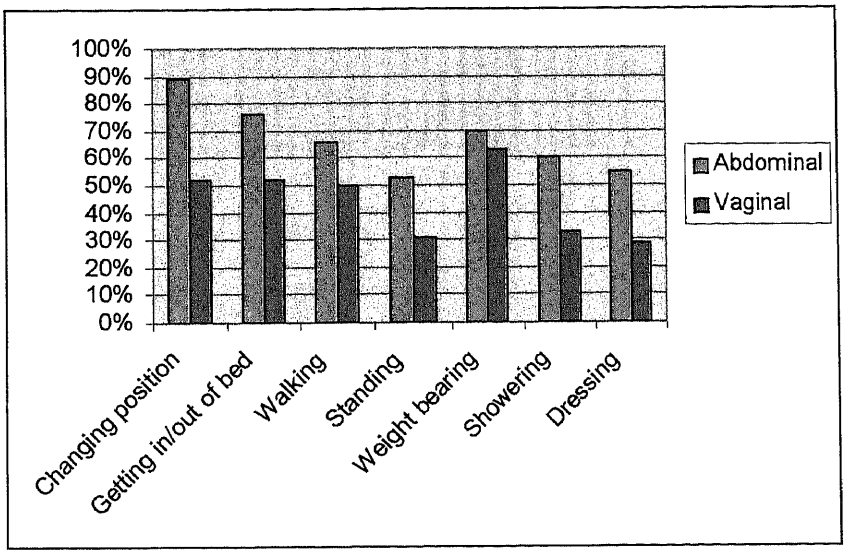
4.5.3 *Return to normal activities of daily living*

At initial interview over 50% of women had some discomfort when walking, changing position when lying or sitting, and when getting in and out of bed. A few (4%) had moderate to severe discomfort requiring the assistance of another person when walking, showering, getting in and out of bed or dressing. The degree of difficulty with activities that require mobility, e.g. walking, changing position, getting in and out of bed, is important given the number of women with pre-existing problems (see Table 4.2).

For isolated activities at initial interview, more women who had abdominal hysterectomy reported difficulty with walking, changing position, getting in and out of bed, and showering, than those who had a vaginal hysterectomy. This is to be expected with an

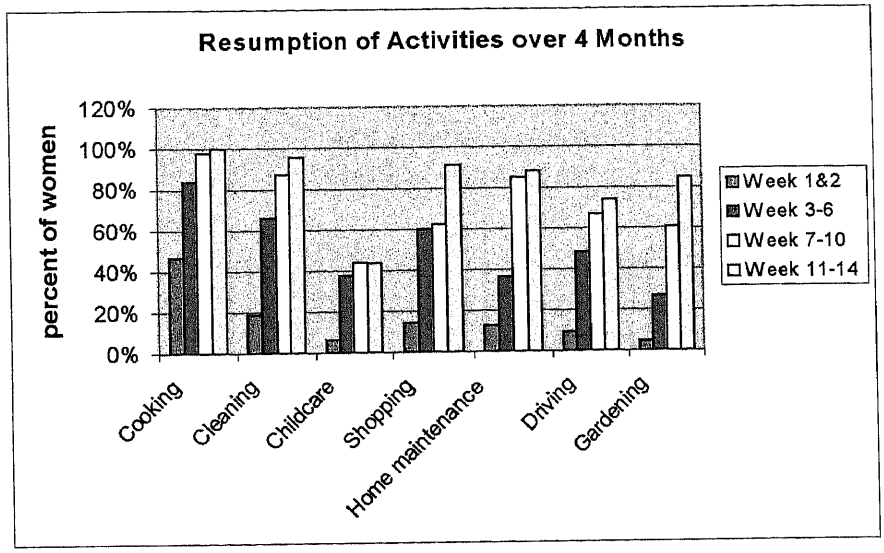
abdominal wound. Areas of mobility where differences were statistically significant are shown in figure 4.2.

Figure 4.2. Difficulty in performing activities of daily living prior to discharge: comparison of vaginal and abdominal hysterectomy groups (n=96).



During the first two weeks following discharge women reported similar restrictions in activities regardless of whether they had had an abdominal hysterectomy or a vaginal hysterectomy. All personal ADLs, for example hygiene, walking, getting in and out of bed were performed by over 90% of women without assistance in the first two weeks and by 98% of women within six weeks of discharge. Complex activities such as driving, cleaning, childcare and gardening were least likely to be done by the women in the first two weeks, with more than 80% of women being assisted with these activities. Figure 4.3 illustrates the progress of return to complex normal activities over the four months.

Figure 4.3 Complex Activities of Daily Living over four months (% women performing activities)

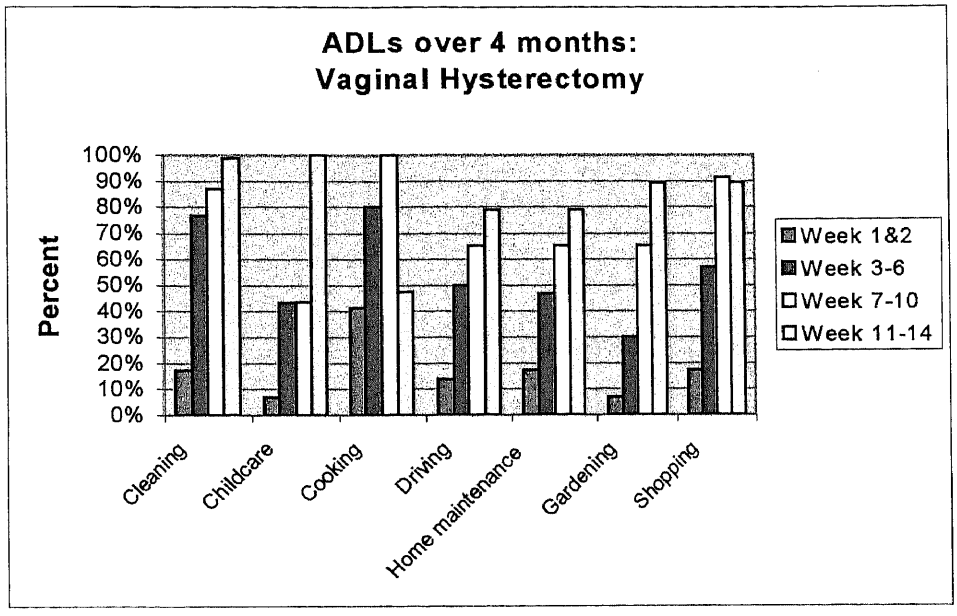


A comparison of activities achieved over the four months, between women who had a vaginal hysterectomy and those who had an abdominal hysterectomy, is illustrated in Figure 4.4. No statistically significant differences were found in the first two weeks between the vaginal hysterectomy group and the abdominal hysterectomy group in the number of women performing most activities (cooking: 41.5% vaginal hysterectomy, 50% abdominal hysterectomy; driving 14% vaginal hysterectomy, 3% abdominal hysterectomy; gardening 7% vaginal hysterectomy, 0% abdominal hysterectomy).

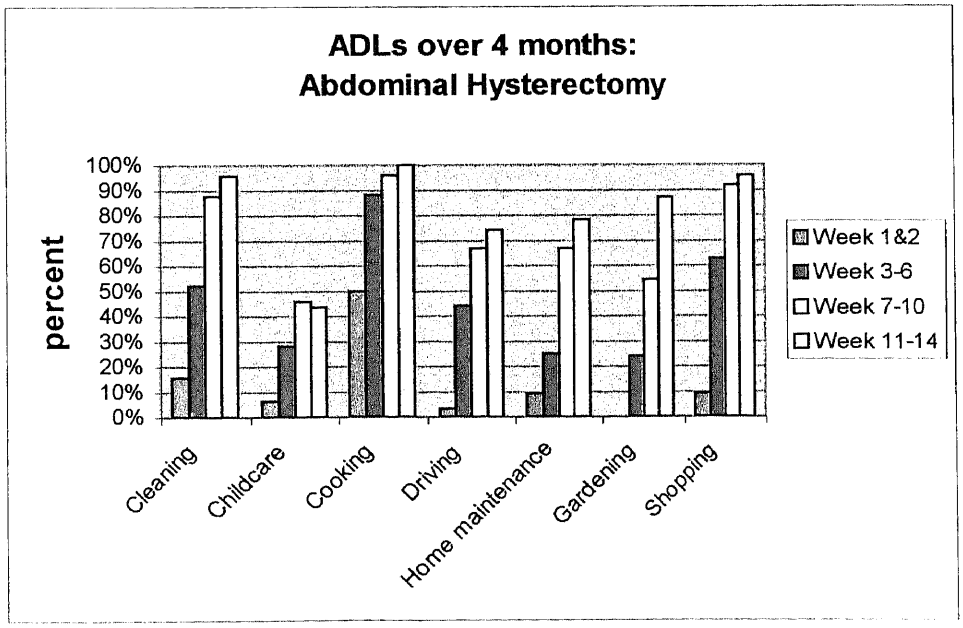
By three to six weeks, differences between women who had a vaginal hysterectomy and those who had an abdominal hysterectomy were statistically significant at the 5% level for driving (X^2=6.393, df=2, p=0.041, n=46) with fewer women in the latter group (50% vaginal hysterectomy; 44% abdominal hysterectomy) who normally drove a car doing so at this time, and sleeping.

Figure 4.4 Comparison in percentage of women performing complex ADLs over four months: vaginal hysterectomy and abdominal hysterectomy groups

4.4a. Vaginal hysterectomy group



4.4b. Abdominal hysterectomy group



More women who had an abdominal hysterectomy (36% compared to 10%) reported that they were not sleeping well during this period (X^2=5.404, df=2, p=0.020, n=46) than those who had a vaginal procedure. For other activities, some women still avoided physically demanding activities, with approximately 30% were still being given assistance with home maintenance and gardening. However, for less demanding activities, 84% of all women were cooking, 66% were cleaning and 60% were shopping (See Figure 4.3).

The women's ability to perform more physically demanding tasks improved at each telephone follow-up until the final interview when almost all women were independent in each activity. At the exit interview, ninety-seven percent of the 74 women interviewed had returned to their normal activities, including paid employment where relevant. Nineteen percent of women said they would have liked more time to recover. More women responded they would have appreciated additional time for recovery following abdominal hysterectomy (31% of 32 women) than following vaginal hysterectomy (11.5% of 43 women). This difference was statistically significant at the 5% level (X^2 =4.415, df=1, p=<0.05). In relation to this, 15% stated they felt pressure from family or employer (14% of those who had a vaginal hysterectomy and 19% of those who had an abdominal hysterectomy) to return to normal activities. This difference was not statistically significant (Fisher's Exact Test p=0.752, n=74). Pressure to return to normal activities was more likely to occur where the women had children under twelve years of age to care for: 32% (n=25), compared to 8% of those without children under twelve (n=49). This was found to be statistically significant (Fishers Exact Test p=0.016, n=74).

4.5.4 *Satisfaction with Family Support*

Of the 74 women interviewed at exit (42 vaginal hysterectomy, 32 abdominal hysterectomy), 77% were satisfied with the amount of support from family members. Other women would have liked additional support in relation to emotional support, visits while in hospital and assistance with home duties. In relation to support provided, 19% (n= 14) of women stated at the final interview that their families did not understand their needs during convalescence. This may have been because of a lack of information provided to family members about the post-operative needs of the women. Forty-one percent of women (n=30) stated that families/significant others were not sufficiently informed about their needs following hysterectomy. There was no statistically significant difference between the women in each hysterectomy group in relation to this: 39.5% vaginal hysterectomy compared to 44% abdominal hysterectomy.

Women with children under 12 years of age (n=30), at initial interview, expected support from a spouse or live-in partner (74%), 84% expected support from older children and 48% from other relatives. In the first two weeks of discharge assistance was given by family members for activities such as cleaning (70% of women), shopping (80% of women) and home maintenance (75% of women).

During weeks 3-6 there were no significant difference in the assistance for various demands of daily living provided by family members to women who had children under twelve years compared to those who did not have children under twelve years. However, 24% of women with children under 12 (n=30) stated they did not have sufficient support during convalescence compared to 6.1% of women without children less than 12 years of age (n=66). This was found to be significant on X^2 ($X^2 = 7.188$, df=2, p=0.027).

Of the women who lived alone, eight were satisfied at exit interview, with the amount of support obtained during recovery. This was accessed from children (n=5), friend (n=2) or relative (n=1). However, two women felt that family members/significant others were not sufficiently informed regarding their needs during convalescence, and two women reported that they were not ready to return to normal responsibilities when required. Neither of these women was employed outside of the home.

4.6 Consultations With Health Professionals

At the time of the initial interview, follow-up visits to either the hospital outpatient gynaecology clinic (13.5%); the gynaecologist who had performed the operation (45%) or the general practitioner (2%) had been arranged for most of the women. Thirty-nine percent had not yet had any arrangements made at that time. Most planned consultations occurred between the third and tenth weeks following discharge (see Table 4.9). Forty-eight percent of women (n=62) consulted a health professional in the first two weeks. The majority of these were unplanned visits to general medical practitioners. One woman consulted a pharmacist and another, an herbalist.

Table 4.9 Number and type of consultations over 14 weeks post-operative period: planned and unplanned.

Consultant	1st week n=62		3-6 weeks n=54		7-10 weeks n=47		11-14 weeks n=43	
	P	UP	P	UP	P	UP	P	UP
Specialist gynaecologist	2	3	18	3	24	1	4	1
General Practitioner	9	14	6	6	1	4	3	3
Clinic	0	1	1	0	0	0	0	0
Other	0	1	0	1	0	0	0	0

Number of planned and unplanned consultations reported during the first fourteen weeks of recovery. P=Planned Consultations; UP= Unplanned Consultations

4.7 State anxiety

Eighty-three women completed the State anxiety questionnaire at initial interview in hospital and fifty-nine women completed the test at four months post-discharge. The mean state anxiety score (20 questions) for all women before discharge was 38.1 (SD.12.3, range 20-66). By four months the mean score for all women (n=59) was 29.3 (SD.11, range 20-67). A paired t-test of those women who completed both tests (n=45) showed a significant decrease in anxiety by four months post-discharge (mean difference 9.2, SD 15.2, t=4.086, df=44, p=<0.05, 95% CI 4.68, higher13.8%).

There was no statistically significant difference in mean anxiety scores at initial interview or at exit interview between women who had an abdominal hysterectomy (initial interview: mean 38, SD 12.1; exit interview: mean 26.6) compared to women who had a vaginal hysterectomy (initial interview: mean 37, SD 11.9; exit interview: mean 31.2) (see Table 4.10).

Table 4.10 Difference between initial and exit anxiety scores for women who had a vaginal hysterectomy compared to those who had an abdominal hysterectomy.

	Group	Mean score	Sd	t-test statistics	95% CI
Initial STAI score	Vaginal hysterectomy n=37	37.0	11.9	t=0.533, df=72, p=0.596	Upper 7.0, lower 4.1
	Abdominal hysterectomy n=37	38.5	12.1		
Exit STAI score	Vaginal hysterectomy n=35	31.2	11.2	t=1.586, df=57, p=0.118	lower 1.2, upper 10.3
	Abdominal hysterectomy n=24	26.6	10.4		

Pre-discharge anxiety was found to be highest in the younger age group (30-50 years): 35.1% (n=20) of these women scored between 39 and 60 (moderate anxiety) compared to 29% (n=5) of women in the over 50s age group. Just over ten percent (n=6) of women in the under 50s age group scored over 60, a high anxiety level (See Table 4.11). A comparison of initial and exit questionnaire scores, where women completed both state anxiety questionnaires, showed a significant decrease in anxiety at four months for the under 50s age group (initial interview: mean 38.7, SD 14.35; exit interview: mean 27.6, SD 9.89. t=4.04, df=32, p=<0.05, n=33). For the over 50s age group, the initial score was lower (mean 32.1 SD 10.61) and therefore the exit score (mean 28.08, SD 8.33) showed a less significant decrease (t=1.127, df=11, p=0.28, 95%CI 3.89, upper 12.05, n=12). The fewer number of women over 50 years of age who completed both questionnaires, compared to those less than 50 years of age, may have affected this result.

Table 4.11 Anxiety score: comparison by age: under 50 years and over 50 years. Number of women in each STAI category

Age	State anxiety 1 (n=74) Prior to discharge			State anxiety 2 (n=59) 4/12 post-discharge		
	<40	40-60	>60	<40	40-60	>60
30-50	31	20	6	37	5	1
51-80	12	5	0	13	2	0
Totals	43	25	6	50	7	1

Twenty-six women with children under 12 years of age completed the state anxiety questionnaire (20 questions) at initial interview. The mean anxiety score for these women was 41.5 (See Table 4.12), which, in comparison, was higher than that for all women in the study (mean 38.1). A comparison between these women with those who did not have children of less than 12 years of age (n=49) found a mean difference of 5.2,

however this was not statistically significant at the 5% level (t=1.783, df=73, p=0.079, 95% CI –1.07, upper 0.61). At exit interview, the mean difference between the groups was 0.4 and was considered not statistically significant at the 5% level (t=0.130, df=57 p=0.89 95%CI). On paired t-test of women who completed both anxiety questionnaires, a significant decrease in scores for both groups at the end of four months was observed (see Table 4.12). This difference was higher in the group of women who had children under twelve years of age (12.7 compared to 7.5).

Table 4.12 Comparison of initial and exit state anxiety scores for women with children under 12 years of age and women who did not have children less than 12 years of age.

Group	Mean difference	t-test statistics	95% CI	
With child <12 n=15	12.7	SD 11.5, t=4.2 df=14, p=0.001	lower 6.27	upper 19.05
No child <12 n=30	7.5	SD 16.6, t=2.4, df=29, p=0.019	lower 1.32	upper 13.73

Only six of the eight women who lived alone completed the state anxiety questionnaire. Five scored in the medium range at discharge and again four months later. Due to the small number of these women the statistical significance of this was not assessed in this study.

4.8 Additional resources used during convalescence.

While women were mainly dependent on relatives and close friends for support during convalescence, many of them also referred to health professionals for guidance and help; a few of them used community support agencies.

4.8.1 *Health Professional Support*

Overall satisfaction with support from doctors, nurses and hospital was high, with similar responses at 86%, 85% and 83% respectively. Of the 74 women who responded to open-ended questions in the exit interview, 15% identified the need for additional contact with health professionals, such as community nurses following discharge. This included the availability of health professionals to give advice, and information regarding the surgical procedure and treatment. The proportions were similar for women who had an abdominal hysterectomy and those who had a vaginal hysterectomy. While all women with children under twelve were satisfied with support obtained from doctors and nursing staff, one felt that she had been discharged too early.

4.8.2 *Community Support*

Formal community services, such as meals on wheels and home care, were not accessed by most of the women (99%) although, again in response to open-ended questions, ten women said they would have used the services if they had been suggested or offered. Their main needs were for help with childcare and transport of children to school (2), home care (cleaning) (7), and home nursing support (5). One woman, who lived alone, accessed community support and 'meals on wheels'.

4.9 Satisfaction with information provided by health professionals

At initial interview, over 40% of women stated that they had not yet been provided with information regarding wound healing, activities to avoid, the need for rest, when to return to work, diet during convalescence, or changes in emotional needs or feelings. At the final interview, over 80% of women reported that information regarding the need for rest, activities to avoid, time for recovery and returning to work were satisfactorily addressed in the literature and/or verbal advice provided by health professionals. Satisfaction with the

information received was lowest in regard to diet during convalescence (26%), emotional needs/feelings (43%) and wound healing (53%). This was similar for all women regardless of the type of procedure (see Table 4.13).

Table 4.13 Satisfaction with information provided by health professionals. (N=74)

Information Provided	Vaginal hysterectomy	Abdominal hysterectomy	Total satisfaction	p* for difference
Diet during convalescence	25.5%	25%	26%	>0.05
Wound healing	58%	44%	53%	>0.05
Activities to avoid	81%	81%	81%	>0.05
Rest	91%	78%	86%	>0.05
Emotional needs/feelings	44%	40.5%	43%	>0.05
Returning to work	88%	81%	85%	>0.05
Time needed to recover	88%	78%	84%	>0.05

The difference of 14% between the groups for wound healing is most likely due to the hidden nature of the wound in women who had a vaginal hysterectomy and is to be expected. Less than 50% of women from both groups were satisfied with information relating to emotional needs/feelings, and less than 30% of women from both groups were satisfied with information regarding diet during convalescence.

4.10 SUMMARY

The initial data indicated that women who had a hysterectomy operation were discharged at a time when they are still experiencing some discomfort from the operation and were dependent on the assistance of other persons to perform selected activities of daily living, such as cleaning, cooking, shopping, washing and childcare.

Women planned for their recovery by organising where they would convalesce and who would support them during the period of time they were unable to perform normal

activities. The majority planned to convalesce in their own home, with less than 10% being cared for by relatives or friends outside their own home. Less than 20% were not sure who would be available to assist them and the needs of these women need to be taken into account when discharge-planning. Most women accessed support from relatives and friends rather than professional groups or other agencies. Over 75% of women in the study had more than one support person assisting them during the first two weeks of convalescence. The majority of women were satisfied with the support obtained from family and friends. However, a small percent felt that family members did not understand their needs during convalescence. This was higher in the women who had a vaginal hysterectomy than for those who had an abdominal hysterectomy. In comparing the women according to the type of procedure it was found that those women who had a vaginal procedure were significantly older than those who had the abdominal operation. Women who had an abdominal procedure were more likely to experience a higher level of pain requiring pain relief medication at the time of discharge. The limited understanding of family members regarding these effects of surgery may be linked to a lack of formal information provided to family members.

Dependency levels were affected by factors, such as complications during hospitalisation, that in some cases prolonged the stay in hospital, and following discharge. They may also have been affected by prior medical conditions causing mobility problems. In some cases women were readmitted to hospital and this affected their satisfaction with the progress of recovery.

More than 80% of women were satisfied with support from medical and nursing staff during hospitalisation, and medical support following discharge. However, a small percent of women would have liked more contact with health professionals, particularly

community nurses after discharge, for advice, information about the hysterectomy and ongoing support.

Women were more likely to experience anxiety related to their recovery if they were fifty years of age or younger. This may be related to their family situation, but did not appear to be linked to whether they had a vaginal or abdominal hysterectomy. Most women were satisfied with information provided by health professionals, with the exception of information regarding wound healing (abdominal hysterectomy) and emotional needs/feelings experienced during recovery (vaginal hysterectomy). This was probably due to the more visible wound in abdominal hysterectomy and the hidden nature of the wound in women who had a vaginal procedure. The majority of women progressed through convalescence as expected and returned to normal activities by the end of four months of follow-up.

Chapter 5.

RESULTS – QUALITATIVE DATA: A Cameo Of Women's Experiences

5.1 Introduction

In this chapter the analysis and results of the qualitative data from diaries and the final face-to-face interviews are presented. Responses to open-ended questions about the women's experience of hysterectomy included their ability to cope with: physical limitations, emotional ups and downs, the responsibilities of family and work and the presence of unexpected transient symptoms related to the surgery. How women cope or manage these experiences is of importance to discharge planners and health professionals who prepare women for the operation and for convalescence.

Diaries were used in order to obtain a record of women's experiences as the events occurred (see Appendix 6). It was considered that information that was recorded immediately would be less likely to be affected by memory lapses or changes in perception that time produces. Diaries, as a source of collecting data relating to personal experience have been used in several studies (Higgins *et al* 1985; Finkelstein *et al* 1992; Marino *et al* 1999). In using diaries for a period of four months it was possible to observe a 'cameo' of the women's experiences over a particular time frame. Ten women agreed and kept a diary of their experiences. The second source of data came from the open-ended questions in the final face-to-face interview with seventy-four women.

In order to structure and focus the women's responses, a number of opened-ended questions were developed relating to: perception/understanding of their family

members/significant others, the type of information they would have desired in regard to their operation and recovery, and what advice they would give other women contemplating hysterectomy. The two sources of data are combined in the discussion.

The diaries also included semi-structured questions to assist the women to provide information about their experience, and yet not to restrict responses. These questions pertained to: the way they felt, the kind of assistance they obtained from family and friends, health professionals and lay organisations, what they could do in regard to activities of daily living as recovery progressed, and finally, whether they had consulted anyone since the last interview. In addition, they were asked to provide other comments as desired on the progress of convalescence in their particular circumstances.

In order to contextualise the comments made by the women, information about the social and medical circumstances of the women is included. A summary of the individual women's details is provided in Table 5.1.

Table 5.1 Details of women who completed diaries.

Name	Age	Diagnosis	Procedure	LOS	Employed	Spouse	No. of Children at home
Angela	36	Fibroids	Abdominal	5 days	Yes	Yes	2
Evelyn	40	Menorrhagia	Abdominal	4 days	Yes	Yes	0
Helen	32	Endometriosis	Abdominal	5 days	Yes	No	2
Irene	45	Fibroids	Abdominal	Not recorded	Yes	Yes	3
Denise	54	Fibroids	Abdominal	8 days	Pensioner	No	0
Janelle	47	Menorrhagia	Vaginal	Not recorded	Yes	No	2
Lorraine	39	Prolapse, Fibroids, Menorhagia	Vaginal	7 days	Yes	Yes	2
Olivia	54	Cancer of the Cervix	Vaginal	1 day	No	Yes	0
Queenie	49	Menorrhagia	Vaginal	3 days	Yes	Yes	0
Penny	42	Fibroids, Menorrhagia	Abdominal	6 days	No	No	1

Note: pseudonyms are used for the women in the above table.

Four of the ten women had vaginal hysterectomies (including one woman who had a laparascopically-assisted vaginal hysterectomy) and six had abdominal hysterectomies. Six of the women had children and six of them lived with a spouse or partner. Diagnoses given by their medical practitioner were consistent with the major reasons given for having a hysterectomy, that is, fibroids, dysfunctional bleeding and prolapse (see Chapter 4, Table 4.3).

The information provided by the ten women indicated that their experiences of convalescence were varied, however there were common themes in the responses.

Issues identified from the comments in the diaries included: the responses and reactions of family members and friends to the women's change of role; a degree of loss of independence and mobility while recovering; transitional physical and emotional symptoms; the positive outcomes in relation to symptom relief; and the need to talk to others about their experience. These issues have been organized under two themes: (1) Education, knowledge and understanding of the effects of hysterectomy surgery affect women's experience during convalescence; and (2) Physical and emotional aspects of convalescence are closely linked throughout the recovery period. The first theme deals with responses and reactions of family members and friends; the importance of support from health professionals; and the importance of talking about the experience. The second theme deals with the women's dependence on others for activities of daily living; emotional ups and downs; pain; other physical symptoms; relief from symptoms and women's advice for others contemplating hysterectomy.

5.2 Education, knowledge and understanding of the effects of hysterectomy surgery affect women's experience during convalescence.

This theme was seen throughout the diary entries and was also expressed in the final interview. The theme deals with responses and reactions of family members and friends; the importance of support from health professionals; and the importance of talking about the experience. Comments about the responses of family members to the women's needs, the need for more information and particularly, reassurance that things were progressing normally were recorded by a number of women in relation to this.

5.2.1 Responses and Reactions of Family Members and Friends

The women's diaries revealed that family members responded to illness and surgery in different ways. The assistance and sympathy given to the woman was dependent on the knowledge and understanding of those caring for her. Where information or prior experience was lacking, unrealistic expectations gave rise to inappropriate responses by carers. With the exception of one woman who expressed no difficulty in performing day-to-day activities, all other women in the first few weeks following discharge, regardless of type of hysterectomy, relied on other people for assistance. Women indicated that understanding of their needs at this time was essential for the family to provide appropriate assistance.

Fourteen women, 19%, in the final interview stated their families did not fully understand their needs during convalescence. Misunderstandings about the severity of the operation may have influenced the attitude of friends and family, particularly where there was no large wound to display. Six weeks after the operation, *Olivia*[3] commented

[3] All names used are fictitious and bear no similarity to the real names of the women in the study

how, because of the hidden nature of the operation, the expected empathy and understanding were lacking.

> I am still concerned about my navel and bowel, for my doctor said it might be on its side time will tell. My friends don't seem to understand a big op and small holes in tummy. Sometimes I feel down a bit, but try to get over it as soon as I can by walking or go out. I am worried for, (doctor) said that I need a Pap smear each 12 months; I thought that was all behind me. (*Olivia*, vaginal hysterectomy).

The level of understanding of how hysterectomy affected the women was shown in the way family members responded to the demands of household tasks. The amount and length of time assistance was given for these differed between women. Two women highlighted different perspectives of what this meant:

> Two weeks after my operation and my husband seems to think I should be over it. It is a shame we can't make other people feel what we feel, just for a while. (*Angela*, mother of 2 young children, abdominal hysterectomy)

> *On* Tuesday *(week 3)* the kids did the housework for me and I watched them. I did some light stuff. It was a warm day and in the afternoon I rested... *On* Wednesday – again I did very little, just read and walked around the house (*Helen*, abdominal hysterectomy)

Another woman, *Denise,* stated that her daughter was still doing the housework in week six following discharge and her son in law drove her to medical appointments. Help from *Denise's* family members was still evident in week eight, however this may have been because of her continuing health problems in regard to anaemia and tiredness.

As indicated in Chapter two, having an elective hysterectomy is considered a common event and family members do not expect it to disrupt the normal flow of life for very long. This is illustrated by *Lorraine*, who found that sympathy for her continuing physical limitations was not forthcoming from those closest to her:

> I now take 4 Naprosyn[4] suppositories 500 mg a day to cope with pain. But the doctor assures me it's only due to the operation. Plus the fact that I've had added stress soon after the operation. As my husband has said: 'if you can breathe you can do it', meaning the cleaning, washing, running children to and from school, running him around. My husband was good for about 3 or 4 days after operation but after that its: 'Get it yourself', or 'I'm too busy'. At the moment my house is a pigsty because no one will help clean up. They are waiting for me to do it. (*Lorraine*, vaginal hysterectomy, mother of 2 young children)

Looking for answers and support outside of her family circle, *Lorraine* consulted an herbalist for advice about alternative pain relief during her convalescence and went to a counsellor to sort out her problems and feelings about the family's reactions.

Responses in the second week of diary entries indicated that some women relied less on other people for assistance in light physical activities, however there were others who still required help with activities such as cleaning, driving, shopping and cooking. Having a vaginal hysterectomy usually meant that the women returned to independent self-care sooner than those who had an abdominal hysterectomy. However, women who experienced complications following a vaginal procedure were forced to rely on family members for a longer period than expected. In this case, the family members did not always respond appropriately. *Lorraine,* for example, was still unable to perform normal daily tasks four weeks after the operation due to complications, whereas *Evelyn*, who had an abdominal hysterectomy, was able to do light cleaning and cooking within two weeks after discharge.

Five women (50%) in this small sample, felt that their family members, especially their partner, were not sufficiently informed about the operation, or about how to give support and for how long. This is supported by the findings of the follow-up interview where

[4] Naprosyn suppositories are used to reduce inflammation in soft tissue.

41% of 74 women also commented on this. In the diary entries, several women made varying suggestions to address this, such as providing verbal advice, as a way to inform the family of the effects of the operation, what the operation involved and the implications for the woman and what to expect in terms of emotional needs (especially if hormone replacement therapy was required). Others felt that what was needed was appropriate written information that could be discussed at home with family and/or friends.

5.2.2 The importance of health professional support

Some women also mentioned the importance of health professional support, in addition to family and friends. The data from the open questions in the final questionnaire showed that information provided to women by health professionals was least satisfactory for the following three items: what diet was appropriate during convalescence, the process of wound healing and changes in emotional feelings during recovery. While the first of these was not mentioned in the diaries, concerns about wound healing and fluctuating emotional feelings were a feature of the diary entries.

As indicated in the comments made by *Janelle:*

> I felt the recuperation period would be as with a virus – day after day you would feel a little better, but that is not my case. Each day isn't getting better. Sometimes I feel I'm going backwards, I am emotional, close to tears for no logical reason. (*Janelle*, vaginal hysterectomy)

A few women identified the need for contact with nurses in the community as a source of information and reassurance. For instance, *Helen* expressed a need for reassurance regarding the normality of her healing process:

> I wish a community nurse would come every 3 or 4 days to check on me and to make sure I am healing OK (I just don't know what to expect). The pain comes and goes "Is this normal"? (*Helen*, abdominal hysterectomy, mother of 2 children).

In the final interview ten women also reported a desire for a community nurse to visit them at home. This suggests that for some women at least, the support provided by health professionals, such as community nurses, is perceived as integral to their recovery and to their sense of comfort and wellbeing.

5.2.3 The importance of talking about the experience

Feelings of sadness were not uncommon amongst the women. Some women were able to express the 'emptiness' at losing their ability to have children and experience menstruation, others did not know why they felt the way they did. In some cases, family members were unable to understand what was happening and women were unable to express how they felt. *Lorraine*, who had 2 children, felt that having someone to talk her feelings over with would have been helpful:

> Women should have a hysterectomy bereavement group because that's how I felt knowing hey, no more babies, no periods forever. I don't think I fully understood what was going to happen to me prior to the operation. You know hormones up and down. The feeling of emptiness. The infections you can get. Women should be made aware of just what they will feel afterwards. (*Lorraine*, vaginal hysterectomy)

While it may not be possible for health professionals to anticipate all events women may experience during convalescence, some discussion of common effects of hysterectomy could be included in the pre-discharge planning. Other studies of women who have had hysterectomy have shown that they experience unexpected feelings of sadness (Dell and Papagiannidou 1999). It is possible that these feelings are related to the knowledge that they no longer have the ability to have children and may be the case even when the woman does not wish to have more children, or was indeed, childless. *Penny*, for example, who had an abdominal hysterectomy, experienced sadness during her convalescence. In week three she reported:

> On the whole I have less pain– can move more, but still feel tired, sometimes sad and wonder if it's hormones or the effects of the operation. (*Penny*)

She was still feeling sad thirteen weeks later:

> I've been very mopey today (week 16). All I seem to want to do is cry. I feel stupid. I'm not on any medication for hormone replacement; I suppose I'll feel better tomorrow. (*Penny*)

Help-groups and community support groups have given people the opportunity to grieve and share their feelings following life change events such as premature infant death, the onset of cancer, in cardiac disease or trying to recover from alcoholism. Even '*ad hoc*' sharing following hysterectomy was seen to be beneficial. As *Helen* commented "I came across two women who had past hysterectomy – great talking and comparing notes".

Some women found that social contact with empathetic others lifted their spirits during the convalescence. *Queenie*, two weeks after discharge from hospital, found the support from those around her to be important to her self-esteem and attitude towards convalescence.

> My brother rang and made me laugh. It's important to have people around that will make you laugh, to keep a balance. Still feel I need to keep having catnaps. Being able to relax and let go is an important part of accepting the healing process, and having a plan for each day. Mine is reading, writing and meditating in the mornings. In the afternoon I rest – this way I'm not sitting thinking, or feel frustrated for a while. It gives me a focus...having people ring you if you are on your own each day is a great support. (*Queenie*, vaginal hysterectomy)

In general these comments show that the women did not fully understand the feelings or symptoms they were experiencing and additional reassurance from someone who understood their needs, or had similar experiences, helped them to adjust to these changes and transient symptoms. Social interaction with women who had a hysterectomy or through visits by health professional such as a community nurse, were seen as

beneficial. In summary, women valued the opportunity to talk to others about their experience, and social contact with other people from family members to health professionals was of help to them during their convalescence.

5.3 Physical and emotional aspects of convalescence are closely linked throughout the recovery period.

This theme focuses on the experience of women by considering the following issues: women's dependence on others for activities of daily living; emotional ups and downs; pain; other physical symptoms; relief from symptoms and women's advice for others contemplating hysterectomy.

Many aspects of recovery affected how the women viewed the outcomes of the operation. The presence or absence of physical symptoms such as pain and tiredness had an effect on the way they felt about the hysterectomy in the first few weeks. Other effects such as emotional fluctuations and complications that developed after they went home, made them unsure of the progress of healing and the value of the hysterectomy. Over the longer term, most women came to the view that having a hysterectomy had benefited them in terms of physical well being and social confidence.

5.3.1 Dependence on others for activities of daily living

Some loss of independence in performing activities or demands of daily living occurs for a short time for most women following major surgery. The women, the family, expect a gradual progression back to self-dependence and the surgeon and women who have had a hysterectomy tend to follow this pattern. For the women in the study, the degree of dependence on others varied with the type of procedure and whether or not they suffered

complications. The degree of dependence on others to do household tasks and the length of time it took to recover were not anticipated by all of the women in the sample.

Two women, *Lorraine* and *Penny,* were not happy with the immediate outcomes of the hysterectomy. Their comments show that the progress of convalescence has a marked effect on satisfaction with the operation:

> I saw (the) doctor. I now have infections left right and centre. I have to have ultrasounds. If I knew I was going to go through the pain now I would not have had the operation at all. But the doctor has told me I should have had the operation some time ago. (*Lorraine*, vaginal hysterectomy)

> All around I do not feel well. Actually I feel lousy. This is a very nasty operation. It really knocks you around. Also I have a lot of pain and bleeding. But I was told this is normal. (*Penny*, abdominal hysterectomy)

Penny lived with her young child and did not have any adult support during her recovery. *Lorraine* lived with her husband and two children. These women's comments highlight what it is like for those who do not experience a trouble-free convalescence. They show that the hysterectomy, for them, was a major operation. Some women are not prepared for the effects of major surgery or the potential for complications that slow down recovery, especially in the early stage. In *Lorraine's* case, the progress of recovery was severely affected by developing a wound infection after the operation and the lack of support from her partner and children. The problems she experienced were unique and were not reported by the other women.

In the initial period after discharge from hospital, the majority of the women depended largely on the assistance given to them by children or spouse, and occasionally neighbours or friends. In some cases the women found it difficult when they could not

return to normal activities quickly even though family assistance was optimum. For these, this resulted in feelings of frustration. *Helen* exemplifies what this meant:

> I'm fed up. Getting in and out of bed is slow. It's almost a week now since I've been home. I'm fed up with this feeling of pain, bored and helplessness of not being able to do things – simple things (like picking up something you dropped) I went to pick up a bag of books today, (I didn't think it was heavy) and a sharp pain in my left side came. I dropped the bag quickly. I was worried then that maybe I had damaged something. (*Helen*, abdominal hysterectomy, mother of 2 children)

Helen's sense of frustration were echoed by *Janelle*, who found that loss of physical independence in the first week after discharge was difficult to adjust to, even for a short time:

> I just wish my body could do what my overactive mind is thinking. I am feeling very lonely. I am very independent and have worked continuously for 29 years. This is the longest I have been away from work, other than after giving birth... I am bored but cannot concentrate on one thing for too long. In general I feel sorry for myself. (*Janelle*, vaginal hysterectomy,)

As one would expect, return to a high level of independence was quicker for the women who had had a vaginal or laparoscopically assisted vaginal hysterectomy. However, even for these women short periods of dependence on others were not welcomed.

> Well, no pain ... only aware of operation when I move about too much. But I have a headache and felt down when I realise how much I can't do for two weeks. I'm normally very independent. (*Queenie* – vaginal hysterectomy)

5.3.2 Emotional Ups and Downs

Some women in the study experienced fluctuations in emotional state, as well as unexpected physical symptoms such as tiredness, during their convalescence. These symptoms were often transient in nature, and were possibly due to the effects of major surgery on the body or a result of the surgical wound. In some instances women indicated the mood swings were related to hormonal changes and they were commenced or re-commenced on Hormone Replacement Therapy (HRT). Women who experienced

these emotional ups and downs found that their feelings had an effect on their ability to self-care and an impact on their perception of the outcomes of surgery.

Feelings of depression and anxiety are well documented in the literature on women who have had hysterectomy (e.g. Raphael 1975; Roeske 1978; Salter 1985). Early studies linked this occurrence with psychotic disorders thought to be a result from the hysterectomy, or in some cases preceding the hysterectomy (Raphael 1972). It is only in the last decade that hormonal fluctuations that can cause emotional ups and downs have been linked to continuance of the hormonal cycle following removal of the uterus where the ovaries have been preserved (Metcalf *et al.* 1991).

It should be noted that, in the experience of some women in this study, the development of complications might have contributed to the way they felt about their experience. A few women in the current study reported emotional ups and downs although none reported severe clinical depression. *Helen* and *Janelle,* two women who had experienced a sense of frustration expressed this as a swing in their emotions that they could not relate to external factors. At the end of week one, *Helen* had this to say:

> Some days I feel like crying... Is there such a thing as 'post op*eration* blues' or is this some sort of hormonal change? How do I tell the difference? Sometimes I get hot, but this could be due to pain. How do I tell the difference between operation symptoms and hormonal changes? Family and friend have been great, with some being more helpful than others. But I am fed up with feeling like this and I have weeks to go yet. (*Helen*, abdominal hysterectomy)

In contrast *Janelle* indicated a more relaxed approach:

> I'm in no hurry to return to work. However I feel very lonely and lost confidence. If I do something and it goes wrong it really upsets me. I particularly like doing crafty things and am enjoying my days, either knitting, sewing, painting or doing ceramics. (*Janelle*, vaginal hysterectomy)

For some women the early experience of fluctuating emotions was eventually linked to hormonal factors and they were commenced on hormone replacement therapy (HRT) or made the decision to use 'natural' phyto-oestrogens. The women indicated that emotional lability was not expected in most instances and, when it happened, the reason was not obvious to the women concerned at the time. *Olivia*, who was readmitted 48 hours after discharge due to pain in her legs from potential deep vein thrombosis, had previously been on hormone replacement therapy that was discontinued before the operation. She commented that she was experiencing severe menopausal symptoms of hot flushes and emotional upsets for some time after going home the second time.

> By Sunday I had a very blue day, crying all the time. *I* had been off HRT for 2 months by then, hot flushes 4-5 times a day for 2-3 days and having to wait *un*til Monday for test to see about the clots, of course no clots, just a weekend of hell. I understand why it was all done but if I stayed in just a day or two longer *after the operation* most of this would not have happened. They started me on HRT on Sunday afternoon (*Olivia*, vaginal hysterectomy).

For one woman emotional ups and downs occurred early in the recovery phase. In other women such as *Queenie,* feelings of vulnerability occurred several weeks into convalescence.

> Sitting around is starting to get to me – when you start feeling OK, you just want things to get back to 'normal'. But when I've been walking about for a while (like *in* the shops) after an hour you're tired out. Still I've got friends coming today, that'll help lift me. It feels like I've lost interest in everything – although it doesn't feel 'mental', more emotional. I feel quite good physically and mentally. Given in a word I would say I feel 'delicate'. (*Queenie* – week 6 after discharge)

As stated earlier, emotional symptoms were not expected by most of the women in this sample. For some, these feelings were possibly due to physical causes such as hormonal fluctuations. For others, they may have been as a result of complications such as anaemia. This was shown in *Denise*'s case where symptoms of tiredness due to anaemia

persisted for many weeks. *Denise* had a number of blood tests done to assess this, throughout the study period.

Frustrations at loss of ability to self-care and meet demands of daily living were common to most women. Some women recognized the importance of acknowledging their emotions and the need to make plans to accommodate changes over the time it took to get well. However most felt that the time required to get well was more than they had anticipated. Women who had adequate support indicated they were able to relax and allow their body to heal. *Queenie* commented on this as she described how she was able to organize her day so that there was time to rest and also for people to visit her.

> Being able to relax and let go is an important part of accepting the healing process, and having a plan for each day. Mine is reading, writing and meditating in the mornings – and if anyone wants to come I tell them to come in the morning. In the afternoon I rest. This way I'm not sitting thinking, or feel frustrated at being incapacitated for a while. It gives me a focus. (*Queenie*, vaginal hysterectomy)

5.3.3 Pain

Dependence on others was largely due to pain in the initial stages of convalescing. As previously noted, pain at discharge, measured on a scale of 1-10 (see page 48), showed a moderate level for most women with a higher score for women who had abdominal hysterectomy. The severity of pain experienced was not anticipated by some of the participants, as indicated by these comments:

> Even after I have taken painkillers the pain can be bad for a while...I am so sick of walking slow and being careful getting in and out of bed. Can't sit for too long – it's uncomfortable. Can't lie for too long – for the same reason. I feel just like a winger. I am fed up. I didn't think it was going to be like this. I thought I would be sleeping a lot, but I can't. Sometimes I feel well enough to do things until the pain reminds me I can't. WHAT A BORING LIFE THIS IS. (*Helen,* abdominal hysterectomy, 1 week post-operatively)

> At the moment my house is a pigsty because no one will help clean up. They are waiting for me to do it. I've tried but as soon as I bend over to pick up clothes I ache with pain. But I will have to do it otherwise my children will have dirty clothes in the second week after the operation. I was doing washing. As soon as I pick up clothesbasket the throb down below was so intense I dropped the basket. (*Lorraine*, vaginal hysterectomy)

Others also show that they had little previous understanding of the physical effects of major surgery on their ability to move around freely and be able to care for themselves. *Denise* and *Queenie* illustrate this:

> I took a slow walk up to the school yesterday to pick up my six-year-old granddaughter, then walked slowly home. Boy, am I out of condition. Ten days in hospital, and all this resting, even losing 12kg in weight. All my muscles began to ache about ½ hour after I got home. I felt like I'd just run a marathon. (*Denise*, abdominal hysterectomy)

> The realization you've had a major op*eration* is difficult, once the pain has gone. If the op*eration* was done vaginally, especially when you saw the others (*patients*) in casts etc., and coming to terms with not being able to do anything except shower for the first two weeks isn't easy. (*Queenie*, vaginal hysterectomy)

What these comments indicate is that the knowledge the women had acquired before the operation gained significance during the recovery phase. The outcomes during convalescence were not necessarily common to all women where they had the same kind of surgical procedure. Women who expected a quick recovery following a vaginal procedure found it difficult to adjust when their expectations were not realized due to complications.

5.3.4 Other Physical Symptoms

It is well known to clinicians that physical symptoms following any surgical procedure are often related to shock, blood loss, the affects of anaesthesia and the creation of a wound. Even when the wound is an internal one, pain related to the incision and the

suturing, is felt by the patient. These symptoms lessen in acuity usually within 48 hours and gradually resolve over the following few weeks. In this study, symptoms of pain, and tiredness, were those most commonly reported by the women in the first few weeks.

Several women identified physical tiredness as something that affected their progress and they continued to feel tired throughout the four months. *Queenie*, who had a vaginal hysterectomy, and *Irene*, who had an abdominal hysterectomy, advocated lots of rest in the early stages of recovery: "Rest is definitely the most important part of the healing process. In that I mean with legs elevated, not just sitting in a chair." (*Queenie*, vaginal hysterectomy) "Feeling tired during the day. I go to bed when it gets too much, for a rest. Doing washing, but taking it very easy. A bit slow doing everything but coping well." (*Irene*, abdominal hysterectomy). Tiredness persisted for some weeks for most women, even when other physical symptoms were minimal. *Helen* was still feeling tired 12 weeks after the operation. This may have been related to the difficulty she had in sleeping.

> Went shopping with my kids. They pushed the trolley and got the shopping. Was tired. When I came home went for a rest (*it* was very hot, couldn't settle down). That night *I* went to a friend's place for New Year's Eve. (did nothing there- came home about 1am) read till 4am. Thursday, up at 7am, couldn't sleep. Had pain come and go. (*Helen*, abdominal hysterectomy)

For *Denise*, the feelings of tiredness were eventually related to a low platelet count. *Denise* still reported feeling tired ten weeks after the operation "7½ weeks – a bit tired – my muscles are aching – had to see the haematologist for my next checkup (low platelet count). Public transport makes me tired." (*Denise*, abdominal hysterectomy)

Previous studies of hysterectomy patients in the literature have shown the main issues, such as tiredness, pain, bowel and bladder disturbances, to be similar to what has been

expressed by these women (Cosper *et al* 1978; Webb and Wilson-Barnett 1983a). Other women, such as *Olivia* and *Helen,* reported physical symptoms related to menopause, and other problems. Multiple problems during the first few weeks added to the low feelings:

> The only good thing to come out of this is the operation itself. No pain in tummy only wind pain and trying to break wind is very hard to do...back in hospital Friday afternoon with pain in top of legs, but numb feeling also, they put white stockings to my thighs...10 tablets per day with food to stop infection plus 2 needles in my tummy per day to thin my blood...By Sunday I had a very blue day, crying all the time. Had been off HRT for 2 months by then, hot flushes 4-5 times a day for 2-3 days and having to wait 'til Monday for the test to see about the clots, o' course no clots just a weekend of hell. I understand why it was done but if I'd stayed in just a day or two longer in the first place most of this would not have happened. (*Olivia,* vaginal hysterectomy)

> The last 2 days *I have been* getting hot flushes (but it has been hot weather). Thursday didn't feel well, had a planned doctor's appointment. Blood pressure was up. She also said I had an erratic heart beat (every 6th beat was a double beat). She wanted an ECG *(electrocardiograph)* done on Saturday. I had the palpitations feeling all day. The doctor said it could be the effects of the operation or maybe a drop in hormone levels. Wait 'til Saturday. Friday I felt good. The palpitations feeling was gone...that night the palpitations feeling came back for a while. (*Helen*, abdominal hysterectomy, week 2)

Several women expressed the desire for everything to return to normal so that they could resume their normal lives. Four weeks after the operation, *Janelle* felt that her convalescence was taking too long:

> The recuperation period is much longer than I anticipated. I have this need for mine and my family's lives to be back to normal – what ever that is! I am in no hurry to return to work. However, I feel very lonely and lost confidence. If I do something and it goes wrong it really upsets me. (*Janelle*, vaginal hysterectomy)

Not all women found the convalescent experience to be difficult. *Irene*, who had three children, felt very good. She was "enjoying a break from work as well as heavy household duties. Visited relatives with small children. Enjoyed the visit but mentally and physically tiring".

Janelle, on the other hand, found that she had to push herself to get out of bed and do things. "I'm writing this at the end of the day and am having trouble thinking and spelling. I wonder if the doctor took out my mind as well as my uterus."

5.3.5 Relief from Symptoms

The data indicated that the most important outcome of the hysterectomy was the relief from unwanted and embarrassing symptoms. As the women recovered and increased their independence they began to focus on the benefits of having the operation. Pre-operative symptoms of tiredness, nausea and pain due to their previous condition had an impact on the ability and motivation of women to maintain their lifestyle. In addition, the unexpected irregular, and often heavy, bleeding had caused them embarrassment in social situations. Many of the women reported that the operation relieved them of these unwanted symptoms. This was noted as a new lease of life and increase in social activity.

Six weeks after the operation, *Janelle* who previously felt less than satisfied with herself, now felt more positive about the outcomes, as she noted:

> Today is six weeks after my operation. I have been told time and time again 'in six weeks you will feel like a new person.' I do feel more in control of myself. I'm still quite emotional. I have a great need for company but when people are around I feel a little panicky. I am able to, and want to, do more work around the house. I am cooking alone. I have lost interest in the things I was doing in the last five weeks e.g. craft and reading. (*Janelle*, vaginal hysterectomy)

Women who had an uncomplicated vaginal hysterectomy were more likely to experience feelings of optimism early in the recovery period. However, some women who had an abdominal procedure also felt that having the operation would lead to an increase in social activity. For instance *Irene,* sixteen weeks after discharge, felt more satisfied:

> *I am* feeling great since the operation. No pain, discomfort, nausea, *or* feeling faint. Feel like a different person. Exercising 4-5 nights a week, no weight loss but feel good... I can go out without worrying about any 'accidents'. I've started to plan what I want to do each weekend, go and see places I haven't seen for years (*Irene*)

The diary data about the women's feelings after two months of recovery are consistent with that reported in the final telephone interview, where 52% felt happy, 56% were satisfied and 60% were optimistic about the outcomes of the hysterectomy. Towards the end of the study, the women's comments became more positive as symptoms subsided and more women expressed satisfaction with having had the procedure. As *Irene* again commented:

> Everything has happened at the right time. Now it's my time to enjoy my life. Having the hysterectomy has given me a new lease of life and I'm going to enjoy every minute of it now my children have grown up. (*Irene*, abdominal hysterectomy)

5.3.6 Women's advice for others contemplating a hysterectomy

When the researcher met participants for the final interview, the women had a lot of advice for others contemplating a hysterectomy. Their advice was similar to what had been stated in the diary entries. The suggestions included the need to be prepared prior to surgery and plan with their family what to do during recovery. Below are some of the suggestions made by the women:

> Be prepared
>
> Make sure of support at home
>
> Inform the family of *your* needs
>
> *You* should prepare *yourself* and *your* family before the operation about what to expect
>
> You need a lot of support afterwards from family and friends, especially emotionally

> Inform your family or primary care giver that they need to be there for you to give support and help when you get home from hospital
>
> Go ahead, but make sure someone is with you during your convalescence.

The women were of the view that information about the operation and its effects was crucial to their long-term recovery. They also felt strongly that they wanted to be involved in the decision about having the hysterectomy:

> Find out as much as you can before, during and after the operation
>
> Go into more detail with gynae (*specialist)* regarding operation performed and outcomes of operation and the effects on the body of the operation
>
> Speak to other women who've had the operation
>
> It's a good idea to read "Everywoman" because it gives you all the information you need about the operation and afterwards.
>
> Make up your own mind about having it. Check alternatives
>
> Take a hard look before deciding to have the operation to see if there are other options. It knocks you about afterwards.
>
> Only have it (*the operation*) if there are absolutely no other options. Each person is an individual and the recovery time varies.
>
> Don't listen to all the sensational hype regarding having the operation. Go with your gut instincts about having it or not.

Advice included comment about the length of time it takes to recover and the limitations that having pelvic surgery places on physical tasks:

> Don't go back to work too early if your job involves lifting and pushing
>
> Realise your recovery takes longer than you expected.

The above responses highlight a range of views, yet collectively they also indicate that women have a strong desire to be better informed and more actively involved in processes and decisions concerning hysterectomy. After four months, the majority of women were very positive about having had the operation and said they would recommend it to other women if they were suffering similar pre-operative symptoms.

5.4 CONCLUSION

This chapter has focussed on two themes in regard to the women's experiences following hysterectomy. Theme one described the education, knowledge and understanding identified as necessary by the women, what to expect after going home, and information needed by family members so that the support they gave could be appropriate and timely. Attitudes of family members and friends were important to the woman's experience and her ability to cope with the effects of surgery. The emotional support of family and health professionals was seen as essential to their recovery process. Physical symptoms and emotional ups and downs gave rise to further need for contact with, and information from, health professionals after discharge. In particular, the general practitioner and the community nurse were identified as experts who understood what they were experiencing and could define what was 'normal' in relation to their progress and this was important to the women.

Theme two described the physical symptoms and emotional ups and downs that affected the women's feelings about the hysterectomy. It was found that women's feelings concerning the value of the operation changed over the period of the study. Early symptoms of pain and tiredness, that were associated with physical limitations, affected their feelings about having the hysterectomy. Prolonged dependence on others gave rise to frustration and feelings of loss of control. Feelings about the operation were also affected by the presence or absence of complications and the assistance obtained from family and friends. As convalescence progressed, the needs of the women moved toward communicating their inner feelings about the loss of their uterus and what that meant to them, and being reassured by family and friends that things were progressing normally. Once the initial effects of surgery passed, the women expressed a more optimistic view

of the operation and most said they would recommend surgery to other women who had the same gynaecological symptoms.

Women who had sufficient physical and emotional support and who planned for the temporary loss of independence were happier with the outcomes of the hysterectomy, as were women who obtained help in normal household tasks from other adults. Women, whose expectations of a quick recovery were not met, expressed some frustration at the length of time they took to recover. It can be noted that, while having a vaginal hysterectomy may reduce the length of time in hospital, some women have complications following discharge that lengthen their dependence on others.

The event of having a hysterectomy procedure is one that takes the woman out of the 'normal flow' of life (which may consist of work, home duties, caring for children or elderly relatives, relating to a spouse or partner) to a point where a certain amount of introspection and self-examination becomes important. What is sometimes perceived as a necessary operation to relieve unwanted, or unpleasant, symptoms does not always proceed as expected. For women who have others to take over the normal tasks expected of them, the period of convalescence can be a time of reflection, rest and renewal as a person, a time to re-evaluate what it means to be a woman. For women who find it difficult to 'let go' or who have family members whose expectations of swift recovery are high, there is often insufficient time for reassessment, self-reflection and self-actualisation. For most women in this study, the satisfaction with outcomes following hysterectomy was high. Issues raised by the women focused mainly on the level of knowledge they had and the additional information they would have liked to have before the operation.

Chapter 6

DISCUSSION

6.1 Introduction

This study describes a cohort of women recovering from hysterectomy and makes comparisons between groups in regard to their experience and how they manage this. The results show that women's experience of hysterectomy is affected by the type of procedure, the effect on their health and well-being of complications at various times during the first six weeks, the availability of support persons over the first few weeks, and the response from others in the family towards the woman's loss of ability to self-care and perform normal daily tasks.

In the literature, most studies focus on one type of procedure or the other with a few looking at comparisons between outcomes for women who have different procedures (Rorarius *et al.* 2001). In the current study, significant differences were found for a number of areas between women who had different procedures, and between women who had different home circumstances. Medical reasons given for the hysterectomy did not differ greatly between the groups, and reflected the main causes identified in other studies, that is, fibroids, dysfunctional bleeding and prolapse (Reiner 1988; Hackman & Navaneethan 1993). Difficulties with performing complex activities of daily living prior to discharge were more likely to be experienced by women who had an abdominal hysterectomy, and this was most likely to be due to pain or discomfort. Pain as a factor in the ability of women to undertake normal activities has not been assessed in the literature searched, although in some studies (Taylor *et* al 1993; Clarke *et* al 1995) an assessment was made of some activities of daily living before the women went home.

Clarke *et al's* (1995) study showed that the women voluntarily restricted their activities early in the recovery period and again at six weeks. This is consistent with the current study and may be due to discomfort because of the wound, complications or unexpected adverse symptoms related to surgery.

While complication rates as a whole were low, these may also affect the women's ability to move around and self-care, and affect the speed of recovery. Similar complication rates while in hospital may have influenced the finding that there was no significant difference in the need for support in the first few weeks following discharge between women who had a vaginal hysterectomy and those who had an abdominal hysterectomy. New complications also affected women some weeks after discharge when they resumed normal activities.

As recovery progressed, family members withdrew their support. The diary entries indicated that, for some women, support was withdrawn too soon and this was attributed to a lack of understanding of their needs. Although most women had returned to their normal activities by the four-month exit interview, a small percentage was still relying on family members for some complex tasks, especially those requiring physical effort. It is possible that an increase in activity levels after the first few weeks affected the numbers of women contactable by telephone for the periodic follow-up interviews, and this may have affected the results, although there were equal numbers of both types of procedure represented.

In comparing other factors, younger women under 50 years of age reported a higher state of anxiety prior to discharge. Correlation between the type of hysterectomy and state anxiety was not found, so it would appear that the type of operation did not contribute

greatly to anxiety in this cohort of women. Other studies (Warrington and Gottlieb 1987; Rhodes *et al.* 1999) have found that anxiety levels may be higher in younger women due to their uncertainty about sexual attractiveness following the operation. While this was not tested in the current study, it was apparent that home conditions were more of a factor in the level of anxiety for these women, than the type of surgery. The presence of young children at home has been identified in other studies as a disadvantage for women recovering from hysterectomy, in particular where a shortened hospital stay is anticipated (Reiner 1988; Taylor *et al* 1993; Hackman & Navaneethan 1993). The criteria for these studies excluded women from early discharge programs where there were small children at home These aspects are discussed in terms of the objectives of the study.

6.2 Women's Level of Dependence.
To determine the level of dependence of women at discharge from hospital following hysterectomy.

The current study found that women are discharged in a state of dependence on others and initiate a number of management strategies in order to cope throughout convalescence. The findings show that women have functional deficits in terms of walking, weight bearing, changing position from lying to sitting, standing, and getting in and out of bed, just before discharge from hospital and they require assistance for a number of weeks for physically complex activities until recovered from the effects of surgery. Linenberger (1996) found that physical restrictions were the main concern of women after discharge from hospital, and this supports the findings of this study. At initial interview, a small percentage of women who had an abdominal hysterectomy still required assistance of another person or mechanical support (for example leaning on the wall) in some of these activities. This was expected given the short length of time since surgery.

Multiplicity of procedures at the time of hysterectomy, and a shorter hospital stay in the case of women who had a vaginal hysterectomy, may also have an impact on the experience of women after discharge. Dependence on others may have been influenced by post-operative complications that occurred such as urinary retention, bowel disturbances, wound infection and haematoma, or pre-existing health problems.

Activities that women usually performed and were most likely to require assistance in the first two to four weeks at home were cleaning, cooking, driving, childcare and home maintenance activities. All of these tasks require physical activity and some amount of physical flexibility and weight bearing that is not reasonable to expect in the first few weeks following this procedure. It was expected that these difficulties would resolve over the study period. Generally, these problems are not reported by six months after the operation (Linenberger 1996) and the return to normal tasks by four months by the women in this study is consistent with expectations expressed in the literature. Tasks related to personal grooming and independent locomotion were performed by most women without assistance within the first two weeks, although a small percentage still required help with these aspects of daily living.

In comparing differences, women who had an abdominal procedure took longer to return to some complex tasks such as driving and gardening (See Figure 4.4, page 46). This is expected in women who have had an abdominal procedure because of the impact on the pelvic floor muscles accompanied by an abdominal suture line. Women who had an abdominal hysterectomy were found to have a higher mean pain score at initial interview and were more likely to complain of pain they related to the operation for a longer period of time, than those who had a vaginal hysterectomy. Some women reported discomfort during convalescence that was explained by their medical officer as settling of the organs

usually supported above the uterus. Women in this study used the opportunity in providing diary entries of their experience to raise issues such as the physical effects of the operation, the problems with caring for themselves, their concerns about healing and unexpected symptoms such as hot flushes, tachycardia, severe pain, bleeding, urinary problems and emotional ups and downs. Tiredness was a major feature of the diary entries and has been found in other studies of women post-hysterectomy (Webb and Wilson-Barnett 1983a). This is a not uncommon symptom following surgery and reportedly can be a factor impacting on the women's ability to perform normal tasks for some months.

Identification of the needs of post-surgical patients is often done as part of discharge planning (Titler and Pettit 1995) and generally includes an assessment of bladder and bowel function. The medical criteria used to determine whether the women were ready for discharge was not assessed in this study. Further studies of these women would benefit from including an evaluation of the criteria used in assessing discharge readiness.

This study shows that identification of factors that contribute to self-care deficit, such as pre-existing health problems, the amount of debility associated with complications, and the type of wound, would inform a pre-discharge evaluation of the women's needs. This is supported in other studies where women have been sent home after a short hospital stay and where there was an acknowledgement of the need for professional and non-professional assistance during the first 1-2 weeks (Taylor *et al.* 1993; Hancock & Scott 1993). A formal assessment could include the woman's ability to self-care, the level of pain and discomfort affecting mobility, and an individualised needs-based plan of management for the early part of convalescence (Taylor *et al.* 1993; Brooten *et al.* 1988; Clarke *et al.* 1995).

6.3 Support Structures Accessed During Convalescence

To describe the positive strategies and support structures (formal and informal) used by the women.

In relation to support structures, it is evident from the current study that women plan for their needs during convalescence and use a limited range of strategies and support persons to effectively recover. Plans for managing the experience included an expectation of the length of time it would take to recover, and who would be available to take over their normal responsibilities for that time. The initial interview showed that reliance on informal carers was a predominant feature of the women's strategies for convalescence. Non-professional carers, such as partner or spouse, children, parents, other relatives and friends were expected to take over the day-to-day assistance until the woman was able to resume her normal activities.

There has been some debate as to whether women need professional support during this time or whether non-professionals, such as family and friends, would suffice (Brooten *et al.* 1996). In many instances, the care of family and friends is sufficient, particularly where the progress of recovery is straightforward with no complications. However, where a woman experiences a lack of family support or complications that impact on the speed of recovery and the ability to self-care, professional assistance or intervention may be necessary. Professional follow-up by expert nurses has been implemented in hospital-at-home or early discharge programs (Hackman & Navaneethan 1993; Taylor *et al.* 1993) and promoted in other studies (Brooten *et al.* 1996). While women who recover successfully following an uncomplicated vaginal hysterectomy may not need professional follow-up, as in Reiner's (1988) study, there are other women who may benefit from this type of intervention.

Support from health professionals, with the exception of planned follow-up visits to the gynaecologist or hospital clinic, was not anticipated by participants in the current study once they left hospital, but would have been appreciated, if it had been offered, in some cases. For most women in this study the continuance of professional care after discharge from hospital transferred to the woman's general medical practitioner and was used as needed. This aspect of convalescence is not reported in early studies such as that of Reiner (1988) or Ng and Hogston (1994). However, the use of the family doctor is very important to most women once they are discharged from hospital and away from the direct supervision of a specialist.

Taylor *et al.* (1993) and Brooten *et al.* (1996) suggest that support from specialist gynaecology nurses would provide the women needed advice, emotional reassurance, and easy access to hospital if suffering from complications after discharge home. This level of care from registered nurses is not common in the Australian experience, unless women have ongoing needs for nursing care, such as intravenous medications or an indwelling urinary catheter. Whether the women require this additional support at home, in the early stages of convalescence when complications usually occur, may need to be the focus of further study. Hackman and Navaneethan (1993) found that, after evaluation of their study results, their cohort of women did not need professional support after the first week. However, a small percentage of women in the current study expressed a desire to continue contact with health professionals after discharge. It is possible that this is an aspect of post-discharge care that needs individualised assessment.

Childcare is traditionally the responsibility of women and it was found that assistance in caring for children under twelve years became less available as time went on, compared to assistance with other responsibilities such as shopping or cleaning. Where women had

dependent children but no live-in partner/spouse they were reliant on the children for support. Women with young children felt pressured to return to normal activities sooner than other women and this should be included in an individual assessment of their needs (Reiner 1988; Taylor *et al* 1993). In addition, anxiety levels, while not statistically significant, were higher in the group of women who had children under the age of twelve years compared to other women. The effect of young children on women's recovery after hysterectomy is an area that is not covered in other research and further study of women with small children is required.

The importance of support provided by the woman's partner, as well as from friends and relatives, is highlighted in the study by Webb and Wilson-Barnett (1983b). This is supported by diary data in the current study where the women expressed a need for emotional support during their recovery, which was expected in the first instance from their spouse or partner. The importance to the women of being able to discuss their situation with the person closest to them (their partner) was also identified by Bernhard *et al.* (1997). Communication problems between the women and their partners were highlighted in the diary data provided by two women, who were given minimum support in the early stages of recovery. Suggestions regarding the helpfulness of post-hysterectomy discourse with other women were also put forward.

In the diary data some women identified a number of strategies including planning their day to include time to themselves and time for visitors; a gradual change in activity level as they improved; and consulting other agencies such as herbalist and counsellor. The support of relatives and close friends was important in lifting spirits and dealing with emotional ups and downs.

6.4 Effect of Support on Outcomes.

To discover whether or not these strategies and support structures have an impact on the women's health outcomes in terms of readmission to hospital, medical consultations, return to normal activities, and resumption of responsibilities e.g. childcare, home duties, employment.

In terms of the effect of support on outcomes, it was found that the majority of women (75%) in the current study had more than one support person at home and 98% had returned to all normal activities at exit interview. The most common period of vulnerability for some women was the first six weeks, when complications and readmissions occurred. Early adverse symptoms and complications related to the effects of the operation, such as bowel problems, pain and bleeding were, as suggested by Clarke *et al.* (1995), transient and self-limiting in nature. The greater number of later wound and urinary tract complications occurred at a time when most women had resumed normal activities around one month to six weeks after the operation, after the time when the level of support from relatives decreased. It is possible that the incidence of these at this time may have been affected by the activities undertaken by the women in some instances although this was not statistically proven. Readmission rates for this group of women were low and appeared similar to that reported in other studies (Roos 1984b; Hancock & Scott 1993; Hackman & Navaneethan 1993; Taylor *et al.* 1993; Ng & Hogston 1994), (Chapter 2, Table 2.2). Complication rates were similar to that observed by Taylor *et al.* (1993), although they were somewhat better than Clarke *et al.'s* (1995) study where women reported a low level of support (47%) and a higher complication rate. As the majority of women in the current study had more than one person assisting them during early convalescence, correlations between overall complication rate and level of support was not demonstrated.

Interestingly, the overall complication rate did not differ significantly between women who had a vaginal hysterectomy and those who had an abdominal hysterectomy. This

was not expected given the difference in the technique and the assumption that women with a small abdominal wound would recover more quickly and with fewer problems (Reiner 1988; Stoval *et al.* 1992; Wood and Maher 1995). As both groups of women were dependent on others at the time of discharge and were given the same level of support for the first few weeks, this may have affected this outcome.

An increase in the rate of vaginal hysterectomies has resulted in women being sent home in a very short time (24-72 hours) following the operation (Reiner 1988; Ng and Hogston 1993) and this may affect the dependency levels of women following this procedure in the future. However, as these women may also suffer from complications in the early post-discharge period, additional routine follow-up by health professionals, eg. community liaison nurses, should be considered, not just for those who have an abdominal procedure, but also for those who have a vaginal one.

Women felt pressured to return to normal activities early if they had small children and stated that they did not have sufficient support during convalescence. However, while the percentage of these women experiencing complications was higher than other women, this was not statistically significant. Further research to inform discharge planners is required if women with small children are to be given adequate support. Other women felt pressured to return to normal activities, however less than 20% expressed the need for more time to recover. Demands of normal employment are a factor in the amount of time taken to convalesce, with some women advising in the final interview that it was important not to return to work too early if it involved lifting and pushing.

The small percentage of women in the study who lived alone (8%) was satisfied with the support provided. Comparisons could not be made with any confidence in regard to whether support for these women had an impact on the complication and re-admission rates *per se* due to the small numbers. Further study is required for these women's needs to be fully understood. The short time women were followed up did not allow for consideration of any long term problems that have been reported by other researchers as occurring later than twelve months after the hysterectomy (Schofield *et al.* 1991; Bernhard 1992; Henderson 1995).

6.5 Satisfaction With Pre-and Post Discharge Information.

To determine the women's satisfaction with the level of pre-and post-operative information and education.

The potential for fragmentation of care is greater when the women are moved from unit to unit during the course of one hospitalization. For example, in one admission the woman may move through the pre-admission clinic, the operating theatre, the recovery unit and the post-surgical ward before going home. While physical benefits to the patient, in terms of fewer infections, fewer complications, less time away from home, have resulted from the changes in the surgical procedure and a reduced length of hospital stay, the relationship between nurses, doctors and the woman (that previously may have elicited the concerns of the patient regarding discharge) are now of necessity very brief. Other researchers have identified problems of inadequate information or education on what to expect when fragmentation of care occurs (Cosper *et al.* 1978; Haddock 1994). As Kuczynski *et al.* (1987, page 3) suggest "patient teaching and patient counseling time is precious, and becoming more so, it must be utilised in the most efficient and effective manner possible."

Strategies used by the women in the current study included the use of written information provided in the pre-admission clinic and verbal advice from the doctor or nurse. Satisfaction with the information was found to be high in most areas with the exception of that for wound healing for women who had an abdominal hysterectomy and on potential emotional effects following the operation for women who had a vaginal hysterectomy. Women were also dissatisfied with information regarding diet during convalescence, and while there may be expectations that the general population is well educated regarding a healthy diet, this may be an area of education that needs attention post-surgery. Other studies support that many women either do not recall or do not understand the information given to them pre-operatively (Salmon & Marchant-Haycox 2000) and this may be the case in these instances.

The findings of the current study suggest that women who have an invisible wound, as in the case of vaginal hysterectomy, may not anticipate some effects of surgery such as emotional lability or other adverse symptoms. In comparison, the wound in the case of abdominal hysterectomy is highly visible and may continue to concern the women for some weeks after discharge. The role of education in relief of stress and anxiety has been proposed by Marchant-Haycox & Salmon (2000) however satisfaction with most aspects of information was high in this study and did not overtly appear to contribute to the anxiety levels for most women.

The comments of some women in the diaries and questionnaires highlight the need for carer preparation prior to surgery. In less than 20% of cases, it was felt that inadequate information was provided to family members and this may have affected the quality of care the women received. Carer's ignorance of women's needs is a factor that affects the experience of women following hysterectomy, and other researchers, such as

Montalto and Dunt (1996), and Williams and Clark (2000), advocate the need for educational preparation of carers to ensure that they are more confident in their role. Educational preparation of family members or carers would also address knowledge deficits and has the potential to improve the quality of care provided to these women. This need would be of particular concern where women plan to manage their recovery without onsite support. In the current study less than 20% of women stated that their families did not understand their needs during convalescence, and overall satisfaction with family support was high. This is in contrast to other studies where women have reported a lack of communication with spouses about their needs following hysterectomy (Bernhard *et al.* 1997; Richter *et al.* 2000), or a lack of fulltime care given by family members (Clarke *et al.* 1995).

Evidence in the current literature and the results of the present study indicate that the type of support required by the women during convalescence is a factor that should be considered during the discharge planning process (Clarke *et al.* 1995; Hancock & Scott 1993). The availability of physical support does not necessarily mean that the woman will obtain help in understanding the emotional feelings they experience, the impact of the operation on fertility, the loss of child-bearing capability and/or the presence of a hormonal cycle (if one or both ovaries are intact) despite the lack of menstruation. The inclusion of this information may be considered when developing information brochures or other written material for these women. Prior studies have shown that husbands or other relatives are less likely to know how to allow the woman the opportunity to explore her emotions during the adjustment phase following surgery than health professionals (Richter *et al.* 2000; Williams & Clark 2000). Although not explored here, it would be appropriate to identify women's concerns about convalescence and include these issues in pre-and postoperative education. Potentially, education of the woman and her family

in regard to the process of healing after surgery could reduce the number of complications reported by improving the level of care. The majority of problems such as bleeding and urinary tract problems were reported at a time when women become more active (i.e. one month to six weeks) and when families expected them to take up their normal responsibilities.

6.6 Women's Experience – Other Issues.

To explore the experiences of women as they progress through convalescence.

The current study indicates that the experience of women who have a hysterectomy is not the same for every woman. Women who have an abdominal procedure, or who suffer complications, have a different experience in terms of pain level and length of dependence compared to other women. Women who have children under the age of twelve have the pressure of small children's needs to accommodate. Women who live alone have to cast the net wider for support from adult children or extended family or friends. There are similarities in some aspects of recovery, while other aspects differ, as explained earlier.

Very few women in this study raised other issues, such as loss and grief in terms of childbearing capability or menstruation although this has been reported in other studies as long ago as 1958 and appears to be still relevant (Drellich & Bieber 1958; Dell and Papagiannidou 1999). Several women identified the need to talk to others about their feelings of loss and sadness that in some instances were unexpected. It was suggested that a post-hysterectomy group or talking to other women who had experienced a hysterectomy would help them to come to terms with the change. This is an issue that health professionals may wish to take up when counseling women prior to and after the hysterectomy.

As expected, feelings changed as the women recovered and regained physical 'wellness'. Most expressed happiness that the symptoms they had been suffering from would not be there anymore. Several stated that they felt more energetic and were looking forward to a more social life with no embarrassment. Initial problems such as incontinence, constipation and haematoma eventually resolved for most women, although a small number continued to have difficulties with these at four months. The women's satisfaction with the overall reduction in symptoms is consistent with recent studies that report a greater level of satisfaction with early outcomes of hysterectomy (Henderson 1995; Linenberger 1996; Kjerulff *et al.* 2000) in comparison with retrospective studies (Bernhard 1992; Carlson *et al.* 1994). The short follow-up period for the current study meant that long-term problems that may occur, as reported in these retrospective studies, were not taken into account.

6.7 Limitations of the Study

The number of women contacted at specific times for follow up varied a great deal over the four months. The first follow up interview had over 60% response rate, however the other telephone interviews had less than 60%, with a 74% response rate at the final face-to face interview. While this may have affected the overall results, sufficient numbers from each group allowed comparisons to be made.

Another aim of the study initially was to examine differences between cultural groups in relation to the support provided and the overall experience. This was not enabled due to the small numbers of women from different groups and the lack of participants who did not speak English. While women were approached with the aid of an interpreter, they declined to participate. The information sheet was translated into the Chinese language as this group was well represented in the hospital heath service. Other groups studied,

such as women with children under twelve years of age and women who lived alone also require further study. A feature of the results is the individualised nature of the women's circumstances and experiences and a larger cohort of these groups would elicit further data to inform health professionals. A factor that affected the recruitment of women was their own perception of time to participate and home responsibilities. Some women who had small children declined to participate because of limited time, however this group is one that requires additional assistance in childcare and would benefit from a needs analysis.

The study was also limited in the number of women recruited after laparascopically-assisted vaginal hysterectomy. These women were discharged within 24-72 hours postoperatively and were not well represented in the study. It would be of benefit to undertake study of this cohort of women for comparison of their experiences, support and progress to wellness.

6.8 Implications for practice

Implications for health professional practice arising from this study relate to a number of issues: (1) the education of women and their families about hysterectomy and its effects; (2) the assessment of self-care deficits before discharge; and (3) linking women who have specific homecare needs to the appropriate support groups/services prior to going home. Some of these issues have been identified in other research and are reiterated in this study. In order to address these issues, health professionals may need further education and information in order to understand the hysterectomy experience and the concerns of women undergoing hysterectomy procedures. A better understanding of women's needs following hysterectomy, using research based evidence, can inform the discharge process and assist in the evaluation of care.

6.9 CONCLUSION

The research over the past two decades has indicated that the effect of hysterectomy surgery on women is not only physical, but often has emotional, psychological, and social consequences. These aspects must be taken into consideration when preparing women for surgery, and in providing assistance and support on discharge from hospital. It is of value therefore to attempt to understand the experience of hysterectomy from the woman's point of view. Health professionals may potentially use the information to develop adequate support mechanisms that will provide women and their families with the knowledge and skills required to ensure that the experience is not a difficult one.

It is inappropriate however, to assume that all women will have the same experience if they have the same procedure. Differences between individual women may include their health status prior to the hysterectomy, the presence of small children or other dependents at home and whether the woman's home conditions are conducive to an uneventful recovery. The availability of other organizations, such as home help, community nurses, or 'dial an angel', that may assist the women in the performance of household tasks needs to be explored with relevant women, particularly those who live alone or who do not have other adult assistance.

Pre-discharge education provided by health professionals needs to include families or significant others in the woman's life so that adequate understanding and support may be given to the woman during convalescence. High expectations for speedy recovery from family members (who are generally the main care-givers when the woman goes home) can contribute to emotional stress and a too early return to the woman's normal responsibilities. Other researchers have proposed education of family members, in relation to the effects of hysterectomy, and it would be appropriate to consider this in the

light of the comments from these women. It is assumed in producing information, such as pamphlets, that all women will understand the information provided and will be able to relate what is told them to the individual experiences through which they pass without further explanation being necessary. It is important, in the current healthcare climate of discharging women quickly from the acute care setting, to ensure that time is given by medical, nursing and allied health staff (for example, social worker) for exploration of their concerns. This could include discussion of accurate, relevant information and additions to pamphlets given to the women prior to surgery.

In the Australian context it would appear that women are not in the habit of accessing ongoing support from health professionals following hysterectomy unless complications occur. Women who plan for their recovery with adequate support and time off normal responsibilities appear to be satisfied with their convalescence and feel positive about the hysterectomy. It is possible that initiation of an individual plan for recovery, that includes (1) education of the woman and family, (2) assessment of home conditions, (3) provision of community support mechanisms where appropriate, and (4) ongoing communication with health professionals such as nurse or medical practitioner, may decrease the number of reported complications and unplanned consultations and reduce feelings of anxiety. Women who feel that they are not supported by their families may under these conditions be able to communicate this to the health professional following them up and obtain the assistance they need before the situation becomes one they cannot cope with.

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APPENDICES

UWS Macarthur
PO Box 555, Campbelltown NSW 2560 Australia

APPENDIX 1A

Division of Public Health

& THE SOUTH WESTERN SYDNEY AREA HEALTH SERVICE

PARTICIPANT INFORMATION SHEET

Thank you for considering to be a part of this research project on "Women, hysterectomy and social support structures".

The aim of this research is to discover what women do during convalescence following a hysterectomy operation in order to successfully recover and return to their normal lives and activities.

In order to find this out, if you agree to participate, we need to determine what you are able and unable to do at the time you are discharged from hospital, and what type of help you are anticipating when you go home.

An interviewer will visit you in hospital on the day the doctor says you may go home. This person will talk to you for approximately 45 minutes and ask questions about the activities you were able to do before the operation, how you are now and what plans you have made for your recovery. This will be recorded on a questionnaire so that the information can be easily compared with other participants.

One week after you go home the interviewer will telephone you to find out what has actually happened in terms of help you have had and how you are progressing in regaining your independence. The interviewer will contact you after this once a month to find out how quickly you are able to do the activities you normally do. At the end of four months, with your consent, the interviewer will visit you at home for about an hour and talk about your experience and activities.

If you are asked to record a personal diary during the four months, you will be given a self-addressed stamped envelope so that you can post it to the University each month. The information we would like you to record in the diary on a regular basis relates to your feelings, how your family and friends have reacted to your illness, what you have had to do to cope with your illness and what help you have wanted and received. This information will help us to understand the individual experiences of women who have had this operation.

You may, at any time during the four months, decide not to continue your involvement in the research project.

All information that would identify you will be kept confidential and only the researchers will have access to it. You will be allocated a code number which will be put on the questionaires used by the interviewer and the personal diary. No identifying information will be used when the results of the research are published.

If you have any questions regarding the research or your part in it you may call:

Dr Maria Quartararo, University of Western Sydney, Macarthur. Phone 046 203 370 or mobile 0417 267 686.

Ms Maureen Giddins Blues, Nurses Registration Board of New South Wales. Phone 02 9281 2182, or mobile 0417 254 191.

This research project has been approved by the University of Western Sydney Macarthur Ethics Review Committee (Human Subjects). Any complaints or reservations about this research may be directed to the Ethics Committee through the Executive Office, Kokila de Silva, phone 046 203 641. Any complaint you make will be treated inc confidence and investigated fully and you will be informed of the outcome.

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APPENDIX 1B

Division of Public Health & The South Western Sydney Area Health Service

悉尼西南區保健服務

患者信息介紹

感謝你考慮參與這項"婦女、子宮切除手術與社會支持結構"的調查項目。

這項調查的目的是了解在子宮切除手術恢復期間，婦女患者做些什麼使自己成功地恢復健康並恢復正常生活。

爲了了解這一點，如果你同意參與調查，我們需要了解你在出院時能夠做和不能夠做的事，以及你回家以後期待得到哪些幫助。

在醫生指定的你可以出院的當天，會有一位調查員來醫院訪問你，同你談話約45分鐘，了解你在手術前能夠做哪些活動，你現在的情況如何，以及你有哪些恢復健康的計劃。這些信息將記錄在一份問答調查表上，以便我們能夠比較容易地與其他參與人作對比。

你回到家裡的一周後，調查員會給你打電話了解你得到哪些實際幫助，以及你在恢復獨立生活能力方面有哪些進展。此后，調查員會每月與你聯係一次，了解你恢復正常活動能力的進展情況。四個月後，經過你的同意，調查員將上門訪問你，進行約一小時的談話，了解你的體驗和活動。

如果你被要求在這四個月中記一份個人日記，你會得到印有地址和付過郵資的信封，以便每月將日記寄到大學。我們希望你能夠定期記下你的感受，你的家人和朋友對你的病的反應，你如何應付疾病帶來的問題，以及你希望得到和實際得到的幫助等信息。這些信息可協助我們了解做過這種手術的婦女的個人體驗。

在四個月中的任何時候你都可以決定終止參與這項調查計劃。

任何可暴露你的身份的信息將保密收存，只有調查員才可查閱。你會得到一個代號。在調查員使用的問答調查表和個人日記中將只用這個代號。調查結果發表時不會使用任何會暴露你的身份的信息。

你可打以下電話詢問有關此調查的問題或者你在其中的作用：

Maria Quartararo 醫生，西悉尼大學麥克阿瑟校園，電話：046 203 370 手提電話：0417 267 686。

Maureen Giddins Blues 女士，新南威爾士州護士注册局，電話：02 9281 2182，手提電話：0417 254 191。

此調查經西悉尼大學麥克阿瑟校園職業道德審查委員會(人文類)批准。有關此調查的任何投訴或意見可通過行政辦公室的 KOKILA DE SILVA 向職業道德委員會提出。電話是 046 203641。我們對你的任何投訴將保密和進行徹底調查，並將調查結果通知你。

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BASELINE QUESTIONNAIRE

Personal Characteristics

1. Ethnic background (circle one): ATSI / Vietnamese / Korean / Chinese / Italian / Greek / Portuguese / Cambodian / United Kingdom / Other
(other, specify)_____

2. Language (circle one) English as a first language / English as a second language / Non-English speaking (NESB)
Language spoken at home:_____

3. Age.....(years)

4. Lives alone Y/N

5. Dependents: (circle any)
1. Children (ages & no.)_____
2. Spouse/Partner
3. Parent
4. Other relative (specify)_____
5. Other person_____

6. Occupation (main)_____Fulltime/Part-time
Occupation (second)_____
Occupation of partner: _____ Fulltime/ Part-time
(N/A if not applicable)

7. Do you belong to any Club/Social Organisation?:
_____

8. Reason for surgery:
_____
_____

9. Membership of Health Fund:_____

10. Please indicate what activities you normally engage in from the list below. Tick [✓] more than one box.

Cleaning	☐	Shopping	☐
Ironing	☐	Driving a car	☐
House maintenance	☐	Childcare	☐
Gardening	☐	Washing clothes etc.	☐

Other (specify type):

_____

_____

_____

Other (e.g. clubs, volunteer work, hobbies):

_____

_____

_____

11. Prior to the operation did you experience difficulty with any of the following: Please place Y or N in the box. Y = Yes; N = No.

Walking	☐	Weight bearing	☐
Showering/bathing	☐	Breathing	☐
Dressing	☐	Standing	☐
Toileting	☐	Grooming	☐
Eating	☐	Sitting	☐
Getting in/out of bed	☐	Sleeping	☐

12. Where are you intending to convalesce? Tick [✓] one box only.

At home	☐	A relative's home	☐
A friend's home	☐	Other: _____	

13. Who will be helping you during your convalescence? You may tick [✓] more than one box.

Self	☐	Friend	☐
Spouse	☐	Neighbour	☐
Son	☐	Community Help	☐
Daughter	☐	Community Nurse	☐

Other (specify)

_____

_____

14. What tasks are you expecting them to do?

_____

_____

_____

15. For what period of time will they be available to help you? If more than one support service/person please indicate length of time for each.

_____

_____

_____

16. a. How would you rate the level of pain/discomfort you are now experiencing? Indicate on the following scale.

1 2 3 4 5 6 7 8 9 10

None Severe

b. How would you describe the pain you are feeling?

_____

_____

17. Are you requiring any pain relieving medication due to your operation? Y/N ☐

18. How often do you need medication for pain related to your operation? Please tick [✓] one box only.

Once a day	☐	5-6 times daily	☐
Twice daily	☐	Only in the morning	☐
3-4 times daily	☐	Only at night	☐

19. What period of time do you anticipate needing for your recovery?

_____

20. Do you have any concerns about your discharge home? Please indicate what these are.

_____

_____

_____

_____

_____

_____

21. At this time, what of the following are you able to perform? Please tick [✓] the appropriate box if you have difficulty or need assistance.

	Freely, No discomfort	With discomfort	Some support, e.g. wall,furniture	With Mechanism Aide,e.g. frame	With assistance 1 person	With >1 person assisting
Walking						
Shower/bath						
Dressing						
Eating						
Toileting						
Getting in/out of bed						
Weight bearing						
Standing						
Changing position while sitting/lying down						

Interviewer: In answering this, the subject needs to indicate specifically if the activity is as easy as prior to the surgery, or what level of difficulty is being experienced.

21. What activities do you find the most difficult? Why?

_____

_____

_____

23. Are there any other normal activities you anticipate having difficulty with at home due to your operation?

_____

_____

_____

24. What advice has your doctor or other health professional given you about:

a. Activities to avoid:

_____

_____

b. Returning to work/normal duties

_____

_____

c. Wound healing

_____

_____

d. Convalescence requirements (e.g. diet, exercise, hygiene, rest)

_____

_____

e. Other

_____

_____

25. Do you have any other health problems affecting your return to normal activities? If so, specify the degree to which this will be affected.

_____

_____

Subject ID..... **Hospital.....**

STATE ANXIETY QUESTIONNAIRE

Please answer the following statements regarding how you feel right now, that is, at this moment. There are no right or wrong answers. Give the answer which seems to describe your present feelings best.

		Not at all 1	Somewhat 2	Moderately So 3	Very Much So 4
1.	I feel calm				
2.	I feel secure				
3.	I am tense				
4.	I am regretful				
5.	I feel at ease				
6.	I feel upset				
7.	I am presently worrying over possible misfortunes				
8.	I feel rested				
9.	I feel anxious				
10.	I feel comfortable				
11.	I feel self confident				
12.	I feel nervous				
13.	I am jittery				
14.	I feel 'high strung'				
15.	I am relaxed				
16.	I feel content				
17.	I am worried				
18.	I feel over excited and "rattled"				
19.	I feel joyful				
20.	I feel pleasant				

Reference: Speilberger CD, Gorsuch RL, Lushene RE. STAI Manual for the State-trait Anxiety Inventory "Self-evaluation Questionnaire". Consulting Psychologists Press, Inc. California 1970.

Project: Recovering from Hysterectomy

Additional information to be obtained from medical records:

1. Admission date....., Discharge date.....
2. Type of operation (procedure) .....
3. Medical diagnosis .....
4. Wound status on discharge: healed; vaginal discharge; other

   .....
   .....
   .....
5. Complications .....
   .....
   .....
   .....
   .....
6. Ongoing health problems resulting from complications.....
   .....
   .....
   .....
   .....
7. Consultation with physiotherapist/ social worker/ clinical nurse consultant/ other
   .....
   .....
   .....
8. Planned follow-up.....
   .....
   .....

TELEPHONE QUESTIONAIRE

Code No..... **Date.....**

Ethnic Group..... **Interview No.....**

Recovery Week No..... **Interpreter Y/N**

ACTIVITIES

What activities have you been able to perform this week?

Cooking	Cleaning	Dressing
Driving	Childcare	Hygiene
Sleeping	Gardening	Walking

ASSISTANCE

Have you been given any help in the following this week?

Activity	Person Code	Frequency
Cooking		
Cleaning		
Childcare		
Shopping		
Home maintenance		
Showering		
Getting in/out of bed		
Walking		
Dressing		

Codes:

1.Live-in spouse/partner
2. Parent
3. Child
4. Other relative
5. Friend
6. Neighbour
7. Community nurse
8. Meals on Wheels
9. Other

PAIN

Do you have any pain related to the operation? On a scale of 1 - 10 how would you rate your pain?

1 2 3 4 5 6 7 8 9 10 (1=none; 10=severe)

Are you taking any medication for pain relief?
Name of product.....

How often do you need medication for pain related to your operation? Please tick [✓] one box only.

Once a day	☐	5-6 times daily	☐
Twice daily	☐	Only in the morning	☐
3-4 times daily	☐	Only at night	☐

FEELINGS

Describe your feelings today. (tick any)

Negative Feelings	Positive Feelings
Depressed	Happy
Tired	Energetic
Uncomfortable	Comfortable
Unhappy	Satisfied
Angry	Content
Dissatisfied	Optimistic
Pessimistic	

MEDICAL CONSULTATIONS

Have you consulted a health professional this week?

Was this planned (follow-up) or unplanned? (Circle one)

Person consulted: GP / Gynaecologist / Nurse/other -specify (Circle one)

Was the consultation by: Phone / Surgery visit / Medical Centre / Hospital / Home visit /other – specify
What was the result of the consultation?

.....

.....

.....

UNEXPECTED OUTCOMES FROM THE OPERATION

Did anything negative occur this week in relation to your operation that you did not expect?

Bleeding Excessive Pain Nausea Loss of mobility
Other

Did anything positive occur this week in relation to your operation that you did not expect?

.....

.....

.....

.....

.....

RESEARCH PROJECT: Recovering from hysterectomy: An exploratory study of how women manage following discharge from hospital.

PERSONAL DIARY

Date:..... **Identification Number.....**

How do you feel today?	
Did any of these people help you today? (please tick)	**Husband** **Children** **Friend** **Community Nurse** **Other relative**
Did you experience any difficulty performing any of these tasks today?	**Cooking** **Cleaning** **Driving** **Dressing** **Gardening** **Childcare** **Other (specify)**
Have you sought medical help today?	

Any other comments you wish to make.	

Any additional comments

You may add additional pages if you wish.

APPENDIX 7

FOUR MONTH FOLLOW-UP QUESTIONAIRE

A. Participant to complete STAI Inventory.

B. The following questions are to be answered by the participant:

1. Have you returned to your normal occupation? Y/N (circle one)

2. A. Of the following activities, what are you able to perform?

	Freely, No discomfort	With discomfort	Some support, e.g. wall,furniture	With Mechanism Aide, e.g. frame	With assistance 1 person	With >1 person assisting
Walking						
Shower/bath						
Dressing						
Eating						
Toileting						
Getting in/out of bed						
Weight bearing						
Standing						
Changing position while sitting/lying down						
Driving						
Shopping						
Childcare						
Lifting						
Other (specify)						

Interviewer: **In answering this, the subject needs to indicate specifically if the activity is as easy as prior to the surgery, or what level of difficulty is being experienced.**

B. What activities do you find the most difficult? Why?

_____

_____

_____

3. How would you describe your recovery?

A. Slower than expected B. As expected C. Quicker than expected.

4. Are you experiencing any pain? Y/N (circle One)

How would you rate your pain? 1 2 3 4 5 6 7 8 9 10
Mild Severe

Are you on any medication for pain? Y/N (circle one)

How often do you need medication for pain related to your operation? Please tick [✓] one box only.

Once a day	☐	5-6 times daily	☐
Twice daily	☐	Only in the morning	☐
3-4 times daily	☐	Only at night	☐

5. Did you obtain enough support during your recovery period so far? Y/N

Who gave you this support? You may tick [✓] more than one box.

Self	☐	Friend	☐
Spouse	☐	Neighbour	☐
Son	☐	Community Help	☐
Daughter	☐	Community Nurse	☐
Other relative	☐	Meals on wheels	☐

Other (specify) _____

_____

What tasks did they perform for you?

_____

_____

What additional support would you have liked to have? What would you have liked them to do?

a. Family member

_____

b. Friend_____

_____

c. Nurse_____

_____

d. Doctor_____

_____

e. Hospital_____

_____

f. Community Help (i.e. Meals on Wheels, Cleaning)_____

_____

6. Are you satisfied with the amount of support given by:

a. Nursing staff	Y/N
b. General practitioner	Y/N
c. Specialist	Y/N
d. Community nurse	Y/N
e. Hospital	Y/N

What additional support do you feel could have been provided?

_____

_____

_____

_____

7. Are you satisfied with the amount of information provided regarding the operation?

8. Are you satisfied with the information provided regarding the outcome of the operation?

9. Are you satisfied with the information provided regarding:

a.	Wound healing	Y/N
b.	Diet	Y/N
c.	Emotional needs/feelings	Y/N
d.	Rest	Y/N
e.	Activities to avoid	Y/N
f.	The time it would take to recover	Y/N
g.	Returning to work.	Y/N

10. Do you feel that your family/significant others understood your needs during your convalescence? Y/N

11. Do you feel that your family/significant others were sufficiently informed regarding your needs following the operation? Y/N

12. Is there any information that you think your family/significant others should have in order to understand the effects of your operation?

13. Were you satisfied with the amount of time provided for your recovery? Y/N

14. Were you ready to return to normal activities at the time you were required to? Y/N

Did you feel any pressure from family or work to return to normal activities before you were ready? Y/N

15. Would you have preferred more time to recover from the operation? Y/N

16. Do you feel the need for further support, either emotional, educational or physical as a result of having a hysterectomy?

17. Who do you think should provide this support?

18. Do you have any advice you would like to give to other women having this operation?

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APPENDIX 8

Division of Public Health

& THE SOUTH WESTERN SYDNEY AREA HEALTH SERVICE

Principal Researchers
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Nursing Officer
Nurses Registration Board of NSW
Ph: 02 9281 2182

Dr Maria Quartararo
Senior lecturer
Division of Public Health
University of Western Sydney, Macarthur
Ph: 046 203 760

Women, Hysterectomy and Social Support Structures

CONSENT FORM

I .....have read and understood the Information Sheet and this Consent Form. I understand that my decision whether or not to participate in, or subsequently withdraw from, this study will not affect any current or future treatment or my relationship with the South Western Sydney Area Health Service or any institution co-operating in this study or any person treating me.

I understand the purpose of the study and what is being asked of me, and that I can stop participating at any time. With this understanding, I agree to take part in this research.

NAME: _____

SIGNATURE: _____

WITNESS'S NAME: _____

WITNESS'S SIGNATURE: _____

DATE: _____

This research project has been approved by the University of Western Sydney Macarthur Ethics Review Committee (Human Subjects). Any complaints or reservations about this research may be directed to the Ethics Committee through the Executive Officer, Kokila de Silva, (phone 046 203641). Any complaint you make will be treated in confidence and investigated fully and you will be informed of the outcome.

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PROTOCOL FOR ENROLING PARTICIPANTS

Campbelltown Hospital

1. Booking clerk to give Participant Information sheet to patients with their admission papers prior to attending the Pre-Admission Clinic.

2. Liaison person (registered nurse) at the Pre-Admission Clinic to explain the purpose of the research to interested women and to provide them with the Consent Form.

3. Research interviewer to telephone hospital to confirm admission with ward clerk and willingness to participate. Patients' names, locations and appropriate visiting time and language (to determine the need for an interpreter) to be provided by ward staff on an Interview Schedule to be collected by the interviewer.

4. Interpreter to be booked for the interview where needed, by the interviewer.

Liverpool Hospital

1. Liaison person (registered nurse) at the Hospital to identify prospective participants from operating lists the day before surgery.

1. Research interviewer to telephone liaison person at the Hospital to confirm names and locations (as per the Interview Schedule) for the women who have expressed an interest and to determine a time to visit the women to complete the Consent Form.

2. Liaison person to inform the interviewer if consent has been withdrawn or if the woman's condition is not conducive to an interview.

3. Sticker to be placed on patient record to identify them as participants in the study so that the interviewer can be advised when they are about to go home.

Research Interviewer

- Contact liaison person at each Hospital regarding prospective participants
- Visit the women at a convenient time to explain the project and obtain written consent.
- Conduct interview at a convenient time, taking into consideration the need for privacy in a hospital environment.
- Provide diary pages for participants who wish to be included in this aspect of the study.

- Access additional information (as per Medical Records sheet) from the women's records.
- Conduct follow-up telephone interviews to provide consistency.
- Conduct four-month follow-up interview in person at a location determined by the woman.
- Inform chief researcher of progress on a regular basis.
- Maintain confidentiality by storing completed questionnaires and Medical Records information in a designated locked storage area.

****

INTERVIEW SCHEDULE

Please write names and unit numbers of women who have agreed to be visited in regard to participation in the research project. Please leave the list for the researcher at the nurses' station.

Unit number	**Name, date of birth, date of admission**	**Language spoken (need for an interpreter)**